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PUBLIC HEALTH SYSTEMS

Public Health's Roles in Supporting Informal and Family Caregivers

As the population ages, the critical role of family and informal caregivers will continue to grow and needs support.

Introduction

Advances in public health, medicine, and technology are allowing people to live longer and healthier lives and communities to benefit from the knowledge, experience, and wisdom of individuals as they age. It has been estimated that by 2034, Americans 65 years and older will outnumber those who are under 18 years old, and by 2060, about one in four people living in the United States will be over 65.[1] The increasing proportion of the population aged 65 and older means that there will be a corresponding increase in the need for caregivers, both paid and unpaid, and these caregivers will be required to provide more care for longer periods of time and for more challenging needs. Caregivers will also need to help navigate the complexities of our health care system, all while balancing their own health and family needs. State, local, tribal, and territorial public health departments across the U.S. can play a valuable role by supporting the health and well-being of our country's older adults and their caregivers. The focus of this brief is on informal, or unpaid, caregivers, who provide the majority of caregiving services in the U.S. and how the public health system can support their important role.[2]

Trust for America's Health (TFAH) is a nonprofit, nonpartisan public health policy, research, and advocacy organization. TFAH's mission is to promote optimal health for every person and community and make the prevention of illness and injury a national priority. Among its many issue areas, TFAH is dedicated to advancing public health's role in promoting and supporting healthy aging through its Age-Friendly Public Health Systems (AFPHS) Initiative. The AFPHS initiative is designed to help state and local health departments support healthy aging in their communities by working with partners and by adopting healthy aging as a core public health function. TFAH's AFPHS Recognition Program acknowledges the advances that public health departments and individuals are making to build expertise and support older adult health. To date, six state health departments have achieved recognition, 114 local health departments have achieved recognition and over 200 individuals have been designated as AFPHS Champions across more than half of U.S. states.

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Public Health's Role in Building Communities that Support the Health and Well-being of Older Adults

Since 2017, with partnership and funding from The John A. Hartford Foundation, Trust for America's Health (TFAH) has been working with state and local health departments to expand their roles in improving the health and well-being of older adults. The Age-Friendly Public Health System (AFPHS) framework identifies public health professionals' core roles in promoting older adult health and well-being.

TFAH developed the AFPHS 6Cs Framework to provide guidance on public health's roles in healthy aging policies and programs, including caregiving.

AFPHS 6Cs Framework

1. **Creating and leading** policy and systems change to support and promote older adult health and well-being.
2. **Connecting and convening** multi-sector partners to address the health and social needs of older adults through the collective impact approaches focused on the social determinants of health.
3. **Coordinating** existing supports and services to help older adults, families, and caregivers navigate and access services and supports, avoid duplication, and promote an integrated system of care.
4. **Collecting**, analyzing, and translating relevant and robust data on older adults to identify the needs and assets of a community and inform the development of interventions through community-wide assessment.
5. **Communicating** important public health information to promote and support older adult health and well-being, including conducting and disseminating research findings and emerging and best practices to support healthy aging.
6. **Complementing** existing health promoting programs to ensure they adequately meet the needs of older adults.

This brief outlines the current challenges faced by informal caregivers of older adults and potential areas for public health intervention. In addition to highlighting trends among informal caregivers and their experiences, the brief also summarizes existing programs and interventions that support informal caregivers and offers recommendations for public health strategies that are aligned with the 6Cs Framework.

Background and Trends about Caregivers

Caregivers and Their Experiences

Both formal and informal caregivers play a vital role in older adults' health. Formal caregivers have training and education in providing care and are paid for their services. Informal or family caregivers can be family members or friends who may or may not have any formal training in caregiving and who usually provide care without payment.[3] More than one in five Americans are informal caregivers.[4] In 2021, approximately 38 million unpaid family caregivers provided an estimated 36 billion hours of care to adult recipients, which translates to about $600 billion (up from $470 billion in 2017) in unpaid caregiving.[5] These data, collected between 2020 and 2021, are the most recent, comprehensive counts of caregivers nationwide. These data also reflect caregiver counts from the COVID-19 pandemic, which may have exacerbated some of the trends cited in this brief.

Family caregivers typically provide care to support and maintain the health and well-being of those who need help with activities of daily living, such as grocery shopping, meal preparation, housework, and transportation. Caregivers can also perform complex medical and nursing tasks that trained healthcare professionals have historically provided, such as providing insulin injections or changing a catheter. Additionally, they may be tasked with advocating for their care recipients' preferences, dealing with health insurance claims, and coordinating care between various providers and care settings.[6] On top of these caregiving responsibilities, most family caregivers are also employed in the workforce and/or may be caring for older family members, children, and people living with disabilities.[7]

Figure 1: Prevalence of Caregiving by Age of Care Recipient, 2020 Compared to 2015

	2020 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers	2015 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers
Overall	21.3%	53.0 million	18.2%	43.5 million
Caregivers of recipients ages 0–17	5.7%	14.1 million	4.3%	10.2 million
Caregivers of recipients ages 18+	19.2%	47.9 million	16.6%	39.8 million
Caregivers of recipients ages 18–49	2.5%	6.1 million	2.3%	5.6 million
Caregivers of recipients ages 50+	16.8%	41.8 million	14.3%	34.2 million

