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Policy BRIEF

Reforming Long-Term Care Policy

Lessons from the Past, Imperatives for the Future

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Executive Summary

For more than 60 years, Congress has debated public policy around long-term care.[1] Meanwhile, middle-class American families struggle to afford the care their older relatives need. Most people will need help with basic daily activities at some point in their lives, and many will be unable to pay for it. In this brief, we present an overview of the current long-term care crisis and its historical context.[2] We present a range of options for reforming federal policy, from changing Medicaid and Medicare to creating a new public insurance program and addressing private market failures. We also illustrate the very real costs of the status quo, in the words of people facing the challenges of aging with dignity and providing care for their loved ones as they age.[3]

The costs of long-term care pose a significant risk to individuals and families as they age. The statistics are all too familiar: 70% of older adults will need long-term services and supports at some point, and 48% will receive some form of paid care.[4] A 65-year-old will incur an average of $120,900 in paid care expenses over their lifetime, and an estimated 15% of them will spend more than $250,000, with families paying for about one-third of that care themselves.[5] Most families will not have the income or assets to afford the care they need.

And behind every statistic are American families, struggling to care for their elderly relatives and facing possible financial ruin in doing so.

> "Finance is always in the back of my mind because I watched my mother decline with Parkinson's disease and she ended up the last few years in a nursing home. I know how atrociously expensive nursing homes can be and even assisted living and so I always wondered, do I have enough money to be able to support myself..." —*Jodie*

In this brief, we present a snapshot of the long-term care crisis we face, how we got here, and what we can do about it. We also illustrate the very real costs of the status quo, in the words of people facing the challenges of aging with dignity and providing care for their loved ones as they age.[6]

Long-term care is likely the largest uninsured expense most of us will ever face. Our current piecemeal and patchwork approach to financing long-term care has left many middle-class families struggling to afford care for their older relatives. Neither private health insurance nor Medicare typically covers long-term care expenses, although Medicare provides some limited care in the home and in a skilled nursing facility following hospitalization. Long-term care insurance is available in the private market, but premiums are costly, and only 3% to 4% of people over 50 have purchased plans.[7] As a result, many people who need help must rely on family and friends as unpaid caregivers, or must "spend down" their assets to qualify for Medicaid. In turn, unpaid caregivers pay a hefty personal price in out-of-pocket spending, lost wages and benefits, and physical and emotional harms.[8,9,10]

"I took care of my mother for 17 years...My mother could get [Medicaid] long-term personal care, and she could also get the waiver because she didn't own a house, and she would live with me...That was good because I could go to work and had someone to stay with my mom. But [now with my husband] since we own a house, our income we...would not qualify...If they could do something, give me at least about three or four hours a week, so I can go and do whatever I need to do and get back. But in this case, I have to take him [husband] with me." —*Anna*

THE PROBLEM, AND THE PRICE AMERICANS ARE PAYING

The current system of paying for long-term care is a function of medicalized models of care and the trajectory of public coverage programs in the United States. The historical reliance on families or communities to provide long-term care is no longer tenable as the population ages, families have fewer children, more people work outside the home, and chronic illness results in disabilities as people grow older.[11]

Long-term care—or long-term services and supports—refers to a broad range of services that help people with basic daily activities, such as dressing, bathing, or eating. These services can be provided in homes, communities, or residential facilities such as assisted living and nursing homes, and are generally not covered by Medicare or private health insurance. The reality for many older Americans is that help with activities of daily living is what they need to stay in their homes, and what they want insurance to cover.

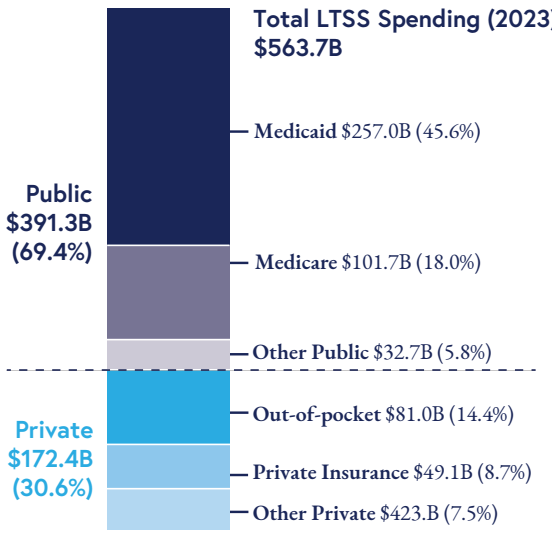
"I would like [the government] to know that I need more health care, like someone to come to my home and do the mopping and washing dishes and prepare my meals for me. Because I had requested that my insurance do that, but they said I had to get a private company to do this and pay for that out of my pocket. That's one of the things I need done for me." —*Sophia*

