Bipartisan Policy Center

The Growing Cost of Inaction

A Practical Framework for Addressing the Long-Term Care Financing Challenge

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Executive Summary

The population of older adults and people with disabilities in the United States is growing rapidly, but the nation's fragmented long-term care system is not prepared to meet their needs. Despite common misconceptions, Medicare generally does not cover long-term care, and complex market challenges have put private long-term care insurance out of reach for many Americans. Medicaid, as the primary payer for long-term care, provides coverage to eligible low-income beneficiaries.

Given these challenges, middle-income individuals often pay out-of-pocket for long-term care until their savings are depleted and they qualify for Medicaid coverage of this care, with millions also relying exclusively on unpaid and often overburdened family members for caregiving. One study estimates that by 2033, 16 million middle-income Americans ages 75 and older may be at risk of ending up on this pathway.[c,1] The status quo strains not only Americans and their families but also Medicaid, state budgets, and employers.

Although policymakers have recognized this complex challenge for decades, they have yet to sufficiently tackle it, and the cost of continued inaction is unsustainable with the aging of the baby boomer generation. Within just five years of this report's publication, all baby boomers will be older than 65, an age when the burden of chronic illness often increases and creates greater demand for long-term care.[2,3] By 2030, 21% of the U.S. population—a projected 73 million Americans—will be 65 or older, up from 15% as recently as 2016.[4] As baby boomers continue to age, the 85-and-older population is projected to reach nearly 14 million in 2040, an age when the incidences of dementia, stroke, and debilitating falls that require more intensive long-term care rise considerably.[5,6]

To chart a path forward, the Bipartisan Policy Center, with support from The SCAN Foundation, convened a private roundtable discussion in May 2025 with national experts. This work builds upon existing research, including the Compendium of Federal LTSS Financing Policy Options by ATI Advisory and LeadingAge LTSS Center at UMass Boston.[7]

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[c] Analysis by NORC at the University of Chicago used 2018 Health and Retirement Study data to estimate the number of adults who could have incomes within a range that puts them at financial risk. Middle income was defined as $26,569–$78,959 for ages 75-84 (about 220-650 percent of the federal poverty level) and $25,984–$101,014 for ages 85 and older (about 210-830 percent of the federal poverty level). Adjusted for inflation according to U.S. Bureau of Labor Statistics Inflation Calculator, 2025 middle income is estimated at $34,059-$101,218 for ages 75-84 and $33,309-$129,490 for ages 85 and older.

BPC's work unfolds amid growing fiscal pressures at both the federal and state levels. Congress recently passed significant reforms to Medicaid financing and eligibility that could further strain state budgets and affect Medicaid's ability to pay for long-term care. In BPC's roundtable, experts cited the pressing need to address the long-term care challenge, noting that without sustained policy attention, recent progress could slow or reverse. They also emphasized that the aging of the baby boomer generation is reshaping the economy, increasing demand for affordable long-term care and creating greater urgency to identify options that do not require working-age adults to leave the workforce to care for aging family members. At the same time, roundtable participants recognized that achieving comprehensive, long-term care reforms remains challenging given the complex landscape and costs involved. Given these realities, experts underscored the need for pragmatic, targeted reforms to improve affordability and access in the near term while also building the foundation for broader federal reforms that will respond to the scale of long-term care needs across communities in a sustainable way.

This report provides targeted policy recommendations to address the challenge in the long-term care system by (1) modernizing health care programs to reduce the trend of middle-income older adults spending down their savings and ending up on Medicaid-covered long-term care, (2) strengthening the declining private long-term care insurance market, and (3) encouraging innovative state and federal solutions.

WHAT IS LONG-TERM CARE?

Long-term care, also referred to as long-term services and supports (LTSS) in this report, includes a range of health and health-related care to assist individuals with performing activities of daily living (ADL), such as eating and bathing, or instrumental activities of daily living (IADL), such as managing medications.[8]

WHAT LONG-TERM CARE MEANS TO INDIVIDUALS

"The girl who helps me here at home … she helps me fill out papers when she takes me to the doctor. She takes me grocery shopping. She's there for everything."

Source: Quote is from "Bonita," an older adult who is dually eligible for Medicare and Medicaid in California, shared through *The People Say*, a public-interest platform to advance equitable policymaking with qualitative research."

Individuals who receive LTSS include children, adults, and older adults who require assistance with daily self-care tasks due to age, chronic illness, or disability.[9] Although not all need long-term care, an estimated 46 million individuals in the United States (nearly 14% of the population) had disabilities in 2022.[10] An estimated six in 10 Americans that year had at least one chronic disease, such as heart disease or cancer, and an increasing proportion of Americans have multiple chronic diseases.[11,12] Researchers predict these numbers will increase as the U.S. population is aging rapidly.[13]

More than 10,000 Americans are turning 65 each day.[14] The number of Americans ages 65 and older is projected to rise from 58 million in 2022 to 82 million by 2050, and the 65-and-older age group's share of the total population is projected to increase from 17% to 23%.[15] As life expectancy increases, the Medicare-eligible population is not only growing but their health needs are also becoming more diverse. This includes a rising number of older adults that are living with multiple chronic conditions, functional limitations, and long-term disabilities.[16]

