

POOLING RISK TO PAY FOR LONG-TERM SERVICES AND SUPPORTS?

EUROPEAN LESSONS FOR THE UNITED STATES

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Abstract

The United States has expanded health insurance coverage repeatedly without building a comparable system of protection against the costs of long-term services and supports (LTSS). Medicare excludes most LTSS, Medicaid functions as a means-tested payer of last resort, and private long-term care insurance represents a minimal and increasingly inaccessible product for families, leaving the financial risk of needing help with functional impairments to fall mainly on individuals, families, and state Medicaid programs. This paper examines how several European countries have moved further toward treating LTSS as a shared social risk, using varied combinations of social insurance, tax financing, cash allowances and supports, and cost-sharing. While no European model offers a template for direct adoption, each illuminates recurring design trade-offs: how broadly to pool risk, how to balance home-based and institutional care, how to structure cash versus in-kind benefits, how to prevent geographic inequity, and how to sustain financing over time. Lessons from European reform suggest that durable U.S. reform requires federal risk pooling, national minimum standards, investment in home- and community-based infrastructure, alongside a formal recognition of family caregivers, and a credible, durable revenue mechanism.

Keywords: Long-term services and supports (LTSS), LTSS financing reform, social insurance, Medicaid, home- and community-based services, comparative health policy, aging policy, informal caregiving, Europe, United States

I. Introduction

The United States has repeatedly expanded health insurance coverage without creating a comparable system of social protection for long-term services and supports (LTSS). Medicare provides nearly universal health coverage for older adults, but it excludes most LTSS. Medicaid is the largest public payer for LTSS, but it functions primarily as a means-tested program for people with limited income and assets, including those with disabling conditions and those who spend down their resources after incurring high care costs. Private long-term care insurance (LTCI) has been in decline for two decades and now plays a minimal role in providing protection against the costs of LTSS. Purchase of private long-term care insurance has been limited because of high premiums, limited coverage, and aggressive underwriting (Cohen et al., 2013). As a result, the financial and practical risks of needing assistance with activities of daily living are still borne largely by individuals, families, and state Medicaid programs (Colello, 2025).

This gap is increasingly difficult to sustain. Approximately half of Americans who reach age 65 will require some form of paid long-term services and supports during their remaining lifetime, and about one-fifth will need care for more than five years (American Association for Long-Term Care Insurance, n.d.; Johnson, 2019). Yet relatively few households have set aside resources specifically for LTSS, and the private cost of care can exceed the income and savings of many older adults, which suggests some irrational optimism with respect to the risk of needing LTSS (Swartz & Feder, 2021). Some studies estimate that median annual nursing home costs exceed the income of older households, while need for care is often inversely related to ability to pay (Genworth Financial, 2019; Gruber & McGarry, 2025). The United States therefore combines three forms of vulnerability: incomplete insurance protection and risk optimism, heavy reliance on unpaid caregiving, and substantial state variation in access to publicly financed services.

European countries face many of the same demographic and fiscal pressures, but several have moved further toward treating LTSS as a distinct social risk requiring some form of partial collective financing. In the last six decades, several countries such as Germany, the Netherlands, Spain, Scotland (UK), France, Slovenia, among others, have adopted different combinations of social insurance, tax financing, cash allowances and supports, alongside cost-sharing designs to face the needs of care in the population. Although these systems are not uniformly generous and do not eliminate private burdens; most remain partial entitlements that combine public protection with limits on benefit scope, user charges, family caregiving, or local discretion. Nevertheless, they offer a useful comparative perspective because they show how countries have tried to move beyond purely residual, means-tested, or family-based approaches.

