



Bipartisan Policy Center

State Long-Term Care Progress

**A BLUEPRINT FOR
FEDERAL SOLUTIONS**

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HEALTH PROGRAM

Under the leadership of former Senate Majority Leaders Tom Daschle and Bill Frist, M.D., the Bipartisan Policy Center's Health Program develops bipartisan policy recommendations that will improve health care quality, lower costs, and enhance coverage and delivery. The program focuses on coverage and access to care, delivery system reform, cost containment, chronic and long-term care, and rural and behavioral health.

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DISCLAIMER

The findings expressed herein do not necessarily represent the views or opinions of BPC's founders or its board of directors.

Executive Summary

The [AARP Long-Term Services and Supports \(LTSS\) State Scorecards](#) (Scorecards) identify state innovations that federal policymakers can scale or encourage among states. In response to an urgent need to improve LTSS nationally, the Bipartisan Policy Center analyzed data from the 2011-2023 Scorecards to develop federal policy reforms that will address persistent challenges in the nation's LTSS system.

KEY TAKEAWAYS

- Bipartisan interest exists to pursue federal reforms that seek to solve challenges within the 2023 Scorecard's five dimensions of LTSS system performance—issues ranging from affordability and access to community integration.
- Federal policy reforms can encourage state innovation and build on lessons learned from innovative state efforts to address LTSS challenges.
- To support states' efforts to improve their LTSS systems, federal policymakers should prioritize federal policy reforms that foster state innovation and increase states' flexibilities.

The following tables summarize these findings and opportunities by the 2023 Scorecard's five dimensions of LTSS performance. **These insights collectively inform federal opportunities to improve the nation's LTSS system.**

If viewing the brief online, click the **Go now!** buttons to navigate to these findings.

Although BPC analyzed data from the Scorecards as part of this effort, the policy positions from this brief are BPC's own and do not necessarily reflect those of AARP or The SCAN Foundation.

Making Long-Term Care Affordable and Accessible

GO NOW!

Challenge	State Insight	Federal Opportunity
Out-of-pocket costs remain unaffordable for most older adults and for individuals with disabilities seeking home care.	States are developing new state-based LTSS financing programs, with stakeholder engagement, actuarial studies, and research playing crucial roles in these initiatives.	Congress should support states' use of flexibilities to develop and support long-term care financing solutions. Congress should also reestablish the Commission on Long-Term Care to conduct stakeholder engagement, an actuarial study, and research on strategies for developing and implementing a national LTSS financing program.
Access to LTSS remains a barrier to employment for people with disabilities who risk losing their Medicaid coverage, which provides long-term care services that are generally not covered by other health insurance programs.	The Medicaid Buy-in for Workers with Disabilities program is an important tool for states to address this barrier, and federal technical assistance and guidance is key to states' effective adoption of these programs.	Congress should direct the Centers for Medicare & Medicaid Services (CMS) to provide technical assistance to states and to clarify existing options that states can adopt when they are designing their Medicaid Buy-in for Workers with Disabilities programs.

Ensuring Choice of Setting and Provider

GO NOW!

Challenge	State Insight	Federal Opportunity
Limited access to integrated care models continues to harm choice for LTSS consumers, including dually eligible beneficiaries and Medicare-only beneficiaries.	Technical assistance, strong incentives, and reduced regulatory barriers facilitate states' adoption and growth of integrated care models.	Congress should support states' efforts to increase access to fully integrated care models by offering incentives for integration, enhancing technical assistance to states on beneficiary outreach and education, and removing regulatory barriers.
The shortage of direct care workers is a significant bipartisan challenge to ensuring patient choice and access to LTSS.	Many states leveraged investments from the American Rescue Plan to implement innovative strategies for increasing recruitment and retention of direct care workers.	Congress should direct the Department of Health and Human Services (HHS) to conduct a national study and provide a report to Congress on the relationship between the increased Federal Medical Assistance Percentage (FMAP) provided by the American Rescue Plan, states' innovations, and its effects on the direct care workforce, associated costs, and quality of care.

Securing Safe and Quality Long-Term Care

GO NOW!

Challenge	State Insight	Federal Opportunity
Limited data collection remains a challenge despite CMS' efforts to improve standardized quality measurement reporting for LTSS.	States across the political spectrum are using national quality surveys to monitor safety and quality, particularly to collect information on the experiences of individuals receiving LTSS.	Congress should direct CMS to develop standardized data measures on the quality and utilization of LTSS for underrepresented communities, including measures on the consumer experience and the direct care workforce. Congress should also incentivize states to report on these measures.

Supporting the Needs of Family Caregivers

GO NOW!

Challenge	State Insight	Federal Opportunity
Medicaid protections for the financial well-being of spouses of individuals applying for Medicaid home and community-based services (HCBS) are set to expire after September 30, 2027.	States across the political spectrum are enacting these protections to support spousal caregivers.	Congress should provide a temporary extension of Medicaid protections against spousal impoverishment for recipients of HCBS.
Unpaid caregivers often incur an uncompensated, financial burden for providing their care.	Financial relief for unpaid caregivers does not exist in most states, and individuals in the few states offering tax credits often encounter barriers to accessing the financial relief.	Congress should establish a refundable tax credit for caregivers to help with out-of-pocket costs for paid LTSS-related care, and this reform should include initiatives to reduce barriers to accessing the financial relief.

Enhancing Community Integration for LTSS Consumers

GO NOW!

Challenge	State Insight	Federal Opportunity
There is inadequate support for LTSS recipients' nonmedical health-related social needs, such as housing affordability and accessible transportation.	States are leveraging federal programs authorized by the 1965 Older Americans Act to adopt innovative practices that address individuals' nonmedical health-related social needs.	Congress should reauthorize the Older Americans Act, including making sufficient investments in the Administration for Community Living's Research, Demonstration, and Evaluation Center. Congress should also direct the center to research best practices for and the impact of the act's programs to promote the nonmedical health-related social needs of older adults and individuals with disabilities.
State and federal policies and systems are often ill-equipped to meet the wide-ranging, growing needs of LTSS consumers.	States on both sides of the aisle are adopting new strategies, such as a multisector plan for aging, to improve their policies and systems to support community integration. Strong stakeholder engagement and continued monitoring and evaluation are key to these efforts.	Congress should support states in developing and maintaining multisector plans for aging. Congress should advance reforms that create a national multisector plan for aging, learning from states' experiences in developing their own plans.

Overview of Long-Term Services and Supports

WHAT IS LTSS?

