



**NATIONAL
WOMEN'S
LAW CENTER**

Justice for Her. Justice for All.

Supporting Home- and Community-Based Care **Advances Gender Justice**

About The National Women’s Law Center

The National Women’s Law Center (NWLC) fights for gender justice—in the courts, in public policy, and in our society—working across the issues that are central to the lives of women and girls. We use the law in all its forms to change culture and drive solutions to the gender inequity that shapes our society and to break down the barriers that harm all of us—especially women of color, LGBTQIA+ people, and women and families with low incomes. For more than 50 years, NWLC has been on the leading edge of every major legal and policy victory for women.

Author

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Dedication

This report is dedicated to the author’s mother, Vicky, who has been a direct care worker for disabled people and older adults for over 25 years, showing them the dignity and care they deserve.

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Over the course of our lives, all of us will both receive and give care.

And that care comes in many forms—as children needing the support of parents and family, partners supporting one another through disability and aging, disabled people receiving support from direct care workers, and disabled adult children supporting aging parents.

While care is fundamental and essential to how we live, our nation's lack of caregiving supports makes dignified care difficult to access and unsustainable for people to provide.

Creating a world where older adults and disabled people can access quality and affordable care in their homes and communities, and where caregivers and care workers are supported and well-compensated, is core to advancing gender justice and centers the needs of disabled people and women of color.

For many older people and disabled children and adults, support for activities like cooking and preparing meals, taking medicine, and getting dressed and bathing is essential. Receiving this support at home—whether from family members, friends and neighbors, paid care providers, or all of the above—is typically the preferred option for people who need it. But for many people who want and need home- and community-based services, this care is out of reach—while millions of care providers struggle to make ends meet with low pay, minimal benefits, and frequently part-time and unstable work hours.

The value of home- and community-based care is diminished and disregarded because of the way our society views the women of color who tend to provide care and the disabled people and older adults who tend to rely on care most critically. **We see this in how hard it is to secure and maintain adequate disability care, and in how little caregivers and care workers are supported, paid, and recognized.**



Receiving care at home can be critical for older adults and disabled people to live with dignity, yet many people who need this care face barriers to accessing it—especially if they are also women, LGBTQIA+, or people of color.

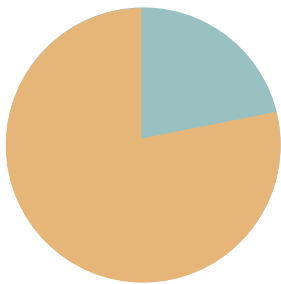
Home- and community-based services (HCBS) enable older adults and disabled people to access long-term support while choosing to live in their homes or community settings instead of moving into a facility like a nursing home.¹

This ability to decide where to live and how to receive support is important to maintain agency over your life. And staying in long-term institutions does not work for all people.

- People are often more isolated from loved ones when they are not living in their communities.
- With minimal oversight, many long-term care facilities spread their workers thin, often resulting in the neglect of residents.² While NWLC supports efforts to improve these institutions,³ such as requirements that nursing homes meet a minimum staffing standard,⁴ we believe that everyone should be able to choose to receive care in more integrated settings, in their communities.

- Disabled people of color may be even more vulnerable in institutional settings due to structural racism that keeps certain areas (and certain demographics of people) resource-poor. And structural racism also leads to more segregated and lower quality institutional settings: Among people living in nursing homes, Black disabled residents are more likely to live in low-quality facilities.⁵

Receiving support in a familiar environment—in the homes they may have lived in for years, with the community members they know and love—can reduce stress and better support people's autonomy. **And a pillar of a person's decision-making power is being able to decide where they live.**



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- Needing help with life's activities should not take away someone's decision-making power. Long-term care facilities and the culture of institutionalization can undermine disabled people's ability to make decisions about their own lives, from when they take their meals to what activities they want to do.
- Remaining in their homes or their communities may be especially important for those who are used to living in a multigenerational home—where, for example, grandparents live with their children and grandchildren. Communities of color, especially those who are Asian, Black, or Hispanic, are more likely to live in multigenerational households.⁶
- Many people prefer to receive care in their homes and communities because of the independence they can assert while still being supported. More than three-quarters (77%) of adults 50 and older want to remain in their homes as they age.⁷

But many disabled people—especially those who are also women, LGBTQIA+, and/or people of color—aren't able to access the home-based care they prefer because it isn't affordable or isn't available, while also facing the brunt of the consequences from a lack of good care.⁸