This paper examines a number of lessons that emerge from the European experience with expanding long-term care entitlements that are of relevance to the United States. Its central argument is that European LTSS reform has been most successful where policymakers have framed care needs in later life, at least partially, as a shared social risk. However, the most durable systems have also had to manage the fiscal consequences of expanded entitlement, and at times even amended their design to make it financially viable, as the German reform in 2008 illustrates (Gruber & McGarry, 2025). The key policy point is not whether the United States should simply import a European model. It is how the United

States might design a politically feasible LTSS financing system that pools catastrophic risk, supports home- and community-based care, recognizes the continuing role of family caregivers, ensures fairness, and rests on a sustainable revenue base.

The paper proceeds in four steps. First, it describes the U.S. baseline: meaningful but incremental progress in home- and community-based services, quality oversight, and caregiver support, but no comprehensive LTSS financing reform. Second, it compares public attitudes toward LTSS responsibility in the United States and Europe, emphasizing both the overarching demand for pooled protection in each setting alongside the political difficulty of paying for it. Third, it reviews major European approaches to LTSS entitlement expansion and the design choices that distinguish them. Finally, it draws lessons for U.S. reform, focusing on risk pooling, benefit design, home care, cash allowances, national standards, informal care, and fiscal durability.

II. The U.S. baseline: Incremental LTSS reform without financing reform

Over the past 25 years, the largest federal advances in U.S. LTSS policy have not involved comprehensive financing reform. Instead, federal policy has gradually moved the system away from an institution-centered model and toward greater support for home- and community-based services, stronger oversight of nursing facilities, and more attention to family caregivers. These changes are important, but they have been layered onto a fragmented financing structure.

Expanding home- and community-based services

A key policy shift has been the expansion of Medicaid home- and community-based services (HCBS). For example, the Deficit Reduction Act of 2005 created the Medicaid section 1915(i) state plan option, allowing states to cover HCBS through their Medicaid state plans rather than relying exclusively on waivers (U.S. Department of Health and Human Services, 2016). The Affordable Care Act (ACA) deepened that shift by creating the Community First Choice option under section 1915(k), which provides an enhanced federal match for states that offer attendant services and supports in community settings (Centers for Medicare & Medicaid Services [CMS], n.d.-a). The ACA also created the Balancing Incentive Program, which encouraged states to increase the share of Medicaid LTSS spending devoted to non-institutional care (CMS, n.d.-b). The Money Follows the Person demonstration, repeatedly extended by Congress, has helped states transition people from institutions into community settings.

Federal policy has also changed expectations about what community-based care should mean. The Centers for Medicare & Medicaid Services' (CMS) 2014 HCBS settings rule established national standards for determining when services truly qualify as home- and community-based (CMS, 2014). The rule strengthened person-centered planning requirements and excluded settings that are institutional in character. This was an important civil-rights-oriented advance because it pushed states to fund services in settings integrated into community life rather than merely smaller versions of institutions. Yet the

settings rule has also been controversial, as it has instituted some requirements that are viewed as excessively rigid restrictions of the structure of patient environments that defy practical consideration regarding patient safety. For example, requirements like mandatory access to private, lockable doors and independent control over schedules can be unsafe or confusing for individuals with advanced dementia. Forcing locked-door policies on cognitively impaired individuals often restricts their ability to find their rooms or safely navigate a care space (LeadingAge, 2023).¹

Strengthening oversight and quality measurement

Federal policy has also made nursing home oversight more visible and data-driven. CMS launched the Five-Star Quality Rating System for Nursing Home Compare in 2008, making inspection, staffing, and quality information more accessible to consumers and families. The federal government later overhauled the Requirements for Participation for long-term care facilities, with implementation phased in through 2019, and updated surveyor guidance in 2022 (CMS, 2022). More recently, CMS required more detailed ownership disclosure for nursing homes and finalized national minimum staffing standards for long-term care facilities, along with Medicaid institutional payment-transparency reporting (CMS, 2023, 2024).