Source: Caregiving in the U.S. – AARP, May 2020

The recipients of care could be a spouse, aging parent, relative, friend, or other individual who is unable to fully provide for their own care.[8] Caregivers may experience feelings of purpose, satisfaction, and meaning in their supportive role. However, depending on the level of care needed, caregiving can be a challenging task with few available support services. The physical, mental, and financial burdens of caregiving can negatively impact caregivers' mental well-being and physical health. Caregivers experience higher levels of stress, depression, and anxiety, and lower levels of self-efficacy compared to non-caregivers.[9] Informal caregiving is also associated with loneliness and social isolation.[10, 11, 12, 13] Given the negative impact caregiving can have on caregivers, and with the predicted increase of older adults in the population, the current support systems for caregivers in the U.S. must be evaluated and enhanced.

The prevalence of caregiving for care recipients age 50 and over in the U.S. has increased significantly from 14.3 percent in 2015 to 16.8 percent in 2020, as noted in Figure 1. Caregivers for older adults (including those with disabilities) comprise most of the caregiving population, with about 41.8 million caregivers out of 53 million in total.[14] This number amounts to an increase of over 7 million adults providing unpaid care to a family member or friend, age of 50 or over.

Caregivers often support adults who have increasingly complex needs. Compared to 2015, caregivers in 2020 were more likely to report that their adult care recipient required increased care due to physical conditions, Alzheimer's disease and related dementias (ADRD) or other memory problems, or emotional/mental health issues.[15] As recipients' needs increase, caregiving responsibilities increase as well, placing additional strain on the caregiver, which can negatively affect the caregiver's health. Specifically, according to an AP–NORC Center for Public Affairs Research poll, more than one in four caregivers struggle to take care of their own health needs.[16] Rates of chronic disease and disability status among caregivers range from about 30 percent to over 50 percent.[17] Not only can caregiving affect physical and mental health, but a caregiver's decreased overall health status can translate to negative health outcomes for the care recipient.

Demographic Composition of Informal Caregivers

A recent survey of informal caregivers found that their median age is 42, and the majority (59 percent) are female.[18] In addition, most female caregivers work outside the home, with one estimate noting that 20 percent of all women in the workplace provide some type of caregiving, whether for an older person or a child.[19] Since women live longer than men, they usually outlive their spouses, and may have fewer finances to rely on when their spouses die. Thus, not only are female caregivers subject to financial stress, but as they age, the physical demands of caregiving may also take a toll on their health. In addition, caregiving responsibilities can result in less income and financial stability over time. Older women tend to have higher rates of poverty, for some linked to reduced lifetime income due to time spent on caregiving responsibilities.[20]

Caregivers are racially and ethnically diverse: about six in ten caregivers identify as non-Hispanic white; 17 percent Hispanic, 14 percent non-Hispanic Black, 5 percent Asian American/Pacific Islander, and 3 percent multiracial or some other race/ethnicity.[21]

Some caregivers face additional barriers associated with accessing healthcare, such as limited knowledge of services, a mistrust of healthcare systems, and literacy and language challenges.[22]

Caregivers from communities of color provide more hours of care per week than white caregivers on average and report overall worse physical health status; they also report more financial impacts as a result of providing informal care.[23] Hispanic and Asian American caregivers experience higher rates of depressive symptoms than white caregivers.[24] Additionally, Asian American caregivers may be less likely to utilize professional support services because of limited culturally relevant services, and 26 percent of Hispanic caregivers report having no source of help or information.[25, 26] When there are communication barriers with medical providers, patients are bound to suffer in response to the poor reception or dismissal of the caregivers' input.[27] Multiple studies find that Black caregivers experience less stress and perceive greater rewards from caregiving than their white counterparts.[28] However, Black and Hispanic caregivers often find that they feel ignored in medical settings and are left out of crucial care discussions.[29]

In tribal communities, caregivers play a significant role in honoring tribal elders through direct care and support. Older generations pass the value and responsibility of caregiving along to younger generations, often taking a uniquely communal approach to caregiving compared to other cultures.[30] This approach can support older adults physically, emotionally, and spiritually. The current Western medical model for aging and caregiving does not align with some tribal communities' approaches to caregiving. Compared to older adults from different population groups, older adults who are American Indian and Alaska Native experience a higher disease burden while reporting less access to care.[31] Support services should take into account the cultural dynamics of tribal communities in order to help meet caregivers' needs.[32]

Caregivers for Individuals with Alzheimer's Disease and Related Dementias (ADRD)