Long-term services and supports (LTSS) refers to a broad range of health and health-related care to assist individuals with performing activities of daily living (ADLs)—such as eating, bathing, dressing, walking, or other self-care tasks—or instrumental activities of daily living (IADLs)—such as managing medications or transportation to medical appointments.¹

WHO USES LTSS?

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.²

WHERE DO PEOPLE RECEIVE LTSS?

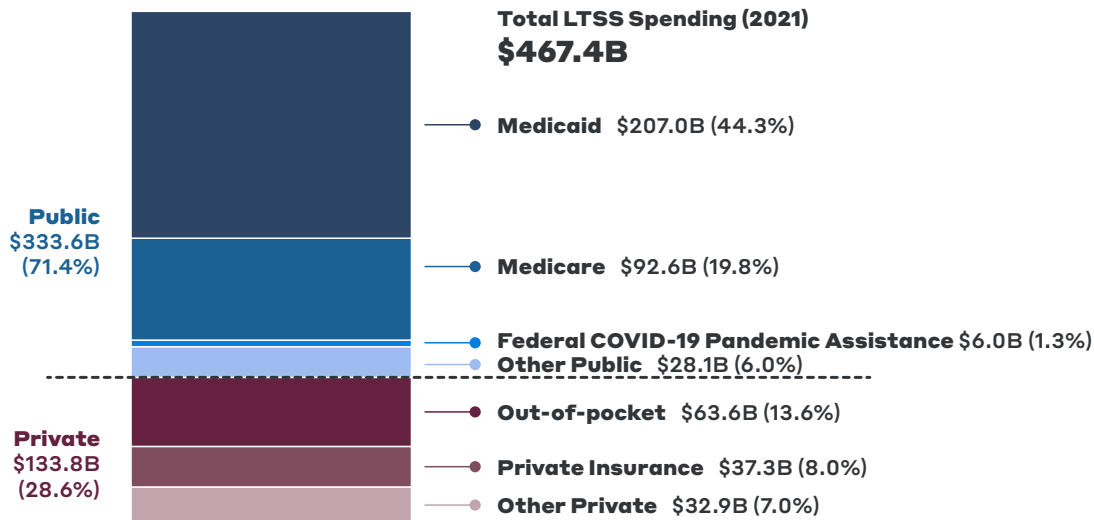
Individuals receive these services in both institutional care settings, such as nursing homes or assisted living facilities, and in home or community-based settings.³

WHAT IS THE NATION'S LTSS SYSTEM?

The nation's LTSS system is a complex patchwork of public and private payers and programs that are administered at the federal, state, and local levels.

Medicaid, which is jointly funded by the federal government and the states, is the predominant payer for LTSS.⁴ Most states pay for LTSS programs out of general revenue. Other public and private payers also finance these services to a lesser extent. For example, Medicare, which generally covers only limited LTSS that are short term and focused on medical or skilled care, financed almost 20% of total LTSS expenditures in 2021.⁵ Private funding continues to be an unaffordable financing option for most Americans and accounted for only about 29% of total LTSS spending in 2021.⁶ Other private funding, federally funded public programs, and COVID-19 pandemic assistance accounted for the rest of the total LTSS spending in 2021.⁷ Among the other notable federally funded public programs, the Veterans Health Administration spent \$7.5 billion on LTSS in 2021.⁸

Figure 1: LTSS Spending by Payer, 2021



Source: [Congressional Research Service](#) analysis of National Health Expenditure Account data from CMS, November 2022

Several public programs under the Older Americans Act provide nutrition services, transportation, and family caregiver support to help meet the long-term care needs of older adults.⁹ Also critical to the nation’s LTSS system is the more than 48 million family caregivers who provide this care, often without compensation.¹⁰

To target federal LTSS reforms in the areas that would have the greatest impact on states’ LTSS systems, this brief focuses on specific programs and populations. Among others, it addresses Medicaid reforms to reach the 5.6 million low-income beneficiaries with complex needs, Medicare reforms to improve HCBS affordability for the “Forgotten Middle” who will reach 16 million in 2033, and certain programs under the Older Americans Act, which serves 11 million older adults.^{11,12}

HOW DO STATES’ LTSS SYSTEMS VARY?

States’ LTSS systems vary significantly. These differences stem from the flexibility granted by federal law and regulations. For example, federal law and rules allow states the choice to deliver Medicaid services, including LTSS, through managed care, fee-for-service, or a hybrid model.¹³ Current federal law and rules also allow states to further customize their LTSS systems through flexibilities provided by state plan amendments and waivers. Figure 2 provides an overview of these various Medicaid benefits and program design options.

Figure 2: Medicaid Benefits and Program Design Options Related to LTSS

State Plan Benefits that Include HCBS	HCBS Authorities	Research and Demonstration Programs	Integrated Care Programs	Managed Long-Term Services and Supports (MLTSS)
<ul style="list-style-type: none"> • Home health • Personal care services • Case management and targeted case management • Section 1945 Health Home 	<ul style="list-style-type: none"> • Section 1915(c) • Section 1915(i) • Section 1915(j) self-directed personal care services • Section 1915(k) Community First Choice 	<ul style="list-style-type: none"> • Section 1115 demonstrations • Money Follows the Person demonstration 	<ul style="list-style-type: none"> • Programs of All-Inclusive Care for the Elderly (PACE) • Integrated care for people dually eligible for Medicare and Medicaid 	<ul style="list-style-type: none"> • Including those authorized under Section 1915(a) or 1915(b) waivers

Source: [CMS Long-Term Services and Supports Rebalancing Toolkit](#)

WHY DO POLICYMAKERS NEED TO ENHANCE THE NATION'S LTSS SYSTEM?

Despite some progress and increasing public and private spending on LTSS, significant challenges persist, and the current LTSS system does not effectively meet Americans' long-term care needs. The ongoing challenges within the LTSS system contribute to both inadequate and costly care.¹⁴ For example, HCBS remain financially out of reach for many individuals, and the nation has grappled with a shortage of direct care workers for over two decades, a crisis worsened by the COVID-19 pandemic. These barriers, among others, contribute to increased federal spending because the unaffordable cost of LTSS often results in many Americans depleting their savings until they qualify for Medicaid LTSS. In addition, people with functional limitations who lack adequate care might rely on higher cost services, such as those at the emergency department.

Rising demand for LTSS as baby boomers age and as individuals live longer are exacerbating these long-standing problems. The population of adults ages 65 and older will increase from 57.8 million in 2022 to 78.3 million in 2040, while the number of adults ages 85 and older will more than double during the same period, from 6.5 million to 13.7 million.¹⁵ LTSS will continue to be heavily utilized. About 1 in 5 of all adults will require LTSS for five years or more, and a majority of adults want to age in their homes or communities.^{16,17} However, many Americans lack a plan for financing their long-term care and mistakenly believe that Medicare will comprehensively cover these expenses (it does not).¹⁸ These systems will need to adapt to meet the needs of this aging population.