On the Medicare side, federal policy has focused more on care coordination and transitions for people with serious functional limitations. The IMPACT Act of 2014 required standardized assessment data across skilled nursing facilities, home health agencies, inpatient rehabilitation facilities, and long-term care hospitals (CMS, n.d.-c). Medicare has also tested more home-based models, including the Independence at Home demonstration (CMS, n.d.-d). More recently, the Guiding an Improved Dementia Experience (GUIDE) Model was launched to provide comprehensive dementia care and caregiver supports, with the explicit goal of helping delay or avoid long-term nursing home placement (CMS, n.d.-e).

Temporary and incremental funding expansions

There have also been important recent funding and benefit expansions, though most have been temporary or incremental. During the pandemic and its aftermath, the American Rescue Plan Act temporarily increased the federal Medicaid match for HCBS under section 9817, allowing states to expand services, stabilize providers, and strengthen the direct care workforce. Separately, the Bipartisan Budget Act of 2018 allowed Medicare Advantage plans to offer broader special supplemental benefits for the chronically ill, opening the door to some non-medical supports relevant to long-term care. Yet the coverage of LTSS has been quite limited, and recently Medicare Advantage plans have retreated from offering LTSS benefits (Bhaumik & Grabowski, 2025).

¹ A related but often underappreciated advance is that family caregiving became a clearer federal policy target. The RAISE Family Caregivers Act led to the National Strategy to Support Family Caregivers, released in 2022 and updated through progress reports, giving the federal government a cross-agency framework for supporting the relatives and friends who provide most long-term care. That did not create a universal caregiver benefit, but it marked a meaningful change in federal recognition of caregiving as part of the long-term care system rather than a purely private family matter.

Yet, despite all these changes, the United States still has not enacted a comprehensive federal LTSS financing program. Medicaid remains the primary public payer for LTSS; HCBS remains optional for states in important respects; access varies substantially across states; and waiting lists remain common. In the last 25 years, the U.S. LTSS policy has looked less like a single LTSS reform and more like a series of meaningful but partial advances layered onto a fragmented system. The one exception to that approach was the enactment of the Community Living Assistance Services and Supports (CLASS) Act. The CLASS Act was part of the ACA of 2010, but was never implemented because it could not be financially sustained in the long term. The program in great measure failed because enrollment was voluntary, creating incentives for adverse selection into the program. The risk that enrollment would be disproportionately among those in need of care would undermine the solvency of a program that was designed to be self-sustaining (Wiener, 2012).

III. Political feasibility, attitudes, and financial preparedness

The central political challenge in LTSS reform is that the public recognizes the problem but remains divided about responsibility, financing, and institutional design. In both the United States and Europe, people express concern about future care needs and affordability. However, attitudes differ in how strongly LTSS is framed as a collective social risk and in how much confidence people have that government will act.

The U.S. politics of shared responsibility

Support for older adults and family caregivers is common in both Republican and Democratic rhetoric. Recent administrations have explored different approaches to LTSS: one emphasizing private long-term care insurance and family caregiving, another emphasizing the care economy and workforce supports. During the 2024 presidential campaign, Vice President Harris proposed adding a home care benefit to Medicare for beneficiaries with significant functional impairments, while President Trump proposed new supports for family caregivers.

Polling suggests substantial public concern about LTSS costs and broad support for some government role. Pew Research Center surveys generally find that a majority of Americans believe long-term care should not be solely an individual or family responsibility (Parker, 2026). Support tends to be strongest for government help for low-income individuals and for middle-class families facing catastrophic costs. Many Americans prefer a model in which government provides a backstop for very high or prolonged costs, while individuals remain responsible for more modest needs.

Support for policies aimed at assisting family caregivers is widespread among both Democrats and Republicans, with majorities in each party endorsing all of the measures considered. However, substantial partisan differences remain. Democrats are considerably more likely than Republicans to support government-funded short-term care that provides respite for family caregivers (80% vs. 63%), mandatory paid family leave provided by

employers (80% vs. 59%), and direct financial payments to help cover caregiving costs (74% vs. 53%). These figures include independents who lean toward either party and suggest that, while caregiving support enjoys broad bipartisan backing, Democrats are generally more supportive of government intervention and financial assistance in this area (Parker, 2026).