Alzheimer's disease and related dementias (ADRD) are brain diseases that affect memory, thought processes, and functioning, and recent reports note that over 7 million Americans are living with Alzheimer's dementia.[33] People with ADRD often require intensive caregiving and other long-term services and supports.[34] In 2011, over half of caregivers for someone with ADRD reported providing care for four years or more.[35] ADRD caregivers face unique challenges compared to other caregivers, such as care recipients who exhibit aggressive behavior, resist aid, hit or bite, and wander or get lost.[36] These additional factors can make the responsibilities of caregiving overwhelming; almost 60 percent of caregivers of people with ADRD rate the emotional stress of caregiving as "high" or "very high," while only 36 percent of caregivers in a general survey found caregiving to be highly stressful.[37, 38] ADRD caregivers report more substantial emotional, financial, and physical difficulty than non-dementia caregivers and experience more symptoms of depression.[39] While research shows differences in outcomes between ADRD caregivers and non-ADRD caregivers, existing research on ADRD caregiving patterns has not always accounted for racial and ethnic differences; 67 percent of NIH-funded published studies from 1994 to 2015 about ADRD caregiver support interventions did not report results by gender or racial/ethnic group.[40]

Caregivers of people with ADRD help with more activities of daily living, including getting dressed, feeding, and dealing with incontinence, than caregivers who provide care to other older adults.[41] Given the length of disease and the unique challenges associated with ADRD, public health agencies should work with partners to implement unique supports for ADRD caregivers, as their needs may be different than other caregivers. Specifically, the health, well-being, and productivity of these caregivers are especially affected due to the prolonged and intensive care they provide for their recipients.

Caregiving Challenges and Opportunities for Interventions

Financial Strain and Employment

Unpaid caregivers may suffer significant economic impacts, including direct out-of-pocket costs as well as risks to their long-term economic and retirement security. Informal caregivers' duties may require them to take significant time off from work, reduce work hours, pass up promotions or other career opportunities, and even prematurely leave the workforce. Nearly one in five caregivers of adults experience high levels of financial strain (see Figure 2).[42]

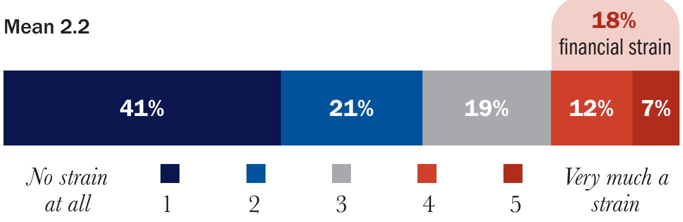
Longitudinal data suggest that older adult caregiving places a caregiver at financial risk over time. One study found an association between spousal caregiving and lower income later in life.[43] As noted above, compared to non-caregivers, women who are caregivers are more likely to experience poverty and/or rely on public assistance.[44] Caregiving is also associated with reduced labor force participation for men and women and reduces the overall net worth of family caregivers when compared to non-caregivers.[45] Most caregivers feel that an income tax credit or program to pay caregivers for the care they provide would be helpful in defraying the financial costs of care.[46]

The level of financial strain for the caregiver varies based on the extent of assistance the care recipient needs. Caregivers who provide substantial assistance with healthcare activities are more likely to report financial difficulty (23 percent) compared to caregivers who provide some assistance (12.3 percent) or no assistance (6.7 percent).[47] As shown in Figure 3, 27 percent of caregivers have a difficult time identifying and utilizing affordable and accessible resources that would ease the burden of care.[48] Financial strain exacerbates the difficulties of caregiving, especially for the caregivers who most need relief.

Figure 2

How much of a financial strain would you say that caring for your [relation] is/was for you?

Mean 2.2



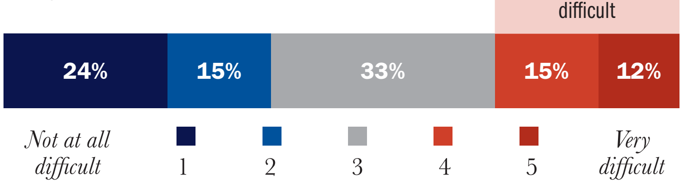
2020 Base: Caregivers of Recipient Age 18+
(n=1,392)

Source: Caregiving in the U.S. 2020 Report

note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Figure 3

How difficult is/was it to get affordable services in your [relation]'s local area or community that could help/would have helped you care for your [relation], like delivered meals, transportation, or in-home health services?



2020 Base: Caregivers of Recipient Age 18+
(n=1392)

Source: Caregiving in the U.S. 2020 Report

Note: Respondents are rounded and don't know/refused responses are not shown; results may not add up to 100 percent.

Inadequate Resources and Support

While informal caregiving can be personally rewarding, it can also be emotionally challenging and strain the individual caregiver, as well as their family relationships. Many caregivers express concern about being unprepared for their roles and not having a choice in taking on caregiving responsibilities.[49] Caregivers commonly express feelings of stress about knowing where to go for help, or how to provide appropriate care and support to their care recipients. These feelings are exacerbated among those providing care to individuals with disabilities and/or complex health needs.[50] Additionally, multicultural family caregivers are more likely to experience strain and worry about making a mistake in caring for their recipient, regardless of income.[51]

The challenges of navigating support systems for health and long-term care services have become more complex—caregivers had more difficulty coordinating care between various providers in 2020 compared to 2015.[52] The difficulty in getting the help they need also increases for caregivers managing medical complexity. These can be high-intensity care situations or providing care for those with behavioral health conditions.[53] Formal caregiving services, such as transportation, home delivered meals, and in-home health services, are unaffordable for many. According to one study, more than a quarter of caregivers have difficulty finding affordable services within their community.[54] One in five caregivers report that they "never got help or information" they needed to support themselves or provide adequate care to their recipient; 62 percent of caregivers reported needing help with at least one aspect of their caregiving duties.[55]