Accordingly, federal policy reforms addressing LTSS affordability and access, consumers' choice of setting and provider, safety and quality, support for family caregivers, and community integration are critical to driving further state progress toward a high-value LTSS system amid this rising demand and spending.

Long-Term Care Reform: Lessons Learned and Moving Forward

THE POSITIVE IMPACT OF PREVIOUS FEDERAL REFORMS

Over the years, federal and state policy reforms have driven improvements in the nation's LTSS system, particularly regarding the number of individuals participating in self-directed care options and the share of LTSS spending on HCBS as compared to institutional LTSS.

Federal changes in how states can administer Medicaid contributed to the increase in enrollment in self-directed care, with states now having the option to allow individuals to direct their own care. The total number of people who self-direct services, including veterans and Medicaid participants, more than doubled from just under 740,000 in 2009 to more than 1.5 million in 2021.¹⁹ Federal legislation that established the Section 1915(j) self-directed personal assistance services state plan option in 2005 and the Section 1915(k) Community First Choice state plan option in 2010 created these flexibilities for states to develop self-direction programs.^{20,21}

Federal initiatives have been pivotal in encouraging states to shift the delivery of Medicaid LTSS spending from institutional settings toward home and community-based settings. As of 2021, the Money Follows the Person demonstration helped over 100,000 beneficiaries move from institutions to home and community settings in 45 states, the District of Columbia, and two territories.²² The Balancing Incentives Program also promoted HCBS adoption in 21 states by increasing the FMAP for those meeting certain spending criteria.^{23,24} In 2021, federal policymakers enacted the American Rescue Plan, which included a one-time, temporary 10-percentage-point increase to the FMAP for Medicaid HCBS.²⁵ Although federal research on the American Rescue Plan's impact is limited, its design incentivized states to further rebalance their spending towards HCBS.

BIPARTISAN MOMENTUM

There has long been bipartisan interest among federal policymakers in achieving a high-value LTSS system. With Congress divided, members will need to work together to create durable, evidence-based federal policy reforms that garner bipartisan support.

RECENT BIPARTISAN INITIATIVES ON LONG-TERM CARE

- A bipartisan group of five senators introduced the Delivering Unified Access to Lifesaving Services (DUALS) Act of 2024 ([S.3950](#)) in the 118th Congress to increase dually eligible beneficiaries' access to fully integrated care models.
- Similarly, in the 117th Congress, a bipartisan group of three senators introduced the Advancing Integration in Medicare and Medicaid (AIM) Act ([S.4264](#)) to require states to develop strategies to integrate care for dually eligible beneficiaries.
- Republican and Democratic representatives introduced legislation ([H.R. 8107](#)) to remove the age limit for Medicaid Buy-in for Workers with Disabilities programs. These programs reduce barriers to work for people with disabilities by allowing those who want to work to maintain their Medicaid long-term care benefits while increasing their earnings.
- Republican and Democratic members of Congress held hearings, solicited stakeholder feedback, and introduced bipartisan legislation ([H.R.2853](#); [H.R.468](#); [H.R. 3227/S. 1749](#)) to address the shortage of direct care workers.²⁶
- Senators reintroduced a bipartisan bill ([S.3702](#)) that would provide a nonrefundable federal tax credit of up to \$5,000 for working family caregivers.

BPC's Analysis: State Lessons Informing Federal Reforms

Leveraging data from AARP's LTSS State Scorecard [reports](#) spanning from 2007-2023, BPC identified long-term care trends across Democratic- and Republican-leaning states. To evaluate states' political landscapes, BPC utilized Cook Partisan Voting Index [data](#), which describes each state's partisan leanings by comparing their performance in presidential elections to the national average in terms of a two-party vote share. Additionally, between January and April 2024, BPC conducted qualitative interviews with an array of experts and stakeholders, including senior-level personnel from state Medicaid agencies, state departments for aging, and LTSS-focused researchers, spanning all four geographic regions and encompassing a balanced mix of Democratic- and Republican-leaning states.

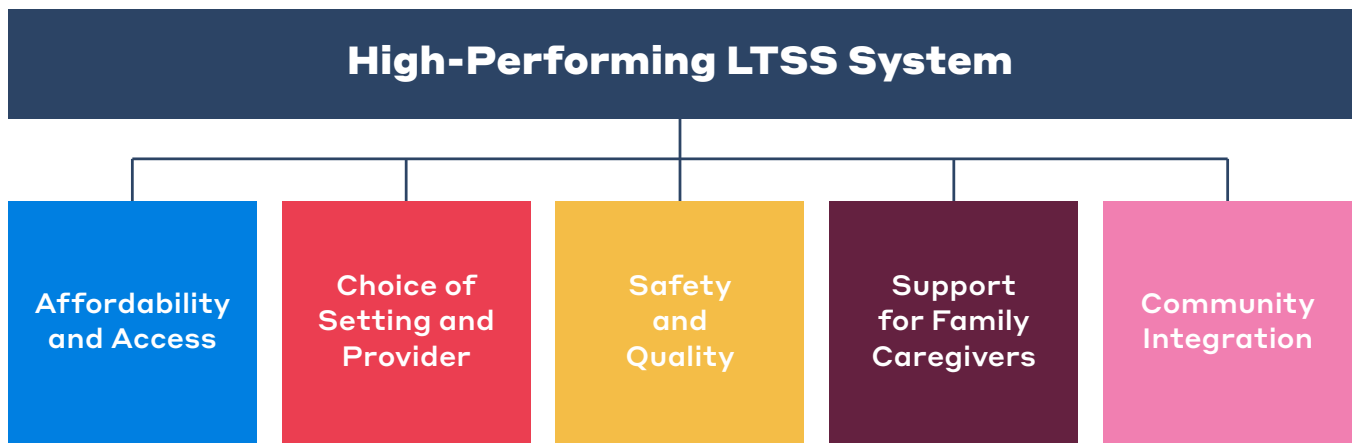
Key Findings and Federal Policy Opportunities

Building on BPC’s [previous](#) work and earlier findings from our [infographic](#), the following summarizes BPC’s analysis of states’ political and LTSS landscapes to understand obstacles to improving the nation’s LTSS system. The following also highlights some states’ experiences tackling these obstacles, providing valuable insights for federal reforms. Collectively, these findings inform federal policy opportunities to advance the nation’s LTSS system.