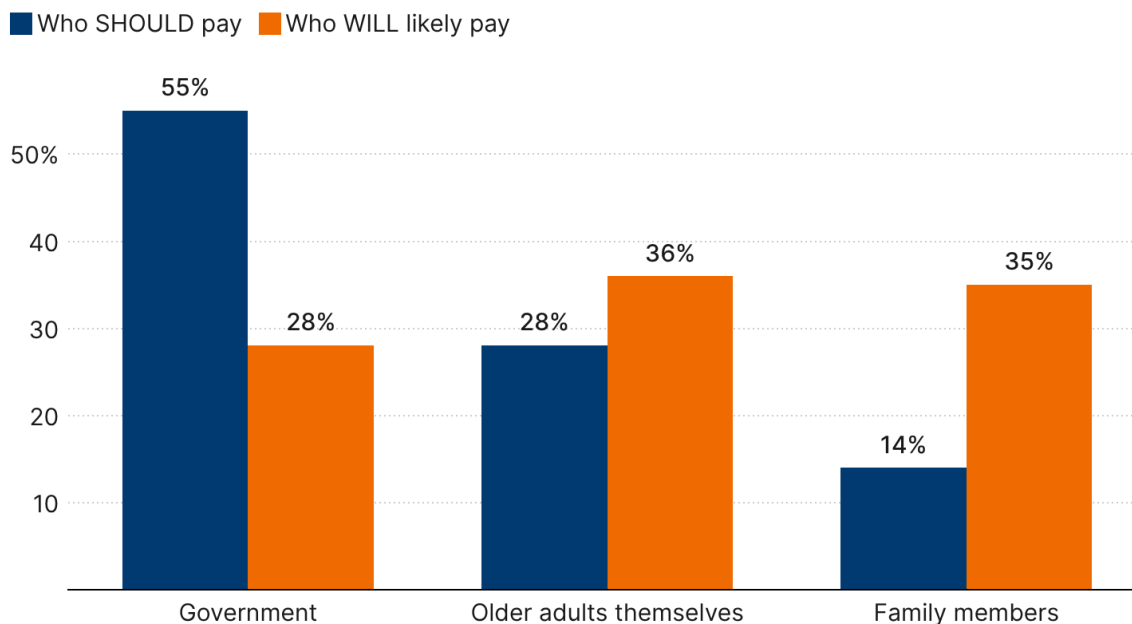
Yet support becomes more fragile when specific financing mechanisms are introduced. Public support often falls when proposals involve payroll taxes, mandatory contributions, or broad tax increases. It tends to improve when financing is framed as insurance-like, for example, through Medicare-style contributions. This suggests that Americans may be more receptive to an LTSS financing model that resembles social insurance than to one framed as a new welfare program or open-ended tax-financed benefit.

The United States also shows a striking gap between what people think should happen and what they expect will happen. Pew survey evidence indicates that many Americans believe government should play a larger role in paying for long-term care, but far fewer expect government to do so (see Figure 1; Parker et al., 2019). Instead, many expect that older adults and families will continue to bear the burden. This “should-pay/will-pay” gap cuts across party lines, even though Democrats and Republicans differ in their preferred role for government. The result is a form of shared pessimism: Americans recognize the problem, but many doubt that the state will provide a durable solution.

FIGURE 1

Who should pay vs. who will pay for long-term care in 30 years

Share of U.S. adults (%)



Source: Parker, Morin, and Horowitz, 2019

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European attitudes toward LTSS as a social risk

European survey evidence points to a stronger collective-risk orientation. The InCARE survey found high levels of agreement that public authorities should organize and provide appropriate care for older people with care needs, and substantial support for universal contributions to an LTSS insurance scheme (Ilinca & Simmons, 2022). Across participating countries, many respondents supported either full public coverage of care costs or at least a basic universal LTSS package. Support for assigning direct financial responsibility to adult children was lower.