Disproportionate Health Outcomes Experienced by Caregivers

The physical demands of caregiving can lead to exhaustion and limit the time that caregivers have to take care of their own health. In 2020, caregivers who reported their health status as excellent or very good decreased by 7 percentage points from 2015, and those who reported being in fair or poor health increased by 4 percentage points over the same period.[56] One in four caregivers found it difficult to take care of their personal health and a similar proportion reported that caregiving had negative impacts on their health.[57]

Caregivers who cannot care for themselves are likely to become unavailable to care for others, increasing the strain on the healthcare system. Only 13 percent reported they were asked by a healthcare provider about support for their own well-being.[58] Stress, depression, fatigue, anorexia, and insomnia are the most frequent and significant health impacts of being a caregiver.[59] Caregivers' physical health can also be negatively affected by muscle strain and musculoskeletal injury from caregiving activities and from being unable to spend time on personal activities such as maintaining a healthy diet and exercise. All these factors can exacerbate the symptoms of chronic illnesses.[60] Half of all caregivers report living with one chronic health condition, and approximately half report that their declining health affects their caregiving abilities.[61]

Inequitable Gaps in Service

Caregivers with low incomes and caregivers of color may experience more gaps in access to support, services, and interventions than white or high-income caregivers due to living in under-resourced communities. About 40 percent of caregivers identify as being a member of a racial/ethnic minority group, and this population will likely continue to grow.[62] Materials regarding long-term care and community resources are not always culturally responsive or printed in languages other than English. The lack of language accessibility can exacerbate stress and isolation for caregivers who do not speak English.[63]

Public health approaches should also account for geographic differences in caregiver support for older adults. Rural locations tend to have a greater proportion of older adults and less access to services, leading to greater reliance on family caregivers.[64] Caregivers in rural communities experience additional challenges, such as greater social isolation and being unable to access care and services for themselves.[65] For example, most of Maine's population lives in rural settings and many older adults live alone, and social isolation for older adults and caregivers has been a primary issue in the state.[66] Maine prioritizes housing, workforce, and transportation for rural caregivers by partnering with key agencies, local foundations, community leaders, advocates, and caregivers themselves to help identify interventions.

In contrast, Hawaii's older adults typically live in highly urban and densely populated areas in multigenerational homes. Hawaii's Kupuna Caregivers Program focuses on keeping caregivers in the workplace and delaying nursing home care by offering financial assistance for adult day services.[67]

In a state with both large urban and rural locations, the North Carolina Division of Aging and Adult Services provides information on community-based services, benefits, and protections for older people across all regions of the state.[68] Public health can connect the partners that best understand the population in need of services to ensure that caregivers receive the right resources at the right time through the right delivery method.

Employment/Workplace

One in six employees in the U.S. is a caregiver of an older adult or disabled friend or family member.[69] Being a caregiver and a full-time employee is challenging and can lead to increased absenteeism, reduced productivity and engagement, loss of talent due to caregiving responsibilities, and increased healthcare costs given the higher rates of chronic illness and poor health among caregivers.[70] Sixty-one percent of caregivers with full or part-time jobs said that caregiving has impacted their employment situation,[71] highlighting the importance of employer support. While caregiving can have a direct impact on employed caregivers, only 9 percent of employers surveyed in the "2019/2020 Caregiving and the Workplace: Employer Benchmarking Survey" stated that caregiving was among their top five priorities for employee health and benefit issues.[72] Relatedly, the survey found that about 24 percent of employers made paid leave for caregiving available to their employees.[73]

Even though over half of today's caregivers are in the workforce, federal policy and most states' family leave policies that regulate private employers do not offer paid family leave for caregiving.[74] The demands of caregiving can also negatively impact caregivers' ability to stay in the workforce, thus affecting their income, job security, retirement savings, health insurance, career opportunities, and overall long-term financial well-being.[75] Low-wage and part-time workers are particularly vulnerable to the negative financial effects of caregiving because they cannot afford to take unpaid leave and their employers are less likely to provide paid time off.[76]

Existing Programs for Caregivers – Impacts of Federal Budget Cuts and Reorganizations

Federal, state, and nongovernmental organizations promote the well-being of caregivers and their care recipients through programs that provide resources, financial assistance, respite care, training, and employment support. However, many caregiver supports are federally funded and are at risk of being eliminated. Congressional and Administration changes to funding streams and federal agencies during the 2025 and 2026 fiscal years may have an impact on caregivers through the programs that support them and their care recipients, including access to long-term care and workforce challenges in care facilities.

In addition, the restructuring of the U.S. Department of Health and Human Services (HHS) may disrupt the continuity of programs that older adults rely on. Most notable is the reorganization of the Administration for Community Living (ACL), which oversees grant programs, many of which are authorized by the Older Americans Act (OAA). HHS has also dismissed large swaths of its workforce, leaving open questions as to how ACL-led programs would be carried out, even if funding were to continue. While some staff have been rehired across the department, these positions may not be permanent, as Congress considers funding for these roles as part of its appropriations legislation for Fiscal Year 2026 (FY 2026).

