



## Family caregiver support: state and federal policy and programmatic solutions

### Family caregiver value



In 2017, **the value of family caregiving was \$470 billion**, 28% higher than total out-of-pocket spending on health care, valued at \$366 billion

More than 43 million U.S. adults, 13% of Americans, provide unpaid care to family members or friends<sup>i</sup>. These care providers administer medical care, run errands, provide transportation, manage finances, and help with household chores, among other activities.

While most family caregivers are not reimbursed for their efforts, they are a significant component of the nation's long-term care system. In fact, the AARP Public Policy Institute estimated the economic value of unpaid caregivers to be approximately \$470 billion in 2017.<sup>ii</sup> For reference, the value of family caregiving in 2017 was nearly \$100 billion higher (28%) than all out-of-pocket spending on health care in the U.S. (\$366 billion).<sup>iii</sup> However, despite their significant contributions,

---

<sup>1</sup> Unpaid care providers are commonly referred to as “**informal**” or “**family**” caregivers. The terms are often used interchangeably to describe someone who provides a broad range of unpaid care or assistance to an individual with a chronic or other serious health condition, disability, or functional limitation that interferes with daily activities. For this brief, the term “family caregiver” will be used.

CHRT is an independent 501(c)(3) impact organization with a mission to advance evidence-based care delivery, improve population health and expand access to care.

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



## POLICY BRIEF- Family caregiver support policies

family caregivers are often undervalued and under or unsupported within the nation's long-term care system.

Recent trends have created a growing sense of urgency to find ways to support family caregivers, alleviate their stress, and help care recipients to remain in their homes and communities.<sup>iv</sup> The COVID-19 pandemic, especially, has accelerated the demand for home- and community-based services, rather than institutional care. Additionally, over the next several decades the population in need of caregiving is projected to grow faster than the population of caregivers. By 2050, there will be only three potential family caregivers for every person age 80 or older.<sup>v</sup> In 2010, the ratio was seven potential caregivers to every person age 80 or older. Seniors that don't have a family caregiver to rely on are seven times more likely to be in skilled nursing care, which costs \$100,000 per year on average.<sup>vi</sup> This shift is creating a greater need not only for more caregivers, but for more caregiver support to enable caregivers to continue their work.

To address this issue, several state and federal policy solutions are used, or have been proposed to enhance caregiver supports. These policies consider the factors that contribute to new and existing caregiver challenges, are inclusive of the different kinds of relationships that exist between caregiver and care recipients, and would support many caregivers. This brief reviews six different state and federal policy options to support family caregivers in the U.S.

### State policy options

#### **Medicaid waivers are being used to support caregivers**

State Medicaid waivers, such as 1115 waivers and 1915(c) waivers, have been used by policymakers to support family caregivers. These waivers allow states to make

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



POLICY BRIEF- Family caregiver support policies

changes to their Medicaid programs that differ from existing federal requirements and to test new approaches. For these waivers to be approved, they must be budget neutral.

As of 2020, nearly half of states used a Medicaid waiver to provide some form of education, training, or counseling support for family caregivers of older adults or people with functional limitations<sup>vii</sup>. These education and training services often cover topics related to medical and nursing tasks, such as medication management, disease pathways, performance of instrumental activities of daily living (I/ADLs) or body movement, and medical equipment. With nearly 60% of family caregivers helping their recipient with medical and nursing tasks and 99% helping with IADLs, this type of training has the potential to be useful for many Medicaid waiver family caregivers in the state.

To assist a greater number of caregivers, states can act inclusively when offering caregiver support through Medicaid waivers. Although all fifty states allow Medicaid enrollees to use Medicaid funding to pay for aides of their choice for personal assistance services, how states define unpaid caregivers can influence who will and will not receive assistance.

Georgia, for example, has limitations on their qualification guidelines for assistance and does not permit spouses to receive certain education and training services provided through their Medicaid waiver. Georgia also requires caregivers to live with care recipients to qualify for specific caregiver education and training services. Other states, like Utah and Florida, define unpaid caregivers as “any person, family member, neighbor, friend, companion, or coworker who provides uncompensated care, training, guidance, companionship, or support to a person served.”<sup>viii</sup>

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



States can use broader definitions to enable the inclusion of more family caregivers in services and supports offered by Medicaid waivers.

### **Workplace anti-discrimination laws are being used to protect family caregivers**

States can also protect family caregivers by implementing workplace anti-discrimination policies that prohibit employers from discriminating against individuals with caregiving duties. A report from the Harvard Business School found that many employers are unaware of the magnitude and impact that caregiving has on employment.<sup>ix</sup> While 24% of employers believed that caregiving duties influenced workers' performance, more than 80% of employees with caregiving duties indicated that it affected their productivity. This gap in understanding may further perpetuate a lack of comprehensive workplace policies that support productive employment while caring for a loved one.

Workplace discrimination against family caregivers occurs when employers treat employees with caregiving duties less favorably than others, sometimes referred to as "Family Responsibilities Discrimination". This may arise due to various assumptions about lack of job commitment or caregiving duties interfering with job performance.