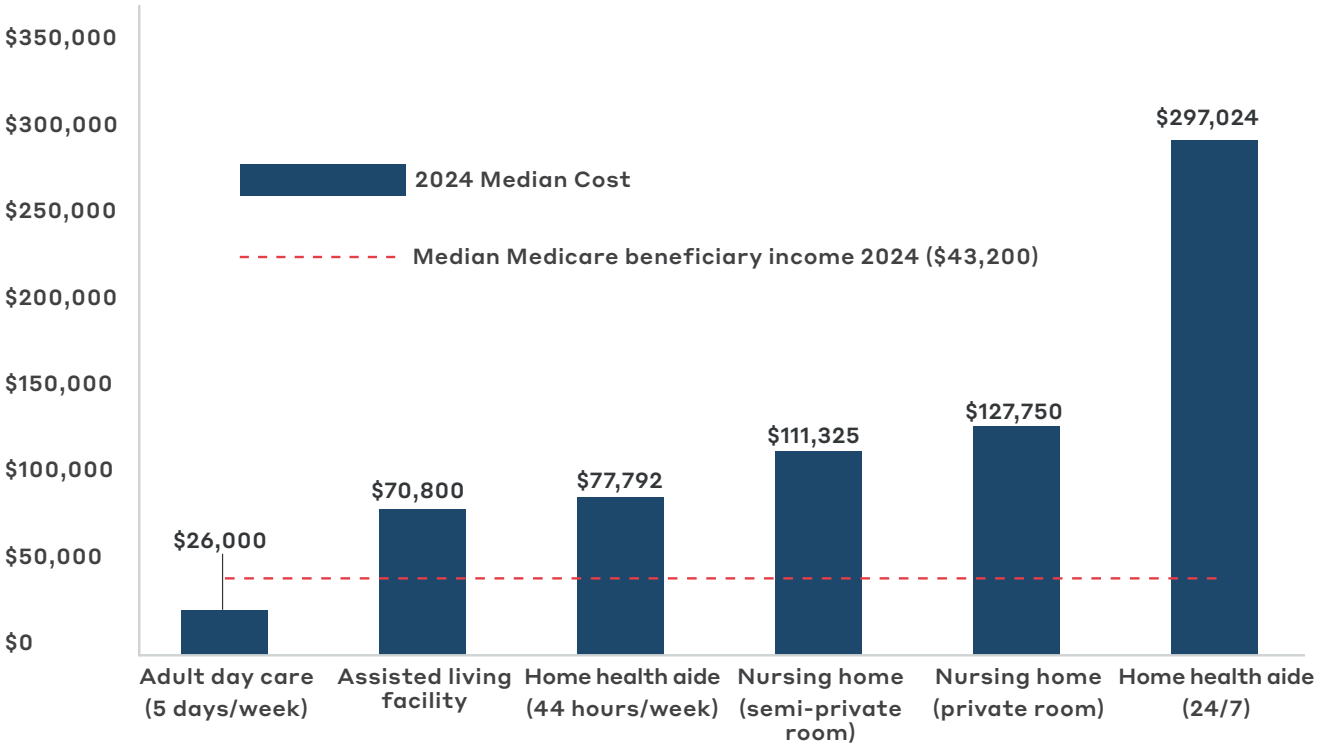
As the country continues to age, more Americans will require some form of LTSS. Projections indicate that around 70% of adults who survive to age 65 will develop severe LTSS needs before they die.[c,17] However, many older adults cannot afford to pay for LTSS out-of-pocket. For example, the 2024 median annual income for individuals ages 65 and older falls short of the cost of nearly all common long-term care services (see figure 1).[18]

[c] Severe LTSS need is defined as (1) having difficulty with two or more ADLs expected to last at least 90 days or severe cognitive impairment; and (2) receiving unpaid care from family or friends or paid LTSS.

HOW IS LONG-TERM CARE FINANCED?

Individuals typically access LTSS through Medicaid, private financing (including private long-term care insurance or out-of-pocket spending), unpaid family caregiving, or a combination of these.[19] Medicaid is the primary payer of LTSS, with an estimated 7.2 million individuals with Medicaid using LTSS in 2022.[20] Current law requires states to provide coverage for institutional LTSS, such as nursing facility care, but they have the option to cover home and community-based services (HCBS). States typically deliver HCBS through a patchwork of waiver authorities and state plan options, contributing to variations across the country.[21] In addition to Medicaid LTSS, the need for unpaid care is substantial. In 2025, more than 63 million American adults reported that they were providing ongoing care for aging parents, spouses with chronic conditions, or adult children with disabilities and serious illnesses.[22]

Figure 1. Annual Private Pay Costs of Common LTSS, Compared with the Median Income for a Medicare Beneficiary, FY2024

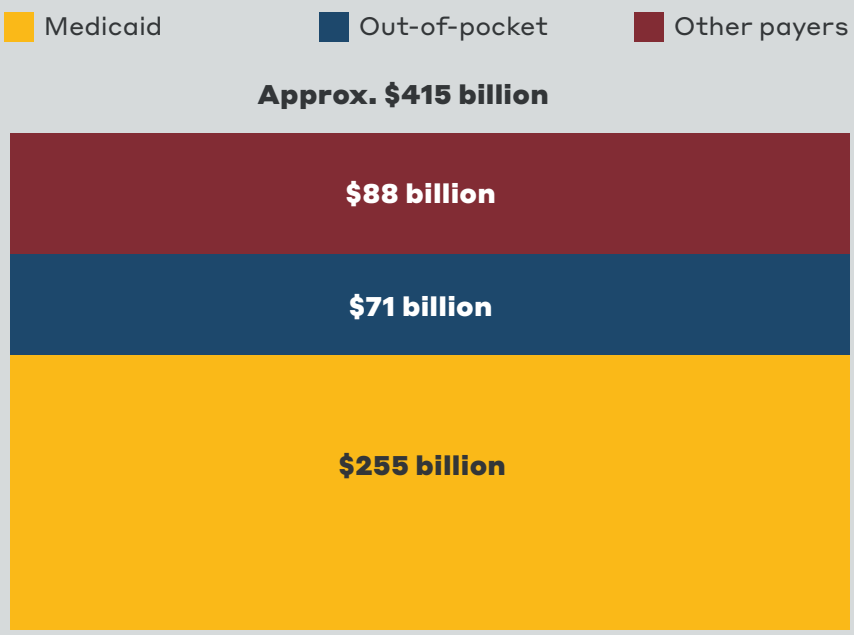


Note: Median income does not include savings or home equity.

Sources: Genworth Financial, Cost of Care Survey Results for 2024, March 4, 2025. Available at: https://investor.genworth.com/news-events/press-releases/detail/982/genworth-and-carescout-release-cost-of-care-survey-results/. Alex Cottrill, Juliette Cubanski, et al., "Income and Assets of Medicare Beneficiaries in 2024," KFF, August 25, 2025. Available at: https://www.kff.org/medicare/income-and-assets-of-medicare-beneficiaries/#cd1586e4-43e1-488e-9ab5-b2fb23d33ca8.

Care for individuals with long-term needs accounts for a disproportionate share of Medicaid spending. In fiscal year 2022, individuals eligible for Medicaid on the basis of disability and enrollees ages 65 and older accounted for about 20% of Medicaid enrollees but 51% of program spending. Many of these individuals were users of LTSS.[23] Because states help finance Medicaid, long-term demographic trends are increasing pressure on their budgets.[24]

Figure 2. Medicaid Paid for More Than Half of the Nearly $415 Billion that the U.S. Spent on LTSS in FY2022



Distribution of spending on LTSS by payer

Notes: LTSS includes spending from Medicaid, individuals, the Children's Health Insurance Program, the Indian Health Services, the Substance Abuse and Mental Health Services Administration, the Veterans Health Administration, general assistance, other federal programs, other state and local programs, school health, and other private revenues. LTSS expenditures include spending for residential care facilities, nursing homes, home health services, and HCBS waivers. Other payers exclude $94 billion in Medicare spending, most of which is post-acute care. Medicaid expenditures may include some home health spending that is rehabilitative and not LTSS. Other payers also exclude spending from private insurance.