This does not mean that Europeans support unlimited public expenditure or comprehensive public coverage without cost-sharing. Many systems include user charges, benefit caps, and partial coverage. But the underlying orientation differs from the United States: LTSS is more often viewed as a legitimate domain of social protection rather than a purely private contingency. This is highlighted by the comparisons between the U.S. and Europe summarized in Table 1.

TABLE 1

Differences between support for long-term care (LTC) insurance in Europe and the U.S.

Dimension	Europe	United States
Responsibility for organizing/providing LTC	Strong support for a public role: 97% agree that public authorities should organize and provide appropriate care for older people with care needs (Ilinca and Simmons, 2022).	More fragmented and residual approach; survey evidence focuses less on public provision and more on who should pay (Wiener et al., 2015).
Responsibility for financing LTC	More collectivist orientation overall: around half support the state covering all care costs or a basic universal LTC package; 62% support contribution to an LTC insurance scheme (Ilinca and Simmons, 2022).	More individualized orientation: 58.7% say financing LTC is the responsibility of individuals; 37.1% say the government should help pay (Wiener et al., 2015).
Support for public insurance	Majority support pooled financing, though support for compulsory LTC insurance has declined since 2007 (Ilinca and Simmons, 2022).	Limited support for mandatory public insurance (18.4%), but greater support for a voluntary public LTC insurance option (62.9%) (Wiener et al., 2015).
Role of family in financing care	Support for family financial responsibility has declined; 35% say children should pay for parents' care if needed (Ilinca and Simmons, 2022).	Family responsibility remains important in practice, but survey responses emphasize individual rather than children's responsibility for financing care (Wiener et al., 2015).
Affordability concerns	Concern centers on adequacy, affordability, and access, especially for residential care, despite broad support for state involvement (Ilinca and Simmons, 2022).	Affordability concerns are acute: 43% are not confident they could afford LTC, and 90% say nursing home costs would be impossible or very difficult (Hamel and Montero, 2023).

European trend data also suggest a gradual weakening of traditional family-obligation norms (Costa-Font, 2010). Support for adult children bearing financial responsibility for parents' care has declined across age cohorts. Younger adults are more likely to favor state responsibility, while older adults are more likely to support means-tested cost-sharing. These patterns suggest that expectations of family responsibility are

not fixed cultural traits. They are shaped by the perceived availability, affordability, and quality of formal care.²

Financial preparedness and the limits of individual responsibility

On both sides of the Atlantic, financial preparation for LTSS remains inadequate (Hamel & Montero, 2023; European Commission, 2007, 2021, 2023, 2026). In the United States, only a minority of older adults report being financially prepared for long-term care costs. Median annual private nursing home costs can exceed the annual income of many older adults (MetLife Mature Market Institute, 2012). As a result, a reform strategy that relies primarily on individual savings or private purchase is unlikely to provide broad protection.

The private long-term care insurance market has also failed to become a meaningful substitute for public financing. In the United States, participation in private LTCI is low (3% of adults over age 50) and declining (compared to about 10%, 15 years earlier). Premiums are high, underwriting is restrictive, and insurers have retreated from the market after underpricing earlier products (Rau & Aleccia, 2023). While in 2000, there were 100 insurers selling LTCI, today there are fewer than 12 (Lamberts & Schutt, 2020). The share of older adults with private LTCI remains small, and modern policies are generally less generous than earlier products. This experience suggests that voluntary private insurance alone cannot solve the LTSS financing problem.

Financial preparedness is also limited in Europe, even though public systems are generally stronger. Survey evidence shows that many Europeans anticipate needing care, worry about affordability, and lack confidence that formal care will be available at reasonable cost (European Commission, 2007). These concerns help explain why financing reform remains politically difficult even where there is strong support for developing a scheme based on collective responsibility. Although individuals demand some form of pooled protection, governments still face the hard task of financing it in a setting of restrictive budgets. However, some European countries have managed to expand their LTSS entitlements.