Within existing workplace anti-discrimination laws, states can explicitly add a provision for family caregivers that includes a comprehensive definition of who qualifies under this term. States can also ensure that existing anti-retaliation provisions that protect those who come forward with discrimination complaints apply to family caregivers.<sup>x</sup>

Four states and Washington D.C. have implemented laws that provide explicit protections to family caregivers, but only two (Connecticut and Washington D.C.)

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



provide protection for all workers with “family responsibilities,” which is considered to cover workers caring for aging family members.<sup>xi</sup> The Washington D.C. law provides the most clear protection for family caregivers in its language, stating that employment discrimination is prohibited against adults with “family responsibilities,” which are defined as “the state of being or the potential to become, a contributor to the support of a person or persons in a dependent relationship.”<sup>xii</sup>

Of the states that protect individuals from discrimination on the basis of family responsibilities, these protections most often extend only to those with childcare responsibilities and not eldercare or other familial care responsibilities.

### **Investments in long-term care and other programs**

Another way states can help caregivers is to create innovative state programs.

In 2019, Washington state passed the first ever Long-Term Care Trust Act which established a 0.58% employee payroll tax, effective January 2022. The premium will be housed in a state trust fund which finances long-term services and supports for state employees. The trust will pay benefits of up to \$36,500 lifetime maximum to those who require assistance with at least three activities of daily living with some additional criterion. It can also pay for respite care, food delivery services, such as Meals on Wheels, home modifications, and direct payments to family caregivers who were previously providing uncompensated care.

Also in 2019, Georgia established a Structured Family Caregiving program, which began offering individualized assistance and a daily stipend to unpaid family caregivers who live with a qualified 1915(c) waiver participant who is elderly and has a disability<sup>xiii</sup>. This assistance includes access to an electronic case management

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



documentation system that is shared among the care team and enables the support of other care team members, a health coach, and a registered nurse. Family caregivers receive at least eight hours of training each year. This training is tailored according to the caregiver's self-identified needs, review of caregiver documentation, and/or case management activities.

## Federal policy options

### Expanding the FMLA

At the federal level, many of the policy solutions that could support family caregivers are predicated on improving existing policies and infrastructures. One example is to expand the Family and Medical Leave Act (FMLA) to better protect family caregivers.

The purpose of the FMLA is to provide eligible workers with up to 12 weeks of unpaid, job protected leave should they need to take time off for a qualifying purpose. Among these includes caring for a newborn, a seriously ill family member (defined as a spouse, parent, or child), or a wounded military member.

Currently, more than 25% of family caregivers provide care to an adult family member that does not fall under the FMLA's definition.<sup>xiv</sup> To support a greater number of family caregivers, the definition of "family" would need to be expanded to include more family caregiver relationships, including siblings, in-laws, and grandparents.

The federal government could also consider broadening the requirements to include smaller employers and part-time employees. Currently, the law only applies to

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



## POLICY BRIEF- Family caregiver support policies

businesses with 50 or more employees or public agencies. These restrictions exclude nearly 40% of all workers in the U.S.<sup>xv</sup>

In addition, it would be advantageous to family caregivers if any amendment to the FMLA included provisions for paid leave. The FMLA as it stands only provides protection from job loss but does not require employers or states to provide paid time off to care for a loved one.

Recently, the Family Medical Leave Modernization Act (H.R.5289) was introduced in the House in April 2021. This bill would amend the FMLA “to permit leave to care for a domestic partner, parent-in-law, or adult child, or another related individual, who has a serious health condition.”<sup>xvi</sup> A similar bill was introduced to the Senate shortly afterwards.<sup>xvii</sup> If passed, this bill would effectively expand the relationships that fall under the protections of the FMLA which acknowledges the varying caregiver-care recipient relationships that exist. No further action has been taken on either bill since they have been introduced.

### **National Family Caregiver Support Program**

In 2000, the National Family Caregiver Support Program (NFCSP) was created under the Older Americans Act. The NFCSP provides grants to states and territories that support numerous caregiver support initiatives.

NFCSP grantees provide five types of services:

- information about available services,
- assistance to access these services,
- individual counseling,

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



## POLICY BRIEF- Family caregiver support policies

- support groups, and
- caregiving training, respite, and other supplemental services.

A 2019 survey of caregivers who utilized these services found that 74% were able to provide care for longer than would have been possible without the services, 88% felt that they were a better caregiver as a result, and more than 60% indicated that the care recipient would be in a nursing facility without the services they received.<sup>xviii</sup>

In 2020, only about 9% of the funding for the Older Americans Act was allocated to the NFCSP (\$186.9 million), even though the original authorized amount for the NFCSP was \$250 million.

The program could better assist the growing number of family caregivers in the U.S. if the allocated funds for the NFCSCP was increased to the original authorized amount. Full funding for this already approved initiative would create more competent and confident caregivers, reduce the risk of adverse outcomes and burnout, and increase the number of care recipients who are able to remain in their homes.