When advancing these reforms, federal policymakers should aim to offset the federal costs associated with the policy recommendations in this brief to achieve budget neutrality.

This brief organizes BPC’s findings by the 2023 Scorecard’s five dimensions of LTSS system performance (see Figure 3).

Figure 3: Dimensions of LTSS System Performance from AARP’s 2023 Scorecard



Source: [AARP LTSS State Scorecard 2023 Edition](#)

BPC's Findings

Go to the page number listed or click the dimension below to navigate to BPC's findings.

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AND ACCESSIBLE**

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**24 ENHANCING COMMUNITY INTEGRATION FOR LTSS
CONSUMERS**

Making Long-Term Care Affordable and Accessible

Challenge	State Insight	Federal Opportunity
<p>Out-of-pocket costs remain unaffordable for most older adults and for individuals with disabilities seeking home care.</p>	<p>States are developing new state-based LTSS financing programs, with stakeholder engagement, actuarial studies, and research playing crucial roles in these initiatives.</p>	<p>Congress should support states' use of flexibilities to develop and support long-term care financing solutions. Congress should also reestablish the Commission on Long-Term Care to conduct stakeholder engagement, an actuarial study, and research on strategies for developing and implementing a national LTSS financing program.</p>

BPC's analysis found that, on average, the median cost of privately purchased home care was more than 80% of the median household income for households headed by someone age 65 or older in both Democratic- and Republican-leaning states in 2021. This finding indicates a need for federal policy solutions that will improve the affordability of home care, particularly for middle-income individuals who do not qualify for Medicaid-covered LTSS.

Although the need for affordable HCBS for middle-income individuals with long-term care needs is growing, there is insufficient federal progress on addressing this long-term care financing crisis. The nonpartisan research organization NORC projects that the number of middle-income older adults, or the "Forgotten Middle," will almost double to reach 16 million by 2033.²⁷

Absent federal action, some states, such as Washington, California, and Minnesota, are building new state-based LTSS financing programs. These states' activities provide insights to federal policymakers as they pursue federal bipartisan initiatives to address the long-term care financing crisis. **Stakeholders from these states cite stakeholder engagement, actuarial studies, and research as fundamental, initial steps in their process.**²⁸

Building on these state initiatives and capitalizing on the bipartisan need to address the long-term care affordability crisis, **federal policymakers should reestablish the Commission on Long-Term Care, which completed its work in 2013, to update research on options to develop and implement a new LTSS financing program.** For example, the commission should explore establishing an HCBS buy-in program to improve access to affordable HCBS for Medicare beneficiaries ineligible for Medicaid (see BPC's 2021 report, [Bipartisan Solutions to Improve the Availability of Long-Term Care](#)). The commission's work should leverage findings from its previous report to Congress as well as lessons learned from states building state-based financing programs.²⁹ The commission should also research how a federal program would complement states' efforts to establish a state-based LTSS financing program, such as Washington's program.

While the commission should investigate potentially establishing a national LTSS financing program, Congress should uphold states’ flexibility to create their own long-term care financing initiatives and assist states in leveraging these flexibilities to develop robust state-based programs. For example, Congress could advance reforms to establish a learning collaborative for states to explore their options in designing these programs.

Challenge	State Insight	Federal Opportunity
<p>Access to LTSS remains a barrier to employment for people with disabilities who risk losing their Medicaid coverage, which provides long-term care services that are generally not covered by other health insurance programs.</p>	<p>The Medicaid Buy-in for Workers with Disabilities program is an important tool for states to address this barrier, and federal technical assistance and guidance is key to states’ effective adoption of these programs.</p>	<p>Congress should direct CMS to provide technical assistance to states and to clarify existing options that states can adopt when they are designing their Medicaid Buy-in for Workers with Disabilities programs.</p>

If they begin working, people with disabilities risk losing their Medicaid coverage, which provides LTSS that are generally not covered by other health insurance programs but that are essential to their ability to work. The Medicaid Buy-in for Workers with Disabilities program allows individuals with disabilities to work and retain all or some of their Medicaid benefits. The 2023 Scorecard analyzed states’ Medicaid eligibility policies to assess the availability of these programs in each state, with a higher percentage score correlating with a less restrictive and more easily accessible Medicaid Buy-in program. **BPC’s analysis found similar averages, under 60%, for both Democratic- and Republican-leaning states. This finding indicates a bipartisan adoption of Medicaid Buy-in for Workers with Disabilities programs and an opportunity for federal reforms to encourage states to adopt program flexibilities and policies that will improve access.**

Current federal law grants significant flexibility to state Medicaid programs to support individuals with disabilities who want to work and increase their earnings. But several issues—program complexities, limited technical assistance, and inadequate federal guidance on these programs—limit states’ implementation. In interviews with BPC, some state officials said they were hesitant to cover the three eligibility groups under the Medicaid Buy-In for Workers with Disabilities programs because CMS never codified these eligibility groups in federal regulations. Some states also reported that they lacked clarity on the flexibilities they have to modify their programs. For example, states can modify income and asset-counting methodologies for eligibility, but they often lack the guidance or technical assistance to make these modifications. Arkansas and Colorado, along with the District of Columbia, stand out for making these programs available in the

most expansive ways, with no asset limits for individuals or spouses.³⁰ **Federal technical assistance helps states' Medicaid agencies adopt available flexibilities, including eligibility modifications.**

To address barriers to employment for individuals with disabilities who want to work, **Congress should direct CMS to issue guidance identifying the full range of options available to states under current law for covering or modifying their coverage of eligibility groups under the Medicaid Buy-in for Workers with Disabilities programs. Congress should also direct CMS to provide technical assistance, focused on highlighting states' flexibilities and promising state innovations that further the programs.** These efforts would enhance states' implementation and encourage state innovation related to these programs, as well as contribute to a more inclusive workforce and improved fiscal outcomes. In its 2022 report, [*Next Steps: Improving the Medicaid Buy-in for Workers with Disabilities*](#), BPC further explored policy challenges and bipartisan opportunities related to these programs.

Ensuring Choice of Setting and Provider

Challenge	State Insight	Federal Opportunity
Limited access to integrated care models continues to harm choice for LTSS consumers, including dually eligible beneficiaries and Medicare-only beneficiaries.	Technical assistance, strong incentives, and reduced regulatory barriers facilitate states' adoption and growth of integrated care models.	Congress should support states' efforts to increase access to fully integrated care models by offering incentives for integration, enhancing technical assistance to states on beneficiary outreach and education, and removing regulatory barriers.