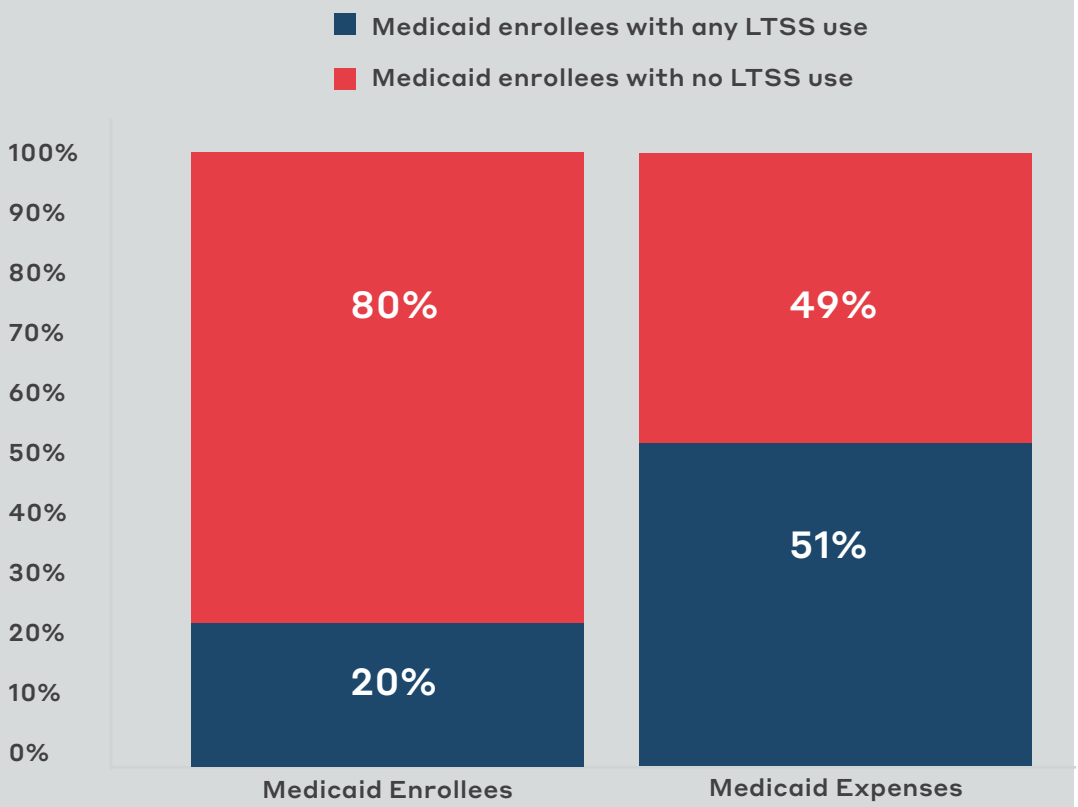
Sources: Priya Chidambaram and Alice Burns, "10 Things About Long-Term Services and Supports (LTSS)," Kaiser Family Foundation Issue Brief, Figure 2, July 8, 2024. Available at: https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/. Office of the Actuary, National Health Expenditure Accounts Data, 2022, Centers for Medicare & Medicaid Services. Available at: https://www.cms.gov/data-research/statistics-trends-and-reports/national-health-expenditure-data.

Medicare provides health coverage for individuals ages 65 and older and some people with disabilities, but it does not provide comprehensive coverage for long-term care.[25]

Unfortunately, many Americans do not realize this; a recent survey found that 58% of respondents incorrectly believe it does.[26] This misconception contributes to many older adults being unprepared for future long-term care expenses.

Despite the likely need, only 11% of adults in 2022 reported having private long-term care insurance, including 14% of those ages 65 and older. This low percentage is contributing to the continued decline of the private long-term care insurance market. A relatively small number of companies comprise the insurance market, with Genworth, John Hancock, and Northwestern Mutual providing the most policies in recent years.[27] Other factors contributing to this decline include difficulty stabilizing the risk pool (due to sicker individuals seeking long-term care,[28] which contributes to insurers engaging in strict underwriting practices that result in denials of those with disabilities or chronic conditions) and widespread misconceptions that Medicare will cover long-term care. Many individuals also cannot qualify for private policies because of preexisting medical conditions or disabilities, yet few Americans recognize this risk.[29]

Figure 3: Medicaid Enrollees Who Used LTSS Had Disproportionately High Medicaid Spending in FY2022



Source: Medicaid and CHIP Payment and Access Commission, MACStats: Medicaid and CHIP Data Book, December 2024. Available at: https://www.macpac.gov/wp-content/uploads/2024/12/MACSTATS_Dec2024_WEB-508.pdf.

These challenges have resulted in rising, unpredictable, and unaffordable premiums; long elimination periods where the beneficiary pays costs before benefits begin; carriers dropping out of the private long-term care insurance market; and private long-term care insurance plans offering limited or insufficient coverage.[30] In 2024, the average premium for an initial $165,000 benefit policy with 3% yearly inflation protection purchased at age 55 was $2,075 per year for a single male and $3,700 per year for a single female. The same policy purchased at age 65 was $3,135 per year for a single male and $5,265 for a single female.[31,c]

HOME CARE IS NOT CHEAP

"[I] work full time and [am] then making sure that [my mother is] good and she's showering and being there with her to help her with that. Having to do the other thing[s]. … So just time management is hard for me. … It's just, I got so much to do and it needs to be done. I know there's home health available … but that's not cheap, you know. If you go through your insurance, by the way, you have to jump through hoops and all the red tape, and then it's minimal …"

Source: Quote is from "Tabitha," a daughter and family caregiver of an older adult in rural Texas, shared through *The People Say*, a public-interest platform to advance equitable policymaking with qualitative research.

WHAT IS THE LONG-TERM CARE CHALLENGE?