The current payment system reflects an outdated distinction between "skilled care" (medical care delivered by health professionals and covered by Medicare) and "custodial care" (personal services delivered by caregivers and not covered by Medicare). For older adults, Medicare pays for acute and some post-acute care, including skilled nursing and home health care for up to 100 days after a hospital stay. Medicaid pays for custodial or long-term care only for people who meet strict means-tested eligibility. Most older adults not eligible for Medicaid must pay for long-term care themselves (out-of-pocket or through long-term care insurance) or rely on family and friends to fill the gaps. About 75% of all long-term care is provided by unpaid caregivers.

In terms of paid caregiving, Figure 1 shows the distribution of long-term care expenses by payer in 2023.[12] Public payers (primarily Medicaid) account for nearly 70% of paid long-term care. Families pay for more than 14% out of pocket, with private insurance paying just under 9%. Importantly, these charts do not include unpaid care by family, which, if valued in dollars, even conservatively, would double the total spending.

FIGURE 1.

Long-Term Services and Supports (LTSS) Spending by Payer (in billions)



Source: Colello et al, *CRS Report*, 2025.

MEDICAID

Today, Medicaid, funded jointly by states and the federal government, covers approximately 46% of the nearly $564 billion spent annually on long-term care.[13] It covers care for about 4.2 million people in home and community-based settings, and 1.6 million in institutional settings.[14] But Medicaid's role in paying for long-term care was not a result of a well-crafted policy strategy. At its onset, it focused on a medicalized model of care in licensed nursing homes; as such, nursing home care is a mandatory benefit, but care in home and community settings is optional and varies by state. Medicaid's use of institutional care as the primary setting for long-term care began to shift in the late 1980s, as federal policies encouraged more use of home and community-based care. Virtually all states now offer home and community-based care through state plans and waiver options, although waiver services are subject to eligibility categories, geographic limitations, and waiting lists.[15] Further, Medicaid reimbursement rates are lower than those of other payers and often do not cover the costs of care, contributing to longstanding shortages of direct care workers.

As a means-tested program, Medicaid is not available to everyone; only 17% of Medicare beneficiaries also qualify for Medicaid. All states have income limits for Medicaid, which in 2025 is typically $2,900 per month for a single adult 65 or older.[16] Almost all states also have asset limits, typically using $2,000 as a threshold.[17] People with assets above this limit must "spend down" before they can be eligible for Medicaid.

> "The way Medicaid is set up for nursing homes, you have to be divested of all your assets and figure out what you're doing with your house so Social Security doesn't take it, and, I mean, it's just kind of a mess. You know, it shouldn't have to be that bad. I just feel like maybe there's a way to prevent people from getting to the point that they need to be in nursing care, 24 hours, seven days a week." —*Cecilia*

MEDICARE

While traditional Medicare does not pay directly for long-term care, it covers some long-term care services incidentally and temporarily, mostly for people needing skilled care after hospitalization. In that context, it funds nursing home stays for up to 100 days per benefit period, with large patient copayments after 20 days. It also covers home care for beneficiaries who are homebound and need part-time or intermittent skilled care. Medicare post-acute spending accounts for 18% of the total spent on long-term care, split evenly between nursing home and home care.

People enrolled in Medicare Advantage plans have new options for Medicare-funded home care through the expansion of supplemental benefits. With the passage of the CHRONIC Care Act of 2017, plans were allowed to include limited "non-medical" supplemental benefits related to the long-term care needs of enrollees with chronic conditions, including the option of personal care at home without skilled care.[18] Data on the use of these benefits is sparse.[19]

PRIVATE PAY AND LONG-TERM CARE INSURANCE

Long-term care is expensive and far exceeds the personal resources of most American families.[20] The median annual cost of a home health aide to assist with daily activities is nearly $78,000; adult day care, $26,000; assisted living, nearly $71,000; and a semi-private room in a nursing home, $111,000.