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- Disabled adults 18 to 64 years old are twice as likely to live in poverty as nondisabled adults in that age range.⁹
- Without Medicaid or other assistance, in-home health care costs a nationwide average of over \$6,000 per month, more than what most people can afford.¹⁰ This can make it extremely difficult to afford care without support like an unpaid family caregiver.
- Disabled women, facing a double bind of ableism and sexism, are especially impacted: Disabled women are more likely to experience poverty than disabled men, across ages, including among those who are employed.¹¹
- Many women, especially women of color, may face financial precarity as they age due to being pushed into low-paid jobs over the course of their working lives.¹² Women of color often have lower savings for retirement (and less money to pay for care as they age) relative to their white and male peers, with Latinas and Black women having the lowest and second-lowest average retirement wealth, respectively.¹³
- Disabled people who are also part of the LGBTQIA+ community may face a high risk of poverty: More than 20% of LGBTQIA+ people live below the federal poverty level.¹⁴ For those who are trans and disabled, the poverty rate increases to 45%.¹⁵
- Black and Indigenous people face higher disability rates than white people,¹⁶ and due to persistent barriers in the health system, poverty, and other inequities that disproportionately impact communities of color, many disabled people of color do not access the health care they need. High costs of health care result in many Black and Hispanic disabled people forgoing care for urgent and chronic needs.¹⁷ Inaccessible HCBS can contribute to people on the intersection of disability and race making impossible choices.

Current public funding does not adequately support individuals' desire to receive care in their homes. Instead, the system funnels people into nursing homes and other institutional settings.

- Most health insurance plans do not cover long-term home-based care.¹⁸ And while Medicare can provide coverage for home health services, it is very difficult to obtain—especially on a long-term basis.¹⁹
- Medicaid provides the majority (69%) of funding for HCBS,²⁰ but many states provide very limited coverage for a small group of people, and Medicaid enrollees seeking care must navigate a complex process.²¹
- Since Medicaid is a means-tested system, aging and disabled people must fall below restrictive income caps and asset limits to access some forms of HCBS—requiring care recipients to remain impoverished or else lose services.²²
- While many states have waivers in place that loosen some of Medicaid's strict requirements,²³ hundreds or even thousands of people in some states remain on waiting lists for the program for years before receiving HCBS, if they receive it at all.²⁴
- The Medicaid program is structured in a way that favors institutional settings over HCBS. For example, it requires states to cover care provided in institutions, including nursing facilities, while not requiring states to fully cover HCBS.²⁵ This creates an institutional bias where the only guaranteed form of long-term care is through an institution, ultimately forcing many people to either enter institutional settings or forgo the care and support they need at home.
- Black and Hispanic older adults particularly bear the weight of these challenges and are most likely to go without help at home.²⁶

Family members and friends often provide care for loved ones who need home-based care—sometimes because it is the preferred arrangement for both parties, and sometimes because professional support is not sufficiently available or affordable. **But due to inadequate public investment and support, this care work is often unsustainable for family caregivers.**



Instead of fostering community support for disabled people, our broken, underfunded care system abandons family caregivers who step in and care for their disabled loved ones at home—even if they themselves lack the support or resources to do so alone.

Too often, family caregivers are left isolated, financially insecure, and ultimately less physically and mentally able to provide the attentive care they want to give. These harmful impacts are especially felt by women, who are most likely to take on (often multiple) family caregiving responsibilities, and by women of color who are already more likely to be pushed into low-paid jobs and struggle to make ends meet.

- 48 million caregivers who provide care for an adult family member or friend are unpaid.²⁷ And in 2021–2022, nearly 60% of unpaid caregivers were women.²⁸
- Not only do many family caregivers go unpaid, but almost 80% of those caregivers are paying out of pocket for caregiving expenses—and spending more than a quarter of their income.²⁹ Annually, this amounts to caregivers spending an average of \$7,242 out of pocket a year on expenses like payments to medical providers and hospitals, rent or mortgage payments for care recipients' housing, and prescriptions.³⁰

- **These caregiving costs can especially harm caregivers who face mounting personal expenses with little disposable income.** About 30% of unpaid caregiving is done by older women (55 years old and older) who may soon (or currently) need to pay for their own care-related expenses, like care worker support or prescription drug costs.³¹ To juggle caregiving costs on both ends, older women may have to dip into their (often limited) pension or retirement funds or cut back on their own health care spending.
- Working Latinas and Black women, who already are typically paid lower wages than their white, male counterparts,³² feel the highest financial strain of caregiving costs.³³ In trying to balance caregiving responsibilities with their jobs, many women caregivers have to opt for lower-paying part-time jobs or roles that have less demanding hours; forgo promotions; or leave their jobs completely.³⁴ **This means less money in caregivers' pockets for themselves and their families—including the people for whom they are providing care.**
- Over 60% of family caregivers caring for an adult also work another job; among younger caregivers, more than 70% are also working a paid job.³⁵ This can include being a care worker in *addition* to an unpaid caregiving role. Twenty-nine percent of home care workers also provide unpaid family caregiving for an older adult (compared to 19% of workers in the labor force overall).³⁶

Despite the fact that so many working people have caregiving responsibilities, many employers fail to accommodate the realities of caregiving.