States have the option to implement integrated care models, such as Medicare Advantage Dual Eligible Special Needs Plans (D-SNPs) and Programs of All-Inclusive Care for the Elderly (PACE). These models have the potential to improve health outcomes, increase access to HCBS, and address health disparities, while simultaneously achieving long-term cost savings.³¹ States have also historically had the option to integrate care through models tested under the Financial Alignment Initiative (FAI). However, this option will sunset in 2025, although it will provide a pathway to transition current enrollees into D-SNPs.³² **Despite these benefits, almost 80% of full-benefit dually eligible beneficiaries were not enrolled in integrated care programs in 2022, and Medicare-only beneficiaries encounter significant barriers to accessing PACE.**³³ In interviews, some state officials explained that access to these models among dually eligible beneficiaries remains limited because the models are complex, and added that states need additional guidance and financial resources to expand these models.

BPC's analysis of the 2023 Scorecard's data on PACE enrollment per 10,000 residents ages 55 and older found bipartisan adoption of PACE. Through its interviews, BPC learned that federal technical assistance to states and enhanced consumer outreach and education help increase access to integrated care models. BPC spoke with some state officials who had significantly increased their states' PACE enrollment recently, and they reported that the [Integrated Care Resource Center](#), an initiative of CMS and the Medicare-Medicaid Coordination Office, offered valuable technical assistance to states, helping them increase access to integrated care models. States that significantly boosted PACE enrollment stressed the importance of enhanced consumer outreach and education to expand access. For instance, Kansas conducted public awareness campaigns during Medicare and Medicaid open enrollment periods, conducted beneficiary outreach, and provided resources like Frequently Asked Questions to inform beneficiaries about the model.³⁴ Kansas saw a 25% increase in PACE enrollment from 2020-2023.³⁵

Officials from several states that BPC interviewed expressed their interest in increasing access to PACE and cited regulatory barriers limiting access to the model. Medicare-only beneficiaries encounter barriers to accessing PACE largely because the Part D premium costs are unaffordable for many. Some states BPC interviewed reported that they are exploring options to increase Medicare-only beneficiaries' access to PACE. For example, New York's PACE Alliance is pitching a pilot program to the CMS Innovation Center (CMMI) that would allow beneficiaries to buy into PACE at a tiered rate depending on the services they need.³⁶

Federal policymakers should establish a framework for integrating Medicare and Medicaid services for dually eligible individuals. This framework should, for example, incentivize states to implement at least one fully integrated care model that would be available to all full-benefit dually eligible beneficiaries, while establishing a federal fallback program for states that choose not to integrate care themselves. Learning from states' efforts to increase enrollment in fully integrated care models, while also ensuring sufficient consumer protections, federal policymakers should couple these reforms with enhanced technical assistance to states on consumer outreach and education.

To improve access to integrated care for non-dually eligible enrollees, such as Medicare-only beneficiaries with long-term care needs, policymakers should allow Medicare-only PACE participants to enroll in either a qualifying, standalone Part D plan or the PACE Part D plan. By allowing Medicare-only beneficiaries the option to enroll in either a qualifying standalone Part D plan or the PACE Part D plan, federal policymakers would make PACE more affordable for Medicare-only beneficiaries. As an interim step, CMMI could develop a pilot program to test innovative approaches to financing PACE to reduce barriers to the model among Medicare-only beneficiaries. These pilot programs could stand as important first steps to creating evidence-based policies that increase access to PACE.

BPC previously released reports outlining policy recommendations to improve access to models that fully integrate care. These reports include [Guaranteeing Integrated Care for Dual Eligible Individuals](#) (2021) and [Increasing Access to and Enrollment in PACE](#) (2022).

Challenge	State Insight	Federal Opportunity
The shortage of direct care workers is a significant bipartisan challenge to ensuring patient choice and access to LTSS.	Many states leveraged investments from the American Rescue Plan to implement innovative strategies for increasing recruitment and retention of direct care workers.	Congress should direct HHS to conduct a national study and provide a report to Congress on the relationship between the increased FMAP provided by the American Rescue Plan, states' innovations, and its effects on the direct care workforce, associated costs, and quality of care.

In interviews with BPC, officials from states of all political leanings agreed that addressing the direct care workforce shortage was a top priority. **BPC's analysis of 2023 Scorecard data found that both Democratic- and Republican-leaning states do not have sufficient supplies of home health or personal care aides.** BPC's analysis also found that these same states are paying direct care workers below the median wage of comparable occupations. Democratic- and Republican-leaning states, on average, each paid direct care workers around \$3.00 less than the average hourly wage for other comparable jobs in 2021.

Many states leveraged the American Rescue Plan investments to enact innovative solutions to increase recruitment and retention of direct care workers. For instance, some states implemented wage pass-throughs that require providers receiving Medicaid reimbursements to pass through a certain amount of the reimbursement to compensate direct care workers. Other states developed training programs to recruit new workers and established career lattices to support the direct care workforce. States used significantly different strategies to grow their workforces.³⁷ This presents an opportunity for the federal government to evaluate the outcomes of states' interventions and identify effective policies for ensuring an adequate direct care workforce to meet rising national demand. **Although the federal government has released some research on states' use of the funds, it has not undertaken or commissioned a comprehensive evaluation of the American Rescue Plan enhanced funding and effects on the direct care workforce.**³⁸

To elevate states' innovative practices and potentially scale successful ones to a national level, **Congress should direct HHS to conduct a national study and provide a report to Congress on the relationship between how states used the American Rescue Plan's temporarily enhanced FMAP for home and community-based services and measures that capture effects on the direct care workforce, federal and state costs, and quality of care.** This study should also explore the effectiveness of states' innovative practices to address the worker shortage, potentially providing the evidence for federal policymakers to scale these practices on a federal level. See BPC's 2023 report, [Addressing the Direct Care Workforce Shortage](#), for more details on these challenges and federal policy reform opportunities.

Securing Safe and Quality Long-Term Care

Challenge	State Insight	Federal Opportunity
<p>Limited data collection remains a challenge despite CMS' efforts to improve standardized quality measurement reporting for LTSS.</p>	<p>States across the political spectrum are using national quality surveys to monitor safety and quality, particularly to collect information on the experiences of individuals receiving LTSS.</p>	<p>Congress should direct CMS to develop standardized data measures on the quality and utilization of LTSS for underrepresented communities, including measures on the consumer experience and the direct care workforce. Congress should also incentivize states to report on these measures.</p>

Although CMS is taking steps to improve standardized quality measurement reporting for LTSS, limited data collection remains a challenge that federal policymakers should address.³⁹ Reporting on LTSS-related quality measures is often inconsistent across states and does not adequately capture the LTSS system. For example, gaps persist in available data on adults under age 65 who need LTSS, the profile of the LTSS workforce, and the experiences of consumers receiving these services. Limited federal data shows racial and ethnic inequities in LTSS access and quality.⁴⁰ These inequities further highlight the need for federal policymakers to incentivize states to improve their data collection and reporting, including the collection of data disaggregated by race, ethnicity, income level, and ZIP code. Through improved data collection, policymakers can more effectively monitor and strengthen the value of LTSS. These efforts could ultimately pave the way for testing federal value-based LTSS initiatives.