The current LTSS financing system is fragmented, poorly coordinated, and expensive.[32] The cost of long-term care varies widely by location, level of care, and care setting. A BPC analysis of a 2022 Department of Health and Human Services (HHS) estimate finds that, on average, an American turning age 65 will incur around $130,000 in future LTSS costs (in 2025 dollars), which can create financial hardship for middle-income families.[33]

Without insurance protection, individuals may be required to draw on their own financial resources to cover LTSS costs when they first develop a need for extensive assistance. The high and unpredictable costs of LTSS, coupled with the common misconception that Medicare covers these expenses, can make it difficult for Americans to plan for their care and can quickly deplete modest retirement savings. Only when they have exhausted much

[c] Based on estimated costs of the leading insurer, as identified by the 2024 American Association for Long-Term Care Insurance annual price index survey.

of their own savings are they eligible for Medicaid coverage. Medicaid has thus become the de facto insurance system for LTSS, but in a way that can place substantial burdens on middle-income households as well as the Medicaid system itself.

The population of middle-income seniors ages 75 and older who are likely to be at financial risk of depleting their resources to afford extensive LTSS is projected to reach around 16 million individuals by 2033.[34,d] Based on HHS's 2019 estimates of paid LTSS risk, BPC projects that nearly 7 million middle-income older Americans in this age group will require paid LTSS and be at financial risk of depleting their assets to afford it by 2033.[35] Many in this group will also rely heavily on unpaid care from family members.[36] This is especially straining for the roughly 18 million caregivers who balance care for both adults and children simultaneously, referred to by many as the "sandwich generation".[37]

Figure 4: Long-Term Care Options Differ by Income

Income category	2025 income and annuitized assets	Estimated percent of federal poverty level (FPL)	Care options
Low-income	$0-$33,308	Up to approx. 200% of FPL	• Family caregivers • Medicaid LTSS
Middle-income	$33,309-$129,490	Approx. 200%-800% of FPL	• Family caregivers • Spend down assets to qualify for Medicaid LTSS
High-income	$129,491+	Above approx. 800% of FPL	• Out-of-pocket paid assisted or independent living • Out-of-pocket or private insurance covered in-home care • Family caregivers

Notes: BPC used income limits from an analysis by NORC at the University of Chicago for individuals 85 and older, adjusted to 2025 U.S. dollars according to the U.S. Bureau of Labor Statistics' Inflation Calculator. Housing equity was not considered for the purpose of assigning seniors to income categories. NORC analysis also provided income limits for ages 75-84, which was available in the source below.

Source: NORC at the University of Chicago, The Forgotten Middle: 2022 Update—Analysis and Findings, 2022. Available at: https://www.norc.org/content/dam/norc-org/documents/standard-projects-pdf/NORC%20Forgotten%20Middle%202022%20-%20Analysis%20and%20Findings.pdf

[d] Some stakeholders refer to this group of middle-income older adults as the "forgotten or overlooked middle."

WHY DO POLICYMAKERS NEED TO ADDRESS THE CHALLENGE?

The long-term care financing challenge is far-reaching, affecting individuals, families, employers, and government. When individuals deplete their savings, they face greater risk of being unable to afford food, housing, medications, or other essential items. Additionally, certain Medicaid restrictions can create barriers to employment and related earnings, as individuals with disabilities often rely on Medicaid's unique home and community-based services to live independently and work; Medicare and private health insurance plans generally do not cover these services.[38]

The lack of affordable home care assistance can also cause families to make difficult trade-offs, such as reducing work hours or leaving the workforce entirely to provide care. According to a 2023 survey of employees who provided unpaid care, some 15% reported leaving the paid workforce for a period of time and nearly 27% shifted from full-time to part-time work or reduced their working hours.[39] Changes in caregivers' employment can worsen their financial outlook by lowering their current income, retirement savings, and future Social Security benefits. Employers are also feeling the impact, with an increasing number of employers starting work-life referral services programs to help employees hire caregivers.[40]

These individual and employer pressures translate into broader fiscal challenges for states and the federal government. As the baby boomer population ages, demand for long-term care is increasing, but the ratio of older adults to available family caregivers will decline.[41] Absent federal reforms to strengthen access to long-term care, this demographic shift will likely increase Medicaid's LTSS expenditures. Because Medicaid is a joint federal-state program, increased Medicaid LTSS expenditures risk adding to the federal deficit and placing additional strain on states' budgets.

HOW CAREGIVING AFFECTS EMPLOYMENT

"I would be more comfortable if he had a home health aide, because, you know, when I'm not here, if someone could, like, fix his lunch, or, like, if I get another job, fix his dinner, or just make sure he's okay. They wouldn't have to sit here all the time, but just make sure he's getting that. But again, because of what we have, they're not going to do it. That would be such a great help to him, but ... they're not going to do it."

Source: Quote is from "Penny," a spousal family caregiver of an older adult with multiple chronic illnesses in urban Alabama, shared through *The People Say*, a public-interest platform to advance equitable policymaking with qualitative research.

POLITICAL LANDSCAPE

There has historically been strong bipartisan interest in federal reforms to address the long-term care financing challenge, and recent federal actions demonstrate this continued commitment.[42] However, despite growing need and bipartisan engagement, broad long-term care reforms remain politically challenging to advance, in part because of the difficulty of financing expanded coverage amid fiscal pressures at both the federal and state levels. For example, Reps. Thomas Suozzi (D-NY) and John Moolenaar (R-MI) introduced the bipartisan WISH Act, or H.R. 2082, which would establish a federal long-term, catastrophic care insurance program designed to provide a cash benefit for individuals requiring extended LTSS. This approach aims to revitalize and stabilize the private long-term care insurance market by addressing insurers' risk for covering individuals with long-term care needs.[43] Supporters of the bill note that the legislation, coupled with strong consumer protections, such as clearly defined benefits and an effective oversight and appeals process, could help stabilize the private long-term care risk pool and reduce premiums.[44] However, the WISH Act does not yet include a dedicated funding mechanism, which will be necessary to achieve a fiscally and operationally feasible program.