Long-term care insurance was once touted as a solution to covering the costs of care. But the market for traditional stand-alone policies has shrunk considerably over the past two decades, as annual premiums have skyrocketed.[21] By 2020, just 49,000 new policies were sold, and most insurers exited the market. The causes of this market failure were complex, but include mispricing, with premiums too low to cover the costs of an aging population, though still too expensive for many; adverse selection—consumers who most needed the insurance were most likely to enroll; and underestimating lapse rates among healthier policyholders. These challenges are not easily overcome and will likely continue to limit the growth of the long-term care insurance market.

RELIANCE ON INFORMAL CAREGIVING

Because of the gaps in coverage for formal care and workforce shortages, about 75% of older adults living at home with long-term care needs rely on informal (unpaid) caregivers, either solely or in conjunction with paid care.[22]

Although the costs of informal care do not appear in the public ledger, they are substantial. By one estimate, an adult caring for their aging parent will face financial losses amounting to about $100,000 per year, roughly the same cost as a nursing home stay.[23] Other studies estimate total lost income, pensions, benefits, and Social Security to be more than $300,000 for a typical caregiver.[24] The total estimated value of informal caregiving for adults in the United States using 2021 average hourly caregiving wages, is $600 billion per year.[25] Not surprisingly, one in five caregivers reports high financial strain due to caregiving, and three in 10 have stopped saving.[26] This financial burden not only threatens the economic security of American families today, it also reduces caregivers' ability to plan for, and save for, their own long-term care needs as they age.

The costs borne by informal caregivers, hidden within households across the country, are, in effect, the invisible but very real copayment of long-term care.[27] They are a function of a payment system that leaves the middle class with limited options, creates misaligned incentives and inefficient use of institutional care rather than home and community-based services, and continues to underpay and undervalue the direct care workforce.

FUTURE DIRECTIONS

In the past three decades, many proposals have been put forward to develop a more coherent federal system of financing long-term care. A recent compendium catalogs and categorizes these proposals, which so far have not been able to overcome considerable political and financial challenges.[28] Nevertheless, we can learn from these proposals, and as the urgency of the need grows, we can borrow from the best ideas. We can also observe and learn from the ongoing long-term care initiative in Washington state (see box).

WASHINGTON STATE

First enacted in 2019, WA Cares is a program that provides qualifying Washington residents with a lifetime benefit of up to $36,500 (adjusted for inflation) to cover long-term care costs, financed by a required payroll tax of 0.58%.[29] The funds can be used to offset a wide range of long-term care expenses, including paying family or formal caregivers, purchasing assistive equipment or technology, and having meals delivered to people who need help with three or more activities of daily living.[30] In its first year, the program accumulated more than $1 billion in reserves. The first benefits will be paid in July 2026.

While this initiative is modest, it is designed to provide valuable support for the middle class and serve as an important proof of concept for other states and for the federal government as it considers how to modernize long-term care policy.[31]

The program's supporters note that even at a relatively modest benefit level, WA Cares will still meaningfully improve the status quo for Washington workers.[32] The state estimates that for about one-third of people, the benefit would cover all the care they need in a lifetime.[33] For everyone else, it will provide immediate relief from long-term care costs without the need to spend down their savings, as well as time to plan for any future needs. For people with private long-term care insurance, WA Cares can help cover the benefit waiting period.

We start by highlighting core principles that should inform new policy and address shortcomings in our present system.[34] Payment policy should promote long-term care that is:

- ***Sufficient and efficient:*** It should fund care that meets the needs of older adults who cannot live independently, regardless of setting or payer, in the setting that maximizes value and respects the preferences of individuals and their families.
- ***Universal and easy to access:*** Care should be available when wanted and needed, and not limited by individual or family resources, or by administrative burdens and complex eligibility criteria.

- *Adequately staffed and resourced:* Payment policy should include adequate training and financial support for formal and informal caregivers.

These principles represent a framework for assessing the trade-offs involved in each policy, and can help policymakers choose the best option for helping American families. Here we discuss three options that measure reasonably well against these core principles.