States across the political spectrum are using national quality surveys to monitor safety and quality, particularly to collect information on the experiences of individuals receiving LTSS. Some states structure these surveys to allow for data disaggregated by demographic information, such as race and ethnicity. Based on BPC's analysis, more than 30% of both Democratic- and Republican-leaning states use the National Core Indicators-Aging and Disabilities (NCI-AD™) survey for one or more HCBS programs in 2023. Despite Democratic- and Republican-leaning states' similar adoption of this survey, data from the 2023 Scorecard indicates that the majority of states do not use this survey to capture the experiences of participants in HCBS programs. Accordingly, there is bipartisan interest in measuring consumers' experiences in HCBS programs, but federal policy reforms are necessary to encourage national reporting.

To strengthen LTSS data collection, Congress should direct CMS to develop a standardized dataset and incentivize states to report on these measures. This dataset should encompass a broad range of measures, including those on users' experiences, and it should disaggregate data based on sociodemographic information. Congress should also direct CMS to develop and implement a standardized set of data measures for the direct care workforce. As federal

policyholders consider additional data collection and reporting incentives or requirements, they should ensure that states have adequate resources and time to implement changes. BPC's interviews revealed that several states face significant financial constraints that impede their ability to improve data collection and reporting. These states said they would need additional financial resources to update their data systems and to provide training to health care workers on the data collection. State officials interviewed by BPC also explained that they would need significant time to complete these activities and emphasized the importance of CMS issuing explanatory subregulatory guidance. Although the time needed for a state to report on a standardized dataset will vary, some stakeholders told BPC that they would need at least three years after CMS issues subregulatory guidance.

Supporting the Needs of Family Caregivers

Challenge	State Insight	Federal Opportunity
Medicaid protections for the financial well-being of spouses of individuals applying for Medicaid HCBS are set to expire after September 30, 2027.	States across the political spectrum are enacting these protections to support spousal caregivers.	Congress should provide a temporary extension of Medicaid protections against spousal impoverishment for recipients of HCBS.

When a spouse requires LTSS, CMS applies special rules to determine their financial eligibility for these services. These rules have historically focused on safeguarding the assets of a spouse when one spouse required LTSS in an institutional setting; the aim was to prevent the non-Medicaid spouse from becoming impoverished. With home and community-based care becoming more common, federal reforms since 2010 have required states to extend spousal impoverishment rules to all individuals when determining Medicaid HCBS eligibility.⁴¹ **However, these Medicaid protections against spousal impoverishment for recipients of HCBS are set to expire after September 30, 2027.**⁴²

Both Democratic- and Republican-leaning states are enacting spousal impoverishment protection policies to support the financial well-being of spousal caregivers. These policies safeguard the financial interests of spouses of individuals applying for Medicaid by ensuring that spouses who are not applying for Medicaid are not forced to deplete their assets or income to cover the cost of the care. Although the federal government sets the maximum and minimum allowance, state policymakers decide their state’s limits within this range. The 2020 and 2023 Scorecards analyzed states’ policies, indicating whether a state allows the spouse of an individual applying for Medicaid to retain the maximum set by the federal government.^{43,44} Based on BPC’s analysis of 2023 data, of the 12 states that allow the spouse to retain 100%, six are Democratic-leaning and six are Republican-leaning. Given this support across the political spectrum, there is a strong bipartisan opportunity to strengthen spousal protections across the nation.

As BPC identified bipartisan support for ensuring the financial stability of family caregivers, Congress should temporarily extend Medicaid protections against spousal impoverishment for recipients of HCBS beyond fiscal year 2027. This extension would promote the financial well-being of the spouses of individuals applying for Medicaid HCBS. It would also support policymakers’ efforts to rebalance LTSS spending towards HCBS by reducing institutional bias in existing LTSS policy. Although policymakers could make these protections permanent to avoid reverting to a system that incentivizes more costly institutional care, bipartisan support is stronger for a temporary extension. Nevertheless, a permanent extension would offer greater reliability for LTSS consumers and their family caregivers.

Challenge	State Insight	Federal Opportunity
Unpaid caregivers often incur an uncompensated, financial burden for providing their care.	Financial relief for unpaid caregivers does not exist in most states, and individuals in the few states offering tax credits often encounter barriers to accessing the financial relief	Congress should establish a refundable tax credit for caregivers to help with out-of-pocket costs for paid LTSS-related care, and this reform should include initiatives to reduce barriers to accessing the financial relief.

The economic value of family caregivers’ contributions approaches \$600 billion, but unpaid caregivers often bear a financial burden for providing their help.⁴⁵ For example, the typical out-of-pocket expense for unpaid family caregivers in 2021 was \$7,242.⁴⁶ Black and Hispanic/Latino caregivers incur a higher financial burden than white and Asian American caregivers.⁴⁷ To address this, some states have enacted state caregiver tax credits.

BPC’s analysis of Scorecard data shows bipartisan interest in supporting family caregivers, particularly toward ensuring the financial well-being of these caregivers. In interviews with BPC, some state officials reported that this support increased during the COVID-19 public health emergency, with states implementing policies that expanded or permitted paying family caregivers for providing Medicaid HCBS. **Despite this growing support, data from the 2023 Scorecard found that only six states have adopted tax credits to offset family caregivers’ out-of-pocket costs associated with providing care.**^o The limited growth could be because the credits are relatively new and innovative. Notably, BPC learned in interviews with some states offering these credits that **individuals often encounter barriers to accessing the financial relief. Limited consumer marketing and education on these tax benefits, as well as complex claims processing, are all factors in these challenges.**

Given bipartisan interest in supporting family caregivers, **Congress should establish a refundable tax credit equal to 30% of a caregiver’s qualified out-of-pocket LTSS-related expenses, up to a maximum \$3,000 credit for each qualifying family member** (i.e., requiring \$10,000 worth of expenses to claim the full \$3,000 refundable credit). The tax credit would begin phasing out for couples with annual household income above \$120,000 (or \$80,000 for single filers), and fully phase out at \$200,000 for couples (or \$133,000 for single filers). BPC described this policy reform in more detail in its 2021 and 2017 reports, [Bipartisan Solutions to Improving the Availability of Long-term Care](#) and [Financing Long-Term Services and Supports](#). Congress should incorporate this tax credit within the broader framework of the nation’s tax system and budget when it revisits a comprehensive tax bill in 2025. Congress should also explore how a federal tax credit will affect states with existing family caregiver tax credits. Based on states’ challenges implementing similar tax credits, **Congress should**

^o At least one additional state, Oklahoma, has enacted a family caregiver tax credit since AARP’s data collection in 2023.

couple this reform with significant consumer outreach and education, as well as ensure a simple process for claiming the tax credit.