- Paid family and medical leave and paid sick days are critical supports that enable people to have more flexibility to meet family caregiving needs and recognize workers' needs to care for themselves. Unfortunately, without a national paid family and medical leave law, only one-quarter of private-sector workers have paid leave through their employers to, for example, care for a family member's serious health condition or their own.³⁷
- In low-paid jobs—which women of color disproportionately hold—that number dwindles to just 13%.³⁸ Similarly, while 80% of civilian workers have paid sick days, in the lowest-paying jobs, only 40% of workers have paid sick days.³⁹
- And while the Family Medical Leave Act (FMLA) provides protected unpaid leave to 15 million workers for circumstances like caring for a disabled partner or one's own health condition, 44% of workers are *not* eligible for this protection. Moreover, because FMLA

is *unpaid* leave, people with lower incomes—disproportionately women and workers of color—are less likely to use FMLA leave, even if they are eligible.⁴⁰

- Black women and Latinas, who are overrepresented in the low-paid workforce, report particularly high instances of cutting back on their paid work hours due to unpaid caregiving responsibilities.⁴¹

Without support, caregiving takes a toll on people's health. This can have disproportionate impacts on disabled caregivers, who deserve to have their own needs met.

- Given that over a quarter (29%) of adults in the United States have a disability,⁴² many disabled people are *also* caregivers for other family members. About one-third (33%) of caregivers are disabled.⁴³ And 41% of caregivers report having two or more chronic diseases.⁴⁴ These numbers are even higher for caregivers who are 65 years old or older.
- In addition to struggling to afford their own care because of the high cost of caregiving for others, caregivers often face isolation and stress as they try to juggle other responsibilities (paid work, caring for young children, navigating a complicated health care system) without adequate support—which, in turn, can worsen disabled caregivers' own physical and mental health.⁴⁵
- And over half (53%) of caregivers report that their declining health makes it harder to provide the level of care they want to their disabled or aging family member,⁴⁶ exacerbating challenges for both caregiver and care recipient.

Family caregivers often want and need professional help, such as direct care workers, to navigate their family member's medical needs with greater ease, but often cannot access the support they need from the **incredibly strained direct care workforce.**



Under our current care system, direct care workers are under-compensated and exploited, driving the mostly women of color workforce out of the profession or into poverty.

Direct care workers support aging or disabled people with life activities, from personal care to health care. They often work from people's homes (home care workers such as home health or personal care aides), and also work in assisted living facilities (residential care aides) and nursing homes (nursing assistants).⁴⁷

As our population ages, the high demand for these jobs will only grow—yet this demand has not translated into adequate pay or job quality. This devaluing of care work stems from our care system's roots in chattel slavery, creating a sense of entitlement to Black and brown women's uncompensated caregiving.⁴⁸

- The direct care workforce—over 5 million people⁴⁹—is nearly entirely comprised of women, most of them Black and brown women and disproportionately immigrants.⁵⁰
- The majority of the direct care workforce are home care workers who make a median wage of \$16.13 per hour, **making this one of the lowest-paying jobs in the United States.**⁵¹

- Moreover, median direct care hourly wages are *lower* compared to jobs with similar and lower entry-level requirements.⁵²
- The low wages in this highly strenuous job force a lot of direct care workers into financial precarity. Forty-nine percent of direct care workers use public assistance programs—like Medicaid, SNAP and TANF—to make ends meet, and two in five direct care workers live in low-income households; for home care workers, this number rises to 58%.⁵³
- **Notably, although direct care workers provide skilled, essential labor for the health care system, their own access to health care is not guaranteed.** Fewer than half of direct care workers have employer- or union-provided health insurance, compared to 68% of the general labor force, and about 11% of direct care workers don't have insurance at all.⁵⁴ Given that a third of direct care workers are Black,⁵⁵ the health care disparities built into the profession contribute to the barriers to health care Black women face.⁵⁶ Many direct care workers doubly rely on Medicaid—as the funder of their low wages and as the health care provider they qualify for *because* of those low wages.⁵⁷
- About a third of direct care workers live in households with children under 18 years old,⁵⁸ with low wages for care work undermining their ability to care for their children.
- Unlike other health care professions that reward expertise, industry norms create very little room for career advancement or promotion within direct care work, making it even harder for the industry to attract and retain workers.⁵⁹

The care system often relies on workers who care deeply about the disabled and aging people they support—and exploits these workers' sense of humanity and pride in their work so they remain in these low-quality jobs. But eventually, many people are pushed out of the profession, and too few are encouraged to enter.