IV. European approaches to LTSS entitlement expansion

European LTSS systems can be grouped into several broad models. These models are not mutually exclusive, and many countries combine elements of more than one. Still, the typology is useful because it highlights the central policy choices facing any LTSS reform: how to pool risk, how to define entitlement, how much cost-sharing to require, how to balance cash and services, and how much discretion to leave to local authorities.

² There are differences between European Union countries with public insurance; differences in coverage of room and board for institutional care appear to be key. For example, room and board is covered in the Netherlands, while in Germany that coverage is means tested and only applies to those who cannot afford it.

Universal social insurance and tax-based approaches

Germany is a leading example of a social insurance model for long-term care (LTC), in which the need for care is collectively insured through mandatory contributions (Kesternich et al., 2025). The statutory LTSS insurance system provides universal coverage, although benefits are capped and do not fully cover care costs. Beneficiaries may choose between cash benefits, in-kind services, or a combination of both, with cash payments generally being less generous than formal care services. The system also recognizes the contribution of informal caregivers through pension credits and other forms of support. The 2008 Long-Term Care Further Development Act (Pflege-Weiterentwicklungsgesetz) strengthened the system by increasing benefits, expanding support for home-based care, introducing care leave entitlements, and improving care counseling and service quality. Subsequent reforms also increased contribution rates, with higher premiums imposed on childless adults to help improve the financial sustainability of the long-term care insurance system. These reforms reflected Germany's efforts to enhance the responsiveness and sustainability of its LTSS system in the face of population aging while maintaining its commitment to universal social insurance principles (Federal Government of Germany, 2023).

The Netherlands has one of the oldest and most comprehensive LTSS systems, based primarily on a social insurance model with supplementary tax-funded municipal services. The 2015 LTC reform significantly restructured the system by limiting nationally funded entitlements to individuals with intensive care needs while decentralizing community-based and social support services to municipalities. Driven by concerns over rising public expenditure, population aging, and increasing demand for care, the reforms aimed to promote independent living, strengthen informal care networks, and reduce reliance on institutional care. The Dutch experience highlights both the strengths of universal public entitlement and the fiscal challenges of sustaining a comprehensive LTC system over time (Bakx et al., 2025; Veghte, 2025).

Spain's System for Autonomy and Care for Dependency (SAAD), introduced in 2007 following the German model, established a universal, tax-funded LTSS system that expanded formal entitlements to a range of services, including home-based care, residential care, and cash allowances for informal caregivers. However, its implementation has been constrained by fiscal pressures, significant regional disparities in service provision, long waiting lists, and a continued reliance on cash benefits (Costa-Font et al., 2025b). Similarly, Scotland introduced Free Personal Care (FPC) in 2002, establishing a tax-funded model that provides universally available personal and nursing care for eligible older adults, regardless of income or assets. The reform aimed to reduce the financial burden of LTSS by separating personal care costs from accommodation and living expenses, which may still be means-tested in residential settings (Costa-Font et al., 2023). While the policy has improved access and equity, it has also generated ongoing challenges related to funding pressures, increasing demand, and workforce shortages, highlighting the trade-offs involved in sustaining universal entitlement to care.

Finally, Slovenia has recently moved toward a more formalized LTSS financing framework, including mandatory contributions. Its reforms place it closer to the social insurance family of approaches, although implementation and long-term fiscal

sustainability remain important questions. However, its implementation remains at an early stage, and questions regarding administrative capacity, fiscal sustainability, and the adequacy of future benefits have yet to be fully resolved.

The main advantage of universal social insurance and tax-based models is that they create a visible and broadly pooled financing mechanism. The main limitation is that contribution rates must rise or benefits must be constrained as need increases (Karagiannidou & Wittenberg, 2022). Germany shows that universal insurance can improve protection while still leaving substantial out-of-pocket costs, if benefits are capped below actual care costs.