HISTORY OF THE REPEAL OF THE CLASS ACT

In 2010, Congress passed legislation creating the Community Living Assistance Services and Supports (CLASS) program, a national, voluntary insurance program to help people with functional limitations pay for community-based LTSS.[45] Monthly premiums paid by voluntary payroll deductions were to fund the program. However, before the program was set to begin, financial analysts predicted that the program's premium costs would have been too expensive for most and therefore projected the program would be financially unsustainable.[46] In 2013, Congress repealed the CLASS program and established the federal Commission on Long-Term Care, a group of 15 appointees created to develop a plan to ensure the availability of long-term care.[47] The commission submitted a **report** to Congress that included public policy recommendations but did not include a comprehensive financing model because broad Commission agreement on a financing mechanism was not possible at the time.[48]

Recently passed federal legislation, as well as administrative changes, are significantly impacting the nation's health care system, with implications for the future of long-term care sustainability and access. With the passage of the 2025 budget reconciliation law, H.R. 1, Congress made significant changes to Medicaid financing, including an estimated $990 billion reduction in federal Medicaid spending over 10 years.[49] Because of strained

state budgets, state policymakers will need to make difficult budgetary decisions, which have historically resulted in disinvestment in optional Medicaid services, particularly HCBS.[50] Although the 2025 budget reconciliation law provides some funding and expanded HCBS flexibilities, advocates worry that these changes fall short of addressing the risk of states limiting HCBS access.[51] Although it is too soon to assess the law's full effect, recent administrative changes, such as restructuring at the Centers for Medicare & Medicaid Services (CMS) and the Administration for Community Living (ACL), are likely to further shape the long-term care landscape. Some stakeholders view these changes as a way to streamline program administration, while others believe they could reduce the administrative capacity and institutional knowledge needed to oversee and implement these programs.

Ultimately, today's changing policy landscape underscores why sustained federal leadership on long-term care financing reform is needed. Changes to Medicaid are expected to increase pressure on public long-term care programs, while the declining private insurance market is struggling to provide affordable options. Bipartisan proposals, such as the WISH Act, demonstrate that lawmakers across the aisle recognize the urgency, even as broad agreement on a sustainable financing mechanism remains challenging. In this environment, broad reforms (while necessary) may be difficult to achieve but incremental, targeted LTSS financing reforms are more feasible and remain crucial for sustaining progress as needs for long-term care continue to grow.

Absent any comprehensive federal reforms, some states have adopted innovative approaches to the long-term care financing challenge. For example, Washington created WA Cares in 2019 as a public catastrophic, long-term care insurance benefit that aims to stabilize the market through public-private collaboration. WA Cares benefits are set to become available in July 2026.[56] The law's mandatory enrollment and financing via a 0.58% payroll tax survived a statewide referendum that would have reduced the viability of the program — potentially highlighting Americans' growing attention to the rising costs of care and their likely need of LTSS.[57] Since collections by Washington state began in July 2023, state legislators have made additional changes to the program, including making the benefit available for eligible individuals who leave the state and adopting new standards for private supplemental long-term care insurance policies.[58] Several states, including, California, Michigan, and Pennsylvania, have explored reforms through commissioning actuarial studies or introducing legislation, but none have implemented a public program like Washington's.[59,60,61]

Roundtable participants, including researchers, private insurers, federal and state policymakers, and advocates, agreed that federal reforms are necessary despite these state efforts, as Medicare changes require federal authority and Medicaid reforms depend on state-federal coordination. Without federal action, they warned, a state-only approach could result in a fragmented and inefficient system.

2025 Budget Reconciliation Law: Select LTSS Implications

Enacted on July 4, the 2025 budget reconciliation law significantly changed the health policy landscape. For a closer look at the law's impacts, see BPC's **explainer**.[52] The following table summarizes key provisions likely to impact the long-term care landscape.

2025 Budget Reconciliation Provision	Potential Impacts on the LTSS Landscape
Eligibility	
Sec. 71108: sets a fixed $1 million cap on home equity for Medicaid LTSS eligibility	• Promotes greater consistency across states, reducing eligibility variation • Limits access to Medicaid LTSS in high-cost areas or as home values rise
Sec. 71119: requires states to establish community engagement (i.e., work) for certain individuals	• Reduces availability of some unpaid family caregivers if caregivers lose Medicaid or reenter the workforce • Increases demand on Medicaid if family caregiving declines • Adds administrative burdens, potentially limiting states' capacity to pursue other LTSS priorities
Financing	
Sec. 70115: extends the higher contribution limits for Achieving a Better Life Experience (ABLE) accounts[53]	• Allows individuals with disabilities to save more for disability-related expenses • Varies in impact by income, with higher-income individuals more likely to take advantage
Sec. 71115: incrementally lowers the allowable provider tax rates[54]	• Increases states' budgetary pressures, which may lead states to reduce provider rates, modify LTSS programs (i.e., changes to HCBS), or raise revenues through other state taxes
Sec. 71116: reduces Medicaid state directed payments	
Delivery	
Sec. 71111: delays implementation of minimum staffing standards for long-term care facilities[55]	• Eases burden on facilities to hire additional nursing staff and maintain a registered nurse on-site 24/7, especially those facing staffing shortages or located in rural areas • Strains the quality of care and family caregivers if prolonged workforce shortages persist
Sec. 71121: allows states to offer 1915(c) waivers to individuals who do not meet the institutional level of care requirements	• Allows earlier access to HCBS • Provides states with added flexibility in Medicaid program design

Notes: Implementation timelines vary by provision. This summary highlights selected provisions and potential effects but does not reflect all provisions and potential impacts on the long-term care system.

Source: One Big Beautiful Bill Act, Public Law 119 21, 119th Cong., July 4, 2025. Available at: https://www.congress.gov/bill/119th-congress/house-bill/1.

STATE INITIATIVES ON LONG-TERM CARE FINANCE REFORM

States, across the political spectrum, have taken a variety of innovative steps that could help address the long-term care financing challenge, such as:

- Developing multisector plans for aging to identify older residents' needs and opportunities to improve coordination and use of resources, often including state-specific research on long-term care financing;
- Leveraging flexibilities to remove age barriers so individuals over age 65 can access Medicaid Buy-in for Workers with Disabilities programs, helping delay or avoid spend-down into Medicaid LTSS;
- Establishing state-level tax incentives for family caregivers to provide financial relief to unpaid caregivers.[62]

KEY ROUNDTABLE FINDINGS

BPC's roundtable discussion identified key considerations to support policymakers, advocates, and other stakeholders as they address the long-term care financing challenge. These findings reflect both the complexity and far-reaching impact of the challenge, while also informing opportunities to design and advance bipartisan reforms.