### **Social Security working credits**

For many middle-aged caregivers, especially women<sup>2</sup>, poverty is a common risk as they take time away from the workforce to care for a loved one.<sup>xix</sup> As an effect of the COVID-19 pandemic, millions of women ended up leaving the workforce, often due to caregiving duties for children or older adults, among other reasons.<sup>xx</sup> The US

---

<sup>2</sup> Women make up 61% of all family caregivers (AARP, *Caregiving in the US 2020*)

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.





Bureau of Labor Statistics has estimated that there were 2.2 million fewer women in the labor force in October 2020 than in October 2019.<sup>xxi</sup>

The federal government could consider amending Social Security to provide working “credits” for family caregivers who leave their jobs to provide care for a family member that is ill, elderly, or has a disability. The implementation of this provision will support the future of individuals who must forgo employment when their caregiving duties demand too much of their time and energy to remain in the workforce.

Different versions of the Social Security Caregiver Credit Act have been proposed in Congress 13 times since 2002 (three times in the Senate and ten times in the House of Representatives).

The most recent version is the Social Security Caregiver Credit Act of 2019 (H.R.4126 and S.2317).<sup>xxii</sup> The bill would have created a credit that would be added to individual earnings to calculate future Social Security benefits.<sup>xxiii</sup> Individuals could claim the credit for up to 60 months and it would vary on an income-sliding based scale. When the caregiver earns more than the average national wage index (\$54,099.99 in 2019)<sup>xxiv</sup>, the credit would phase out. For those caregivers who do not earn an income, a maximum credit equal to half of the average national wage would be provided. However, the 2019 bill was never passed, and a similar bill has not yet been introduced in the new 117<sup>th</sup> Congress.

## Conclusion

The shift from institutional to home-and community-based services in conjunction with a disproportionate increase in older adults relative to caregivers in the near

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



future, creates an imperative to consider various state and federal policies that provide greater support to caregivers.

The programs and policies described in this brief hold promise in meeting the significant, documented needs of family caregivers: providing reimbursement and financial assistance; education and training; and respite and supportive services. Each, in turn, may have the potential to improve the health and well-being of the caregiver, and enable them to provide high-quality care for their loved ones. As policies are implemented, more data, measurement and evaluation are needed to demonstrate their effectiveness in reducing caregiver stress and overall costs and increasing quality, caregiver satisfaction and health status.

## About the Authors

This brief was developed by the Center for Health and Research Transformation, located at 2929 Plymouth Rd, Ste 245, Ann Arbor MI 48105-3206. Contact information: phone number 734-998-7555, email [CHRT-info@umich.edu](mailto:CHRT-info@umich.edu).



The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.

---

<sup>i</sup> <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>

<sup>ii</sup> <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>

<sup>iii</sup> Ibid

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.



POLICY BRIEF- Family caregiver support policies

- 
- iv Center for Health and Research Transformation (2020). COVID-19 adds stress for family caregivers – why that matters
- v <https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>
- vi [https://chrt.org/wp-content/uploads/2021/03/TheHiddenCostOfUnpaidCaregiving\\_Final.pdf](https://chrt.org/wp-content/uploads/2021/03/TheHiddenCostOfUnpaidCaregiving_Final.pdf)
- vii <https://www.nashp.org/wp-content/uploads/2020/10/Medicaid-Supports-for-Family-Caregivers.pdf>
- viii Ibid
- ix [https://www.hbs.edu/managing-the-future-of-work/Documents/The\\_Caring\\_Company.pdf](https://www.hbs.edu/managing-the-future-of-work/Documents/The_Caring_Company.pdf)
- x [https://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/health/protecting-caregivers-employment-discrimination-insight-AARP-ppi-ltc.pdf](https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/protecting-caregivers-employment-discrimination-insight-AARP-ppi-ltc.pdf)
- xi Ibid
- xii <https://code.dccouncil.us/dc/council/code/sections/2-1401.02.html>
- xiii <https://www.nashp.org/wp-content/uploads/2020/10/Medicaid-Supports-for-Family-Caregivers.pdf>
- xiv <https://www.nationalpartnership.org/our-work/resources/economic-justice/fmla/updating-the-fmla.pdf>
- xv Ibid
- xvi <https://www.congress.gov/bill/117th-congress/house-bill/2589>
- xvii Ibid
- xviii <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>
- xix <https://www.caregiver.org/national-policy-statement>
- xx <https://www.forbes.com/sites/robertamatuson/2021/03/01/how-to-stop-the-mass-exodus-of-women-leaving-the-workforce-due-to-covid-19/?sh=61655e51bd7d>
- xxi Ibid
- xxii <https://www.congress.gov/bill/116th-congress/senate-bill/2317>
- xxiii <https://www.murphy.senate.gov/newsroom/press-releases/murphy-lowey-introduce-legislation-to-help-caregivers-with-social-security-credit>
- xxiv <https://www.ssa.gov/oact/cola/AWI.html#:~:text=The%20national%20average%20wage%20index,than%20the%20index%20for%202018.>

The content of this brief has been developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR #90RTHF0001). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). This brief does not necessarily represent the policy of NIDILRR, ACL, or HHS and you should not assume endorsement by the Federal Government.