While ACL would be eliminated, some of its programming would go to the Administration for Children and Families (ACF), Centers for Medicare and Medicaid Services, and the new HHS Office of Strategy.[77] Under the President's budget request, $246 million would be made available for caregiver services at ACF, with $207 million going to family caregiving support services, $12 million to American Indian caregiver support services, $17 million for caregiving associated with Alzheimer's, and $10 million for lifetime respite care.[78,79] While many of the programs highlighted below are often not housed within the public health sector, opportunities exist for public health to work with partners to expand the current efforts to improve caregiver support.

Financial Assistance

State and federal programs offer financial assistance to unpaid caregivers. However, these programs typically only apply to those caring for specific populations such as individuals who have a disability, low incomes, or veteran status. Almost every state Medicaid agency administers a self-directed Medicaid service program that provides financial assistance to an unpaid caregiver or for respite care.[80] Eleven states have created structured family caregiving programs through their Medicaid home- and community-based services waivers and administered by home health agencies.[81] Medicaid programs have different eligibility criteria beyond the care recipient's eligibility requirement. Limitations being imposed on some Medicaid-eligible caregivers may also affect their ability and availability to serve as caregivers.

As part of its Caregiver Support Program, the U.S. Department of Veterans Affairs (VA) administers the Program of Comprehensive Assistance for Family Caregivers (PCAFC) for family caregivers of veterans who were seriously injured or became ill as an active service person in the military, naval or air service during any service era. Eligible veterans must have a VA disability rating of 70 percent or more, which indicates significant impairment on activities of daily living, and require at least six continuous months of personal care services. PCAFC pays family caregivers directly using a monthly stipend and can provide some healthcare-related travel cost reimbursement.[82]

Respite Care

Respite care, a temporary break from caregiving duties, is critical to caregivers' well-being. The federally funded Lifespan Respite Care Program is currently administered through the ACL and focuses on expanding access and standardizing quality of respite services. The program provides grants to state systems and agencies that need funding to improve respite care services through activities such as community engagement, service implementation, healthcare for caregivers, and respite voucher programs. Both the House and Senate have voted to reauthorize the program in FY 2025, with appropriations pending.

The ARCH National Respite Network and Resource Center helps family caregivers find accessible respite programs, provides technical assistance to respite service providers, and advocates for policies that strengthen the respite care field through its National Respite Coalition. ARCH administers the National Respite Locator, which connects caregivers to respite providers in their communities and ensures caregivers have the resources they need to find, pay for, and use respite services. ACL currently funds ARCH through the Lifespan Respite Care Program to ensure the program's technical assistance and community-facing services are accessible.[83] However, the President's budget request for the 2026 fiscal year eliminates funding for the Lifetime Respite Care Program.

Training

As of May 2023, 43 states and the District of Columbia have passed the Caregiver Advise, Record, and Enable (CARE) Act to support family caregivers.[84] This law provides training for complex medical tasks and includes the family caregiver in the care recipient's care team to promote family caregivers' confidence in their caregiving abilities. It specifically supports family caregivers when their loved ones are admitted to the hospital and helps them learn how to safely provide care at home once they are discharged.[85] State-level legislation like the CARE Act helps create a central role for caregivers in the healthcare system and engages caregivers in the care recipient's clinical care.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act is an integrated national caregiving strategy that increases overall caregiver support and well-being. The RAISE Act promotes person- and family-centered care in all healthcare and long-term settings and involves caregivers and their recipients in assessment and service planning. The RAISE Family Caregiving Advisory Council is made up of a diverse membership of individuals including: older adults, individuals with disabilities, healthcare providers, state and local officials, and other advocates and experts in caregiving.[86] The council is tasked with providing the U.S. Secretary of Health and Human Services information and recommendations about family caregiving models and ways to improve cross-agency coordination.[87]

Medicaid 1915(c) and 1115 waivers can allow states to use Medicaid dollars to pay for education, training, and counseling for caregivers. As of March 2025, 26 states cover some or all of these services for informal family caregivers of older adults and people with disabilities who receive Medicaid.[88] The resources that states cover range from coaching on health condition management to providing emotional support services, but most states include at least some form of caregiving training.[89] The One Big Beautiful Bill Act allows states to additionally establish 1915(c) waivers for individuals who do not need an institutional level of care. Additional funding includes $50 million in FY 2026 and $100 million in FY 2027 to states for implementing those waivers; however, states can only access these funds if their program does not increase the wait time for those who meet the need for institutional care.[90]

Employment/Workplace

The Family and Medical Leave Act (FMLA) allows eligible family caregivers to take up to 12 weeks of unpaid leave per 12-month period to care for a family member with a serious health condition. FMLA, a federal protection, shields eligible employees from losing their jobs and employer-sponsored health benefits if they take job-protected leave under the act.[91] Some states have expanded employee benefits by relaxing unpaid leave eligibility criteria and length, allowing employees to use earned sick leave for caregiving responsibilities, and mandating paid FMLA leave and/or sick leave.[92] As of February 2025, 23 states and the District of Columbia have enacted a mandatory or voluntary paid family leave program; before the COVID-19 pandemic, employees in only nine states had access to the benefit.[93]