Congress should scale this tax credit as needed, consistent with a full tax plan that strengthens the federal government's overall fiscal outlook. BPC previously contracted with the Urban Institute to evaluate the cost of this tax credit to the federal government. It estimated that the 10-year federal budgetary cost of the tax credit, in the form of reduced federal revenues and increased tax expenditures, would be \$130 billion over the 2018-2027 window.⁴⁸ Although policymakers should consider the financial implications of this recommendation, this option is one of the quickest and most direct ways to ensure caregiving for a growing elderly population. Notably, some of these costs could also offset other LTSS spending, particularly within Medicaid.

Enhancing Community Integration for LTSS Consumers

Challenge	State Insight	Federal Opportunity
<p>There is inadequate support for LTSS recipients' nonmedical health-related social needs, such as housing affordability and accessible transportation.</p>	<p>States are leveraging federal programs authorized by the Older Americans Act to adopt innovative practices that address individuals' nonmedical health-related social needs.</p>	<p>Congress should reauthorize the Older Americans Act, including making sufficient investments in the Administration for Community Living's Research, Demonstration, and Evaluation Center. Congress should also direct the center to research best practices for and the impact of the act's programs to promote the nonmedical health-related social needs of older adults and individuals with disabilities.</p>

Various federal and state programs offer social support for older adults and for individuals with disabilities, which can help delay or prevent the need for institutional or more expensive care and postpone eligibility for the means-tested Medicaid long-term care program. For example, the Department of Housing and Urban Development oversees two primary programs, Section 202 and Section 811, which help low-income older adults and people with disabilities access affordable housing.^{49,50} The Administration for Community Living's Housing and Services Resource Center also provides a variety of services to help people with disabilities live in the community, and the Older Americans Act awards grants to states to support nutrition, transportation, and other services to older Americans.^{51,52}

Despite these programs, significant challenges persist in addressing the non-medical health-related social needs of older adults and people with disabilities. The 2023 Scorecard measures how easily people can access non-medical services and supports like housing and transportation, which contribute to their health. AARP created the [Livability Index™ platform](#) to measure livability-friendly practices. It scores states and neighborhoods on a scale from 0 to 100, with the higher score awarded to areas with more livability-friendly practices. BPC's analysis found that both Democratic- and Republican-leaning states have low livability averages, with each party averaging around 50 on both [AARP's transportation category score](#) and [AARP's housing category score](#). In interviews with BPC, both Republican- and Democratic-leaning states described the challenges they faced providing nutrition services and meals to older adults, due to the rising cost of food and increasing demand for these services. Some state officials noted that older adults often rely on a single meal provided by the Older Americans Act-funded programs each day. During the COVID-19 public health emergency, many states temporarily provided two meals daily, but as the American Rescue Plan's funds diminish, states are returning to one meal.

States are leveraging federal programs to adopt innovative practices that address individuals' nonmedical health-related social needs. For example, under a 2020 Nutrition Innovations Grant from the Administration for Community Living, Iowa developed the Iowa Café, which modernizes how the state delivers congregate meals under the Older Americans Act.⁵³ This innovative program includes partnerships between local area agencies on aging and licensed food service establishments; allows participants to choose from a menu at any participating restaurant, with the meal paid by the state agency; and aims to reach older Americans who are in the greatest social and economic need, such as older individuals in rural communities and with limited English proficiency. **Despite these innovative approaches, federal research on and evaluation of states' implementation of these programs and states' innovations is limited.**

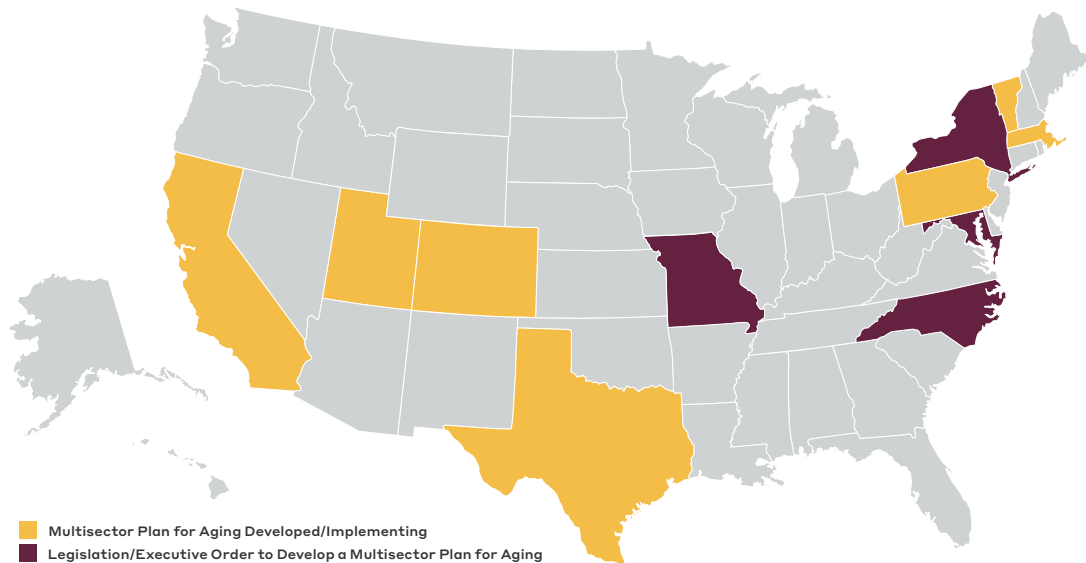
With the older adult population increasing rapidly, Congress should ensure the programs that support the nonmedical health-related social needs of older adults and individuals with disabilities receive ongoing, sufficient federal support to meet the rising demand. Most pressing, Congress should reauthorize the programs under the Older Americans Act and ensure they have adequate funding. Without congressional action, these programs will expire at the end of FY2024. State officials whom BPC interviewed also emphasized the importance of granting states the flexibility to tailor their Older American Act services to the unique needs of their growing and diverse populations. **Ensuring adequate funding for programs under the Older Americans Act should include sufficient investments in the Administration for Community Living's Research, Demonstration, and Evaluation Center. Congress should also direct the center to conduct research on best practices, as well as the impact, of the Older Americans Act programs to promote the nonmedical health-related social needs of older adults and individuals with disabilities.** This work should involve researching opportunities to enhance these programs in rural and frontier areas and localities' innovative practices to provide specialized, person-centered services.