» **A pragmatic path forward:** Given the current political and fiscal landscape, roundtable participants acknowledged that advancing comprehensive long-term care reform remains difficult. They broadly agreed on the need for structural changes, but expressed frustration with federal policymakers' continued inaction and recognized that large-scale reforms may not be feasible in the near term. In this environment, participants underscored the need for pragmatic, targeted reforms to improve affordability and access in the near term while also building the foundation for broader federal efforts that respond to the scale of long-term care needs across communities. At the same time, they noted that pursuing only incremental fixes will fall short of addressing the full scope of the challenge and recognized the need for sustained policy attention.

» **Thoughtful policy design:** Roundtable participants stressed that a clear vision for the future system should anchor reforms. For example, if the vision includes unpaid family caregivers as an enduring part of the long-term care system, then policymakers should design policies to better support and sustain these caregivers. Participants agreed that reforms should reflect a coordinated approach that leverages public and private policy tools across state and federal levels. They also emphasized that policies should include a sound and sustainable financing mechanism, such as payroll contributions, income-adjusted premiums, or hybrid public-private models, often citing the repeal of the CLASS Act as an example of challenges that arise without broadly agreed upon and sustainable financing. And they underscored that

policy design should include flexibilities that are responsive to the diverse needs and preferences of older adults and people with disabilities.

» **Strategies to build political momentum:** Experts said that LTSS financing reform is more likely to succeed when it has strong constituent support and bipartisan legislative backing. Integrating LTSS financing reforms into a broader policy reform package also increases the likelihood that Congress will pass the reforms, as evidenced by passage of the CLASS Act. Garnering broad constituent and legislative support will require effective framing, which should incorporate both aging and disability perspectives, emphasize the broader costs of inaction, and feature personal stories to make the issue relatable. Roundtable attendees noted that there is continued opportunity to build a more effective coalition by breaking down silos and engaging broader stakeholders, such as the business community, children of aging parents, and Democratic and Republican state leaders.

TARGETED BIPARTISAN POLICY RECOMMENDATIONS

Recognizing the ongoing challenges to advancing comprehensive reforms and the growing costs of continued inaction, roundtable experts emphasized the need for pragmatic and sustainable solutions. The following recommendations outline near-term, targeted reforms to improve affordability and access to long-term care for both the aging and disability communities while laying the groundwork for broader solutions to long-term care financing.

Public and private reforms are both necessary. Given that addressing the long-term care challenge will require upfront investment, policymakers should encourage market-based solutions to mobilize additional resources and promote fiscal responsibility. However, private market reforms alone are unlikely to provide sufficient coverage to all middle-income Americans, as individuals may be excluded from coverage due to their medical conditions or the high cost of policies. As such, strengthening public programs like Medicare and Medicaid remains essential because the existing private insurance market is unaffordable to many and falls short of meeting the needs of most low- and moderate-income households. Additionally, given that the scale of the long-term care financing challenge will require significant, sustainable policy reforms, near-term reforms should improve research and innovation in the long-term care sector to support evidence-based, comprehensive long-term care policy in the future.

I. MODERNIZE HEALTH CARE PROGRAMS TO BETTER SERVE AMERICANS

Some policymakers and experts have proposed creating new or expanding existing programs to provide broad coverage and protect against the financial risks of needing long-term care.[63] Others oppose these reforms, in part because the federal government is already struggling to finance existing health entitlement spending and has limited fiscal capacity to support

a major expansion of promised benefits. The recommendations below outline practical, near-term opportunities to modernize Medicare and Medicaid to better meet beneficiaries' long-term care needs. Given the scope of the challenge, policymakers should also explore additional reforms that would more comprehensively address the long-term care challenge.

RECOMMENDATION 1: Congress should establish a modest standalone respite benefit within the Medicare program.

Family caregivers provide an average of 27 hours of care each week.[64] Balancing caregiving with work and personal health is difficult: 1 in 5 caregivers report fair or poor health, and nearly a quarter say they struggle to care for themselves.[65] In 2023, one survey found that nearly 70% of employed family caregivers said they had difficulty balancing work and life.[66]

Respite care offers short-term relief for unpaid family caregivers by arranging temporary substitute care for their loved ones and giving the caregiver time to rest and manage personal needs. This support can be provided in the home, at an adult day center, or in a residential care setting. Medicare currently provides limited respite coverage under the hospice benefit, but this support is only available to beneficiaries with a life expectancy of six months or less.[67] However, caregivers of individuals with chronic or disabling conditions often need support well before the end of life. Policymakers have long recognized the value of respite benefits, previously proposing Medicare expansions to include respite care and, more recently, introducing legislation to increase access through Medicaid.[68]

A Medicare respite benefit outside of hospice could significantly improve the well-being of American families. It would support the health of caregivers and enable more individuals, especially those in the "sandwich generation," to remain in the workforce. This benefit would supplement, not replace, unpaid family caregiving by offering occasional support to sustain care over time. Access to respite can also help delay or prevent the need for institutional care. Although additional evidence is needed, some research suggests that respite may reduce avoidable future costs, such in-patient services, by helping caregivers manage care and respond to issues earlier.[69]

Congress should establish a modest standalone respite benefit in Medicare Part B and Medicare Advantage (MA) to better meet the needs of enrollees and their caregivers. For example, a respite benefit could cover up to 168 hours, or seven days, of in home LTSS per year for eligible Medicare beneficiaries.[70] To qualify, Medicare beneficiaries would need to be in an MA plan or an accountable care organization or receive chronic care management from a Medicare fee-for-service clinician. The beneficiary would also have to have two or more ADL limitations or severe cognitive impairment and have a primary, unpaid caregiver who resides with the beneficiary. Total costs would vary depending on benefit design, but BPC previously estimated that a 10-year federal cost for a respite benefit of up to 168 hours, including for spousal caregivers, would be $54 billion in 2017 (around $70 billion in 2025).[71]

As roundtable participants emphasized that Congress is more likely to pass long-term care reforms as part of broader policy reform packages, such as the CLASS Act, federal policymakers should pursue a modest respite benefit alongside efforts to avoid insolvency of the Hospital Insurance trust fund by 2033.[72] These necessary Medicare reforms present an upcoming legislative opportunity for Congress to also improve the Medicare program to better serve beneficiaries. As such, Congress should establish a modest respite benefit within the Medicare program in tandem with a comprehensive set of reforms that will slow spending increases, raise revenue, and increase competition between traditional Medicare and MA.[73]

SUSTAINING AND IMPROVING MEDICARE

Medicare faces a substantial financial shortfall, with the Part A trust fund projected to become depleted by 2033, at which time payments to hospitals would be reduced by **11%**.[74] BPC **recommends** undertaking federal reforms to better meet beneficiaries' needs while extending the trust fund's solvency.[75]

RECOMMENDATION 2: Congress should permit Medigap and MA plans to market a voluntary, limited LTSS benefit as a supplemental insurance option; this option would be financed exclusively through additional premiums paid by Medicare beneficiaries who choose to enroll.