Over half of U.S. states have established a caregiver tax credit based on the federal Child and Dependent Care Tax Credit (CDCTC). CDCTC provides tax credits for care expenses that enable the caregiver to continue to work. The credit is available on a sliding scale to caregivers of a dependent who is younger than 13 years old, or spouses or dependents who are physically or mentally unable to care for themselves.[94] At least 26 states and the District of Columbia have crafted policies that expand CDCTC, incentivizing family caregivers of older adults to participate and making it easier for family caregivers to stay in the workplace.[95] In one example, Oklahoma enacted a family caregiver tax credit for the 2024 tax year. Under the Caring for Caregivers Act, unpaid family caregivers who meet income eligibility requirements can receive a tax credit for up to 50 percent of eligible caregiver costs. The nonrefundable credit is capped at $2,000 per year for single caregivers with adjusted gross incomes under $50,000 and $100,000 for people who file jointly; caregivers of veterans and people with ADRD can receive up to $3,000 per year.[96] Other states have created their own tax credits based on percentages of the federal CDCTC, made their credits refundable, increased the income eligibility threshold to receive the credits, and found other ways to support informal caregivers through tax policy.[97]

Resources and Support

The National Family Caregiver Support Program (NFCSP) was added to the Older Americans Act (OAA) in 2000 to provide grants to states and territories based on the share of its population aged 70 and older. These federal grants fund a range of supports that assist caregivers in providing in-home care to their care recipients for as long as possible, and in conjunction with coordinated state and local services. The program provides five types of services: (1) information about available services, (2) help in gaining access to services, (3) individual counseling and training, (4) respite care and, on a limited basis, (5) supplemental services.[98] For example, New York uses a No Wrong Door approach through its *NY Connects* system[99] to make it easy for caregivers to identify and access the services regardless of their first contact with state services that NFCSP funds.[100]

Other sectors also support infrastructure for caregiving. *Helping States Support Families Caring for an Aging America* was a national initiative of the Center for Health Care Strategies (CHCS) that supported state development of strategies to prioritize and advance caregiving programs. State and private organizations worked together in cross-sector state teams along with state Medicaid agencies, departments of aging and health and human services, area agencies on aging (AAAs), health plans, universities, and community-based organizations. The technical assistance CHCS provided led to the development of strategies to strengthen caregivers' capacity, enhance data collection to inform future policies, and promote caregiver support in other sectors like housing and transportation.[101]

The John A. Hartford Foundation funds many programs that disseminate resources to caregivers. Rush University Medical Center in Chicago, Illinois, implements its Caring for Caregivers Model as part of its role as an Age-Friendly Health System. Their program, called "Ready, Willing and Able," aims to increase physician awareness of family caregivers' role in the health of older adult patients.[102] The program focuses on incorporating the value of caregiving resources into the direct medical care workforce. Meanwhile, the Benjamin Rose Institute on Aging has created an online resource called "Best Practice Caregiving" that helps both family caregivers and healthcare providers find local, culturally appropriate, and scientifically sound support services.[103] By providing tailored resources to both types of care providers, Best Practice Caregiving streamlines the search for caregiver supports from the clinical and family perspective.

Recommendations: How Public Health can Support Caregivers

While many sectors are involved in supporting caregivers, public health can play a uniquely important role in supporting their needs now and in the future. The AFPHS 6Cs Framework provides helpful structure for public health strategies that support caregivers.

> **Creating and leading policy, systems, and environmental changes to improve older adult health and well-being.**

The public health sector can improve employment security for caregivers by partnering with other entities to support caregiver-friendly changes to workplace protections and employee leave policies. Public health agencies and organizations can create hubs of information to disseminate policies and programs in pursuit of workplaces that make caregiving easier.

States and localities that expanded existing workplace protections and flexibilities (e.g., FMLA) have become leaders in empowering caregivers to remain in the workforce. Access to paid sick leave has grown since the COVID-19 pandemic began, which helped influence an environment more friendly to paid leave. In March 2019, 76 percent of workers had access to paid sick leave benefits; by March 2024, 81 percent of workers had the same benefit.[104, 105] Access to paid sick leave increased more than access to other kinds of paid leave, with paid vacation and holidays increasing only one percentage point over the same five-year period.[106, 107] Public health practitioners can collaborate with organizations engaged in advocacy efforts to support expanded family and medical leave protections and flexibilities. Employees managing illness, disability, or caregiving responsibilities should have the opportunity to do so without fear of employer retribution. Public health's role in protecting the well-being of communities includes protecting the ability to care for one's family or friends.

State agencies and organizations have also focused on bolstering caregivers' financial security. The Maine Public Health Institute partnered with the Maine Department of Health and Human Services' Office of Aging and Disability Services and the five Area Agencies on Aging (AAAs) in Maine to develop the "Respite for ME" grant program, part of the 2021 Maine Jobs and Recovery Plan legislation and funded by the federal American Rescue Plan. The grant program provides up to $5,171 to eligible caregivers for respite care, self-care, and legal consultation.[108] By working between aging, health services, and public health sectors, public health leaders were able to create a resource that can provide caregivers with financial, emotional, and legal support.