- The most recent study on turnover for nursing assistants in nursing homes found that the average annual turnover was over 120%.⁶⁰
- The physical demands of the job—such as transferring people out of bath chairs and mobility aids—also can make it dangerous if there's a lack of support or training.
- Back injuries, strained muscles, and wounds are commonly reported injuries nursing assistants in nursing homes face in addition to contracting illness. During the onset of the COVID-19 pandemic, they were nearly eight times more likely to experience

workplace injuries than the average worker because of contracting illness.⁶¹ Other similarly low-paid jobs may still be more attractive to direct care workers because of the lower injury risk.

- The physical strain of the job can put direct care workers at risk of disability (or exacerbate an existing one). And because of the low wages and minimal benefits, direct care workers may not be able to retire and access care when they need it as they age or incur injury.

The alchemy of high demand and bad working conditions has created a shortage of direct care workers.

- The demand for direct care workers is only increasing—by 2040, more than one in five people in the United States will be 65 or older⁶² and will likely need the aging and disability support direct care workers provide.
- The field is projected to add 860,000 jobs—the vast majority home care jobs—within a decade,⁶³ and the projected growth for home health and personal care aides is greater than for any other single occupation.⁶⁴
- Given that poor working conditions already are yielding worker shortages in the direct care field, it will be extremely difficult for employers to fill direct care roles at a scale in line with projected demand without improving the quality of these essential jobs.⁶⁵

This combination of heavy demand on essential labor while undercompensating for it represents a trend that industries dominated by Black and brown women often face—**a racist and sexist assumption that Black and brown women should be doing this work without regard for their livelihoods and well-being.** The under-compensation of these workers also reinforces the incorrect, ableist belief that the work of supporting disabled people to live their lives and participate in the community is not important.

**We can push our society to recognize
that caregiving is a
shared responsibility**

Recipients of care, family caregivers, and direct care workers—especially those who are Black and brown women—are all acutely harmed by a care system that was not built for them. As it stands, recipients of care and their families are paying more than they can afford while care workers are not being paid enough to take care of themselves and their families. This does not add up.

Workers should be paid more, families should be paying less, and the **solution is for our government to step in and act**, course correcting for the racist, sexist, and ableist beliefs that have structured our current care system and undermine care as “unskilled” or invisible work. **We can push our society to recognize that caregiving is a shared societal responsibility**—not just on disabled people and women of color to figure out in isolation—and invest in its infrastructure accordingly.

While enhanced federal Medicaid funds provided during the pandemic helped states stabilize their care systems,⁶⁶ a more robust national investment in HCBS and support for caregivers is necessary to ensure everyone who needs this care can access it and care workers can access good jobs. Legislation like the Long-Term Care Workforce Support Act, Better Care Better Jobs Act, HCBS Access Act, Family and Medical Insurance Leave (FAMILY) Act, and the Healthy Families Act can work to advance these priorities.

In addition, states can support families and care providers by investing their own resources in HCBS and by sustaining and building on pandemic-era improvements,⁶⁷ including policy changes that expanded eligibility for Medicaid HCBS (e.g., to serve children with behavioral health needs);⁶⁸ reduced waiting lists;⁶⁹ provided housing-related services and supports;⁷⁰ supported family caregivers;⁷¹ and improved compensation and career paths for home care workers.⁷²

States can also support direct care workers by, for example, enacting policies to combat misclassification, promote unionization, incentivize and improve training and career ladders, support immigrant workers, and collect and publish data on job quality metrics for the home care workforce—and by consulting directly with care recipients, family caregivers, and direct care workers to advise on proposed policy changes.⁷³

Collectively, we can push our policymakers to ensure that disabled people can access affordable care that enables them to fully participate in their communities, that family caregivers are financially and emotionally supported in caregiving for their loved ones, and that direct care jobs are good, well-compensated roles that enable women of color to thrive—**so that we all can care and be cared for.**

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