Most older Americans who are not eligible for Medicaid are enrolled in either a Medicare supplemental insurance policy (Medigap) or a Medicare Advantage plan, but the vast majority do not have private long-term care insurance.[76,77,78] This leaves many middle-income beneficiaries financially unprepared for future LTSS needs. A limited LTSS benefit should provide reimbursement for home-based services similar to the level of services covered in the existing long-term care insurance market.[79] (For example, a $75 maximum daily benefit, with a 180-day elimination period that beneficiaries would need to satisfy before the commencement of the benefit.) To ensure portability and competition, it should be a standalone benefit that does not lock beneficiaries into their specific MA or Medigap plan. Medicare beneficiaries would have a one-time opportunity to purchase the limited LTSS benefit at enrollment in either MA or Medigap. If a beneficiary chooses not to purchase coverage, and they seek coverage later, plans could medically underwrite and deny coverage, or permit coverage with a higher premium. This reform would offer a financially sustainable option for middle-income Medicare beneficiaries to prepare for future LTSS needs.

RECOMMENDATION 3: Congress should lift the age limit for the Medicaid Buy-In for Workers with Disabilities programs to allow individuals with disabilities over age 65 to work without losing access to long-term care services that support their employment.

The Medicaid Buy-In for Workers with Disabilities programs allow individuals with disabilities to work and retain their Medicaid coverage, or to use their Medicaid coverage to access wraparound services that are not covered under employer-sponsored insurance or Medicare.[80] However, depending on the authority a state uses to establish its program, individuals are not eligible to participate once they turn 65.[e,81] This age limit poses a barrier for older adults with disabilities wanting or needing to remain in the workforce. Removing the age limit would promote financial independence, particularly for middle-income older adults with disabilities who want to work and gain related earnings but face barriers to employment due to Medicaid income and asset limits.[82] In December 2024, a continuing resolution with bipartisan support, H.R. 10445, did not advance through Congress but notably included a provision that would have removed the age limit. Reps. Juan Ciscomani (R-AZ) and Marie Gluesenkamp Perez (D-WA) reintroduced the Ensuring Access to Medicaid Buy-in Programs Act, H.R. 1598, in the 119th Congress to remove the age limit.

II. MARKET-BASED SOLUTIONS TO EMPOWER INDIVIDUAL PLANNING AND ACCESS

Private long-term care insurance can reduce out-of-pocket costs and ease pressure on Medicaid, but broader participation is needed to strengthen the market. Federal policies can empower planning and access to insurance for individuals by increasing awareness of benefits and lowering barriers to buying policies. One strategy for increasing uptake of private long-term care insurance is encouraging employers to include long-term care insurance in their voluntary benefits packages.[83] Another strategy is to increase public awareness through public education campaigns.[84]

Although market-based reforms have bipartisan appeal and are an essential part of a comprehensive strategy to improve affordable access to LTSS, they can primarily benefit higher-income individuals. For reforms to have a broader impact, policymakers should pair any changes with strong consumer protections, effective outreach and education, and guardrails to ensure the quality of insurance products.

[e] The Balanced Budget Act of 1997 does not establish an age limit for the "Work Incentives Group," so states using this authority can cover eligible adults with disabilities who are above or below age 65.

RECOMMENDATION 4: Congress should establish a safe harbor and other appropriate incentives to encourage employers to voluntarily offer private long-term care insurance as an employee benefit, with automatic enrollment for eligible employees and an opt-out option.

Increasing uptake of private long-term care insurance can help individuals prepare for future care needs while also strengthening the risk pool and stabilizing the broader insurance market. However, access remains limited: Only about 24% of benefit-eligible employees reported that their employer offered long-term care insurance in 2024.[85] When offered, these benefits are typically limited, and more recently the market has shifted from stand-alone policies toward hybrid designs that bundle long-term care coverage with life insurance.[86] Incentivizing employers to offer long-term care insurance to their employees could play a critical role in helping businesses meet the needs of their employees while also improving the stability of the insurance market. Recognizing the role employers play in addressing the challenge, policymakers have considered proposals to allow long-term care products under employer cafeteria plans and flexible spending accounts.[87]

To expand work-based long-term care insurance offerings, Congress should establish appropriate incentives for employers to offer private coverage as an employee benefit. For example, Congress should establish a safe harbor that limits fiduciary liability for employers who automatically enroll certain retirement plan participants into a default, qualified long-term care insurance policy, with the option to opt out. This new safe harbor would include standards for the automatic enrollment process and the default plan design.[88] For example, all policies should include a nonforfeiture benefit, allowing policyholders whose coverage is canceled due to failure to pay premiums to claim benefits up to the amount of the premiums paid if they ultimately qualify. Providing this legal protection to employers could incentivize more of them to offer private long-term care insurance with automatic enrollment.

This approach could efficiently increase coverage while stabilizing the insurance market. Broader adoption would likely improve the insurance risk pool and therefore plan affordability, making coverage more accessible to middle-income earners. Ultimately, an improved insurance market could also enable Americans to obtain coverage without underwriting. While this is a feasible and broadly supported step toward stabilizing the market, its effectiveness will depend on optional employer and employee participation. Because broad employer adoption will require adequate incentives, policymakers should evaluate employer uptake. If necessary, policymakers should consider additional incentives, such as tax credits, to increase participation.

RECOMMENDATION 5: Congress should permit retirement plan participants to use retirement savings without incurring early-withdrawal penalties when they use the money for long-term care insurance premiums.

Permitting individuals to use retirement savings, including from a 401(k), 403(b), or Individual Retirement Account (IRA), to purchase long-term care insurance without withdrawal penalties would help defray LTSS costs, which for many Americans depletes their retirement savings. This policy would provide middle-income Americans with a flexible, tax-advantaged way to plan for long-term care without draining their retirement savings.[89] Members of Congress have introduced legislation similar to this recommendation, such as the LTC Affordability Act in the 117th Congress. This bill, introduced by Rep. Ann Wagner (R-MO) and six Republican co-sponsors, would permit a person to withdraw up to $2,500 per year from their retirement fund without withdrawal penalties to purchase long-term care insurance.[90]

One limitation of this approach is that the greatest benefit may accrue to higher-income individuals, but it offers a politically feasible step toward improving long-term care affordability for middle-income older adults by aiming to stabilize the market.[91] In general, although policymakers should take steps to reduce early withdrawals from retirement savings, long-term care is often a major expense in retirement and a significant threat to financial security, making insurance against that threat a reasonable use of accumulated funds.[92]

RECOMMENDATION 6: The Financial Literacy and Education Commission and partnering federal agencies should coordinate to strengthen educational resources on long-term care and to incorporate long-term care planning into retirement education.