> **Connecting and convening multi-sector stakeholders to address the health and social needs of older adults through collective impact approaches focused on the social determinants of health.**

Public health can connect caregiver support initiatives with existing programs across non-health sectors. The public health, housing, transportation, and education sectors could all better support caregiver needs by partnering across sectors to align with or expand existing programs that support older adult health and well-being.[109] Establishing and leading multidisciplinary teams can break down silos and improve program implementation and efficiency. Partners may include state departments on aging or elder affairs, AAAs, Medicaid agencies, state departments of health and human services, state chapters of the Alzheimer's Association, and AARP. Coordinating efforts among sectors would reduce duplication, which may allow for more emphasis on creative, innovative, and collaborative approaches to caregiver support initiatives. Public health is uniquely positioned to elevate program coordination as an age-friendly model for other sectors.

The public health sector could convene partners at various levels and across sectors to identify and support policy priorities on caregiving. The RAISE Family Caregiving Advisory Council, mentioned earlier, is an innovative national model that could be implemented at the state or local level to build formal relationships and raise public awareness about the importance of caregiving support. Engaging people with lived experience, those who work in health-related fields, and partners that represent agencies and organizations outside of public health can ensure the consideration of well-rounded strategies that span every aspect of the caregiving experience. These teams can develop the design, adoption, implementation, and ongoing evaluation of best practices for caregivers and caregiver support.

The Kansas Health Institute's *Age-Friendly Kansas* initiative facilitates regular advisory committee meetings with the goal of developing an *Age-Friendly Kansas* statewide, multi-sector plan. The committee members represent state and county health departments, other state agencies (including the Office of the Attorney General and Department of Transportation), academic institutions, AAAs, nonprofit organizations, research centers, and healthcare service providers. The diversity of representation across sectors, geographies, and levels ensures that the initiative has both depth and breadth of experiences and expertise.[110] *Age-Friendly Kansas*' workgroups focus on specific public health and healthy aging initiatives with cross-cutting principles, including preventing social isolation, supporting aging in place, supporting financial planning, and promoting health equity.[111] Each of these principles connect into caregiver support. Kansas' public health institute was able to convene these partners because of the cross-sector reach of the public health field.

The Montana Department of Public Health and Human Services (DPHHS) partnered with Montana State University (MSU) to provide meal packages to unpaid family caregivers. The *Caregiver Respite Food Program* aims to support caregivers in Montana by relieving some of the burden from their daily lives and provide healthy prepared meals for both the caregiver and recipient. By partnering with MSU, in just a three-month timeframe, DPHHS ensured 580 meals reached family caregivers in the state.[112] The MSU Extension Montana Healthy Aging Initiative, through which this program runs, is an evidence-based education initiative that also provides year-round caregiver respite retreats and multi-session caregiving training courses across Montana.[113]

> **Coordinating existing supports and services to help older adults, families, and caregivers navigate and access services and supports, avoid duplication, and promote an integrated system of care.**

Public health can play an important role in ensuring healthcare providers understand and can refer caregivers to the non-clinical resources available in their state and community. Caregivers and their recipients should be able to readily participate in community life and easily find the support they need to be able to fully participate in their everyday lives and activities.[114] To foster person- and family-centered care and shared decision making, healthcare providers should include caregivers as valued members of the care recipient's clinical care team.

As of March 2025, 44 states and territories have adopted the Caregiver Advise, Record, Enable (CARE) Act.[i, 115] This act requires hospitals to identify and record a caregiver in the medical record of any patient who provides permission; physicians are required to provide caregivers notice about discharge timing and next steps, including training on care tasks the caregiver will manage at home.[116] Hospitals in states that have passed the CARE Act exhibited better patient experience and outcomes as a result of working with caregivers at the point of discharge.[117] The public health sector can work with hospitals and direct care providers under the CARE Act to improve discharge systems by coordinating services at the point of discharge. Public health agencies can incorporate health-related social needs coordination, often in partnership with human services agencies, into the discharge process for the patient and caregiver—using training to direct caregivers toward helpful resources.

Advocating for the creation and expansion of governmental supplemental financial security programs could help improve the financial security of caregivers. Public health has a role in coordinating access to, and utilization of, existing caregiver

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i The states that have not adopted the CARE Act are Alabama, Arizona, Florida, Georgia, Idaho, North Carolina, South Carolina, South Dakota, Tennessee, Vermont, and Wisconsin.

financial support services while progressing initiatives that can expand these resources. The Colorado Department of Public Health and Environment (CDPHE) manages the Economic Mobility Program, which seeks to improve the financial well-being of Coloradans across their lifespan.[118] The CDPHE Economic Mobility Program administers the *Get Ahead Colorado* campaign, an initiative to inform people about the existing tax credits and services available through state government. The program sends text messages and provides information about tax credits and tax filing services to eligible caregivers.[119] *Get Ahead Colorado* coordinates the Colorado Child and Dependent Care Tax Credit and low-income tax credits, which can improve caregivers' financial security. By alerting caregivers to tax credit opportunities, Colorado's public health agency increases uptake of cross-sector resources that ease the financial burden of caregiving. Existing programs for specific populations of caregivers and recipients can be expanded or replicated to provide payment and tax credits for care provision. In states, such as Oklahoma, that provide tax credits for caregivers of older adults specifically, this innovative coordination model would allow public health agencies and organizations to support caregivers' financial well-being.