Challenge	State Insight	Federal Opportunity
<p>State and federal policies and systems are often ill-equipped to meet the wide-ranging, growing needs of LTSS consumers.</p>	<p>States on both sides of the aisle are adopting new strategies, such as a multisector plan for aging, to improve their policies and systems to support community integration. Strong stakeholder engagement and continued monitoring and evaluation are key to these efforts.</p>	<p>Congress should support states in developing and maintaining multisector plans for aging. Congress should advance reforms that create a national multisector plan for aging, learning from states' experiences in developing their own plans.</p>

As the older adult population grows, the current infrastructure will need to evolve to adequately meet the needs of a diverse population with long-term care needs and the family caregivers who support them. A multisector plan for aging is an encompassing term for broad, cross-sector planning to ensure that state policies and systems are equipped to meet the wide-ranging, growing needs of older adults, people with disabilities, and family caregivers.⁵⁴ Although the development process, titles, and content of these plans vary by state, ensuring access to quality, person-centered LTSS and family caregiver supports is an important aspect of this work.

The 2023 Scorecard measures states' progress on creating multisector plans for aging. Of the eight states that had either enacted or were in the process of creating a multisector plan for aging as of 2023, five states were Democratic-leaning and three states were Republican-leaning. This bipartisan trend proves true when BPC analyzed more recent data (see Figure 4). **Despite the increasing number of states developing multisector plans for aging over the past decade, about half of states still lacked such plans as of March 2024, and the United States does not have a national multisector plan for aging.**⁵⁵

Figure 4: Multisector Plans for Aging Across States as of March 2024



Source: [Multisector Plans for Aging](#)

In interviews with BPC, some states with multisector plans for aging shared key practices for ensuring a plan’s effectiveness, particularly in the creation of these plans and the ongoing evaluation and monitoring of states’ progress. These states recognized the importance of engaging a diverse group of stakeholders throughout the process by conducting public surveys, listening sessions, and community roundtables. One state stressed the importance of establishing a committee to guide the plan’s creation and emphasized that this body should include a variety of stakeholders, including providers, researchers, and advocates. Some states with multisector plans for aging highlighted the value of creating clear goals, including short-term and long-term goals, and developing systems to monitor the states’ progress on these goals. For example, California recently launched an [implementation tracker](#) as a publicly accessible resource to monitor progress on its Master Plan for Aging. This tracker includes summaries of the state’s initiatives aligned with its plan goals and strategies, implementation timeframes, identification of lead agencies, and annual updates on progress toward each initiative’s fulfillment.

Federal policymakers should explore federal strategies and reforms to increase and maintain the number of states with multisector plans for aging. To accomplish this, Congress should advance reforms that provide support and incentives to states, such as technical assistance, a framework for creating these plans, or a temporarily enhanced FMAP. Sens. Kirsten Gillibrand (D-NY) and Bob Casey (D-PA) introduced the Strategic Plan for Aging Act ([S.3827](#)) in February 2024, which is a partisan bill that would create a nationwide grant program for states to create their own strategic plans for aging.

While federal policy reforms could require states to establish these plans, LTSS policy experts and state officials stressed, in interviews with BPC, that development and maintenance will require significant investment and buy-in from state leadership. Many state officials cited challenges funding these plans, and said they frequently relied on a combination of state, nonprofit, and private industry funding to support the plans. As federal policymakers weigh bipartisan opportunities to increase the number of states with multisector plans for aging, they should consider the potential for improved health outcomes and financial offsets against any federal investments.

In interviews with BPC, some state officials emphasized that any federal reforms should broadly define multisector plans for aging. These officials emphasized that supporting states in tailoring their plans based on their distinct landscapes and needs is most effective. For example, one state noted that its Council on Aging was comparable to a multisector plan for aging. This council develops cross-sector aging plans, tracks progress, involves a diverse range of stakeholders, and collaborates with its state government. As Congress supports states’ efforts to pursue these planning initiatives, federal policymakers should pursue reforms that consider states’ broad approaches.

Federal policymakers should also support efforts to create a national multisector plan for aging and leverage promising practices to achieve that goal. This national initiative should encompass broad, cross-sector planning to ensure that the nation’s policies and systems can meet the needs of older adults, people with disabilities, and family caregivers. For example, Congress should reauthorize and fund the Interagency Coordinating Committee on Healthy Aging and Age-Friendly Communities under the Older Americans Act, which is set to expire at the end of FY2024.⁵⁶ The Administration for Community Living leads this committee, which promotes coordination across federal agencies to address key aging issues. The committee is currently working to create a strategic framework around coordinated housing and supportive services; aligned health care and supportive services; age-friendly communities; and increased access to LTSS. As part of this work, the committee is partnering with the John A. Hartford Foundation, The SCAN Foundation, and West Health to conduct interviews with stakeholders, including older adults.⁵⁷

Congress should direct the Interagency Coordinating Committee on Healthy Aging and Age-Friendly Communities to create and maintain a national plan on aging and provide it with the necessary resources. This committee is well positioned to spearhead the development of a national plan and is currently involved in some preliminary efforts, such as creating strategic frameworks and conducting listening sessions to learn from older adults. When designing the national plan, Congress should consider the lessons learned from states’ experiences creating their plans. For example, a national plan should incorporate the input of a diverse range of stakeholders, including LTSS consumers. It should also delineate both short-term and long-term goals and establish transparent mechanisms for tracking progress on these goals.⁵⁸

Conclusion

Although recent federal policy reforms have encouraged states across the political spectrum to improve their LTSS systems, gaps in the nation's long-term care system persist for older adults, individuals with chronic illnesses or disabilities, and family caregivers. To address these gaps and promote high-performing LTSS systems nationwide, federal policymakers should work together to advance policy reforms that foster state innovation and flexibilities while applying lessons learned from states' experiences.

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Early Childhood

Economy

Debt Limit

Higher Education

Immigration

Paid Family Leave

Energy

Health

Housing

Infrastructure

Technology



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