Many Americans are unprepared for the costs of and need for long-term care, with many mistakenly believing Medicare will cover their long-term care needs. This presents a significant challenge for middle-income adults who do not qualify for Medicaid but lack sufficient savings or insurance to cover LTSS expenses. Recognizing the need to improve public understanding of the importance of planning for LTSS, stakeholders have proposed a range of reforms to increase public awareness.[93]

Strengthening federal coordination on long-term care would integrate long-term care planning into existing retirement and financial education efforts, helping Americans better understand their risks and take steps to prepare.[94] Established by Congress in 2003 and chaired by the

secretary of the Treasury, the Financial Literacy and Education Commission coordinates the federal government's financial literacy efforts across federal agencies. Long-term care planning is an important part of preparing for retirement, and the commission can help strengthen public education on this issue.[95] However, increased consumer education alone is not enough. To strengthen retirement security, policymakers should pair these efforts with both targeted and broad reforms that increase access to coverage options (as previously outlined).

III. ADVANCE INNOVATION TO MEET EVOLVING LONG-TERM CARE NEEDS

Increased consumer education alone is not enough, given the scale of the retirement challenge. Federal policymakers should also build the evidence base needed to inform broader, innovative reforms at both the federal and state level. Although incremental in scope, these recommendations represent meaningful progress toward generating the research and momentum needed to drive comprehensive, evidence-based reforms.

RECOMMENDATION 7: The Center for Medicare and Medicaid Innovation (CMMI) should test the impact of innovative long-term care payment and service delivery approaches on total Medicare costs and on improved health outcomes for eligible Medicare-only beneficiaries who have functional limitations.

Drawing on policy experts' research, federal policymakers should design a CMMI model to test innovative long-term care financing and delivery strategies.[96] Throughout the model's design, CMMI should collaborate with policy experts, including state officials and consumer advocacy organizations, to ensure the model is comprehensive and responsive to stakeholders' insights. Demonstrations testing the impact of innovative long-term care payment and delivery approaches should include an independent evaluation to assess the effects on Medicare spending, individuals' health outcomes, and the feasibility of a broader adoption.

A new model should focus on high-value, evidence-based interventions that delay or prevent institutionalization, reduce avoidable hospitalizations, and increase access to long-term care for older adults who are ineligible for Medicaid. This effort could include testing a small Medicare HCBS benefit or providing expanded access to evidence-based health technology that enables individuals with long-term care needs to remain in their homes and communities. For example, some policy experts have proposed an MA demonstration aiming to prevent people from developing more serious health needs through the enhanced use of technology, such as remote patient monitoring and home sensors.[97] This model could make

it easier for providers to use remote patient monitoring tools that help older adults remain at home by removing barriers for providers, such as burdensome billing requirements.[f,98]

CMMI should also explore opportunities to better integrate innovative long-term care payment and service delivery in existing value-based care models, such as accountable care organizations. For example, CMMI could increase participation among long-term and postacute care providers in existing value-based care models by adjusting attribution rules, modifying risk adjustment, and offering technical assistance or incentives to providers.[99]

RECOMMENDATION 8: HHS should conduct research and publish a report on the status and impacts of long-term care partnership programs. It should also pursue opportunities to improve implementation of these programs.

The long-term care partnership program is a joint federal-state initiative that encourages individuals to purchase private long-term care insurance by providing Medicaid asset protection for individuals with qualifying policies.[100] Although most states offer these programs, limited research exists on how variations in states' design and implementation affect insurers' participation and consumers' uptake.[101] Some policy experts have recommended expanding and increasing awareness of partnership programs as one strategy to improve long-term care coverage; however, more research on effective outreach and program design is needed.[102] Targeted federal research could help identify strategies to increase consumer purchases of qualifying long-term care insurance products.[103] One focus of this research should be on how partnership programs intersect with Medicaid eligibility rules, such as how states' policy decisions related to these rules impact the effectiveness of partnership programs or participation in partnership-qualified insurance plans for long-term care, if at all. This research could help inform how states choose to structure Medicaid asset tests for LTSS coverage, as these limits vary significantly across states.[104]

A path forward: broader reforms

This report provides targeted bipartisan reforms that reflect the current political and fiscal environment, but these steps alone will not address the full scope of the challenge. Federal policymakers must also pursue broader reforms.

As these reforms will require significant political momentum and upfront investment, stakeholders should draw on key findings from BPC's roundtable to chart a path forward.

[f] Some payers have begun integrating tech-enabled tools that support aging in place, and CMS's Calendar Year 2026 Medicare Physician Fee Schedule Proposed Rule (CMS-1832-P) included proposals that, if finalized, would reduce certain billing requirements. Nevertheless, barriers to broader adoption among Medicare fee-for-service and MA plans continue.

For example, stakeholders should:

- identify upcoming policy windows where long-term care reform could be integrated into larger efforts, such as Medicare reforms, to ensure sustainability;
- explore federal incentives to states, such as targeted Medicaid flexibilities or financial incentives, to build a more influential coalition of state policy leaders;
- address long-standing policy design challenges that have prevented the development of a broadly acceptable approach to providing and paying for LTSS that can accommodate households with different levels of incomes and resources;
- simplify the fragmented system to reduce inefficiencies, improve access to HCBS, and ensure that private and public coverage options reflect the diverse needs of individuals.

Conclusion

America's long-term care financing challenge requires more than temporary fixes: It requires bold, sustained action grounded in feasible, fiscally responsible, bipartisan solutions. The path forward will require sustained political leadership and a long-term commitment to investing in a system that supports aging with dignity and financial security.

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HEALTH PROGRAM

BPC's Health Program advances bipartisan policy solutions to build a more cost-effective, evidence-based health care system to improve population health. We work to strengthen and sustain Medicare and Medicaid, accelerate the shift toward value, address inefficiencies and misaligned incentives, and responsibly leverage technology and innovation.

DISCLAIMER

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