> **Collecting, disaggregating, analyzing, and translating relevant and robust data on older adults to identify the needs and assets of a community and inform the development of interventions through community-wide assessment.**

Public health can promote research into the scope and experience of caregivers in the United States. National organizations such as the National Alliance for Caregiving and AARP collect, analyze, and publish older adult and caregiver data that are available for public use.[120,121] However, more state and local-level data on caregivers are needed to be able to better understand the current subnational caregiving landscape. Information could include caregivers' experiences, challenges, opportunities, and assets. Local data help stakeholders better understand and assess caregivers' needs and responsibilities and can provide insight on the value of caregivers to the healthcare and public health systems. Because caregivers' experiences differ due to numerous factors, data about states and communities help tailor caregiver supports. The Iowa Department on Aging worked with Iowa's AAAs to implement a standardized family caregiver assessment of older adults and caregivers. The short assessment provides information about the caregiving situation and any issues that need to be addressed.[122] Public health agencies and AAAs can use these data to evaluate the current caregiving landscape in the state and assess opportunities for program and policy improvement.

Program and policy developers and implementers also need more evaluation data from the programs designed to support caregivers to ensure these programs are effective and to understand how they can be improved. Information about caregivers and existing support systems can be used to enhance existing programs, inform policies, and lead to the creation of new and innovative strategies. Program evaluation findings can then inform any adjustments needed to ensure programs are serving the population of focus as intended.[123]

The public health and research and evaluation sectors must assess the availability and capacity of existing services and supports to better prepare resources and systems for the future growth of the aging population and corresponding need for more caregivers. There is a lack of research estimating the gap between predicted workforce capacity and anticipated demand for support services for both aging adults and their caregivers.

> **Communicating important public health information to promote and support older adult health and well-being, including conducting and disseminating research findings and emerging and best practices to support healthy aging.**

Public health must use culturally appropriate communication strategies that respect the diversity of the caregiving and care recipient populations. Caregivers are often clinical advocates for aging adults, so their communication skills and style can have a direct impact on the health and well-being of the care recipient. The public health sector can engage caregivers to develop and implement messaging that emphasizes the importance of caregivers and their roles, contributions, and value to the healthcare system. Communication can be used to highlight the value of caregivers in society and the challenges they face, which can shape cultural norms to proactively support caregivers. Public health should also increase awareness of, and access to, evidence-based programs and services that assist caregivers and care recipients. Improving communication about caregiver support can lead to engagement with cross-sector partners to compile and consolidate existing resources to improve accessibility.

The public health sector should call for the improvement of policies that promote increased support for caregivers, especially among caregivers from communities of color. AARP Michigan created the *Voices of Michigan Caregivers* campaign—a project that highlights the diversity of the estimated 1.73 million unpaid caregivers in the state.[124] The storytelling campaign aims to increase awareness of, and support for, the societal and economic contributions of Michigan's family caregivers. In Michigan, the Southeast Michigan Senior Regional Collaborative created a caregiving coalition to amplify caregivers' perspectives on relevant policies and programs using funding from philanthropic partners such as Grantmakers in Aging and the Michigan Health Endowment Fund. The coalition centers the diversity of the unpaid caregiver workforce in Michigan when informing education, social support, and health services access resources.[125]

> **Complementing existing health promoting programs to ensure they adequately meet the needs of older adults.**

By ensuring support programs complement training and care provision, especially for programs managed by public health, the public health sector can create a system that provides caregivers with the tools they need for themselves and their care recipients.

Using grant funding from the Centers for Disease Control and Prevention, the Wisconsin Bureau of Aging and Disability Resources hired community health workers (CHWs) as members of its aging and disability resource centers. The CHWs directly administered support services, such as meal delivery and memory screenings, mostly to tribal, rural, and under-resourced communities. CHWs also built connections between sectors of the community such as local businesses, law enforcement, and public facilities to advocate for increased accommodations for aging community members and their caregivers. Finally, CHWs coordinated support services for older adults and caregivers.[126] Including a CHW in the caregiver support process allows caregivers to feel confident that the resources they receive, or are referred to, are appropriate, helpful, and non-duplicative.

Conclusion

Caregiving for a rapidly growing older adult population should be a public health priority given that caregivers are a critical national resource as the primary source of home care and support for older adults in the U.S. Supporting informal caregivers can help care recipients live in their homes and communities as they age and is a cost-effective strategy that supports the overall health and well-being of older adults. Specifically, public health can embed support for caregiving within current systems, policies, and environments so that caregivers can provide care in a way that protects their health and well-being, alongside their care recipients.

Public health and cross-sector partners can work together to develop systems to provide relief from the demands and stress of caregiving and help to reframe how society views the value of caregivers' contributions. Public health leaders can identify and prioritize the needs of caregivers, examine the existing systems and identify gaps in infrastructure, set national and local goals, evaluate program and intervention-specific effectiveness, monitor progress, and scale up implementation of successful programs that have demonstrated effectiveness in supporting caregivers.

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