Expanding Medicaid

One approach would be to make home and community-based care a mandatory benefit under Medicaid, on par with institutional long-term care. This would simplify and standardize benefits, eliminating the wide variability in state coverage. Further, it would remove the considerable barriers some Medicaid beneficiaries face in accessing these services, such as eligibility restrictions and waiting lists. Beneficiaries and their families would have a choice about where to receive care, and fewer eligibility mazes to navigate. The Bipartisan Policy Center has proposed one such baseline of required home and community-based services.[35]

This approach would have budgetary implications for states, which would struggle to fund it without additional federal contributions. A recent article suggested that the federal government could encourage states to improve coverage of these services by increasing federal match funding.[36]

The drawback is that, without eligibility changes, this proposal would only benefit people who qualify for Medicaid. It would still leave out more than 80% of Medicare beneficiaries and require middle-class families to impoverish themselves before receiving any support.

Adding to Medicare

A more comprehensive approach would be to add long-term care coverage to Medicare. This would place long-term care on par with other health-related needs, reflecting the increasing prevalence of chronic conditions in the Medicare population over the past 60 years. It is possible to take an incremental approach to adding long-term care to Medicare. The Brookings Institution recently proposed adding a universal home care benefit to Medicare, a proposal that also arose during the 2024 presidential campaign.[37] While Congress has debated this idea many times since the passage of Medicare, we believe that the current gaps in care warrant another look. This option would provide access to all beneficiaries, including the middle class, and would eliminate unequal access across settings and uneven benefits across states.

The major stumbling block is that such a benefit would be expensive, and it would require substantial public resources to maintain the financial integrity of Medicare.

Creating a New Public Program, or Combining Public and Private Options

The considerable costs borne by informal caregivers can be thought of as insurable harms: long-term care expenses are uncertain, potentially large, and unevenly distributed. This type of risk is well-suited to public insurance, especially since private insurance has failed to provide a feasible alternative.[38] It is also possible to consider a hybrid approach, where public and private insurance are complementary. Creating a new public program avoids the potential roadblocks of adding an expensive new Medicare benefit, but it comes with design and administrative challenges.

These challenges were evident after Congress created the Community Living and Assistance Services and Supports (CLASS) Act as part of the Affordable Care Act in 2010. The new voluntary program would be offered by employers and paid entirely by employees. By design, it was an incomplete solution, providing eligible employees a minimum of $50-per-day lifetime cash benefit to help with future long-term care services and supports. Congress left the details up to federal officials, but required that the program be solvent over a 75-year period. As envisioned, it left room for private insurance to supplement the limited daily benefit. In the process of implementing the CLASS Act, federal officials determined that the voluntary nature of the program made it actuarially unsound, and Congress subsequently repealed it in 2013.[39] The critical lesson is that, like the private insurance market, a voluntary public insurance program cannot overcome the forces of adverse selection and will need taxpayer support to be sustainable.

A number of proposals have focused on ways to make private long-term care insurance more affordable and accessible, through the tax code and by encouraging employers to offer coverage.[40] The history and current status of the private insurance market make it unlikely that tax subsidies alone can address the considerable supply-side and demand-side factors that constrain uptake of these policies. And as noted in the compendium, tax incentives skew toward subsidizing private insurance for higher-income individuals.[41] Moreover, a voluntary and private insurance

market alone would be insufficient to protect the most vulnerable Americans, who could be excluded from coverage due to medical conditions (underwriting) and affordability issues (premiums).

CONCLUSION

Long-term care needs loom large for American families, as the population ages and as chronic disease and related functional and cognitive impairments become more prevalent. The health and financial risks associated with unaffordable long-term care weigh heavily on older individuals and take a toll on families as they care for their loved ones. The opportunity to alleviate these burdens should propel us forward and compel us to act.

> "[If I had a magic wand] I would change that at least for us elderly, all healthcare is fully covered. And when we get old, we can have some support...from the government that we can rely on, so it's not necessary to rely on family members... For example, if now both spouses are together and one of them passes away, then you are left alone. You have children, but they don't have much time, they have to work. So at that time, there should be something to support us [that allows] us to live out our old age peacefully and comfortably until the end." —*Yaqi*

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This brief is based on the review article, The Evolution of Long-Term Care and Health Policy in the United States, by Rachel M. Werner, Allison Hoffman, and Tamara Konetzka. It also draws from The People Say, an online resource that features first-hand insights from older adults and caregivers, and a Compendium of Federal Long-Term Services and Supports (LTSS) Financing Policy Options, a comprehensive overview of the public and private financing solutions proposed over the past three decades.

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