Means-tested approaches

England represents a predominantly tax-funded and means-tested approach to LTSS. Public support is available through local authorities, but eligibility is determined by both care needs assessments and financial means testing, requiring individuals with assets above specified thresholds to self-fund their care costs. This model has helped contain public expenditure compared with universal entitlement systems, but it exposes many middle-income households to substantial financial risks and uncertainty. The absence of comprehensive social insurance coverage has contributed to persistent concerns about catastrophic care costs and has made LTC reform a recurrent and politically contentious issue in England (Banks et al., 2025).

The United States shares some features with this model, though in a more fragmented form. Medicaid finances a large share of LTSS, but eligibility is means-tested and varies by state. Medicare covers post-acute skilled care but not long-term custodial care. Private insurance and out-of-pocket payment fill only part of the gap. The result is not a coherent tax-funded LTSS system, but a residual structure in which Medicaid functions as a catastrophic payer after impoverishment or spend-down.

The central weakness of means-tested systems is that they control public spending by shifting risk to households. They may protect the poorest individuals, but they leave many middle-income households exposed to catastrophic costs.

Mixed universalist approaches

Italy combines national policy frameworks with strong regional variation and continuing reliance on family care (Brugiavini et al., 2025). While the country has traditionally relied heavily on informal family care and cash allowances, the availability and quality of formal LTC services vary considerably across regions. Emilia-Romagna has developed a more integrated and extensive network of home-based and community care services supported by stronger regional investment and coordination (Tediosi & Gabriele, 2010). France's Allocation Personnalisée d'Autonomie (APA) provides a conditional care allowance based on need, with benefit amounts adjusted by income and administered through departments (Le Bihan & Martin, 2010). These systems provide broader public recognition of dependency than the U.S. model, but their decentralized governance produces variation in access and generosity (Ghailani et al., 2026).

The central lesson from these systems is that legal entitlement does not automatically produce equal access. When responsibility for implementation is delegated to regions or municipalities without adequate funding and national standards, geographic inequality is likely.

Family-care-reliant systems

Some countries rely heavily on unpaid family caregiving, whether explicitly or implicitly. Poland is the clearest example among the European nations reviewed here, with substantial dependence on family care and limited formal service capacity (Golinowska & Sowa-Kofta, 2017). Spain and Italy also rely heavily on family caregiving, in part as a result of how caregiving is designed. However, the design of caregiver allowances also raises concerns about monitoring, targeting, and the potential misuse of public funds. Unlike in-kind services, unconditional cash allowances give recipients greater discretion over how benefits are used, which can weaken the link between public expenditure and the provision of care. Evidence from Spain is particularly relevant. Exploiting the gradual implementation of the Spanish long-term care system (SAAD), Costa-Font and Vilaplana-Prieto (2017) find that the expansion of public LTSS subsidies was associated with a reduction in private saving among younger older adults, who primarily received unconditional cash benefits. The estimated reduction in saving was equivalent to approximately 13% to 39% of the subsidy, whereas no comparable reduction was found among recipients of home-help services. This suggests that cash benefits were not fully translated into additional current care consumption and, instead, partly relaxed households' need to save for future expenses. More broadly, comparative research on cash-for-care schemes shows that their effects depend substantially on eligibility rules, monitoring, and restrictions on how benefits can be used (Da Roit & Le Bihan, 2010; Le Bihan et al., 2019). Thus, while caregiver allowances can provide valuable flexibility and recognize the contribution of informal carers, their design involves a trade-off between beneficiary choice and the ability of governments to ensure that public resources generate additional care rather than simply substitute for private resources.

Family-care-reliant systems may limit visible public expenditure, but they do so by making a greater share of costs the responsibility of households (Costa-Font & Vilaplana-Prieto, 2025). These costs include lost earnings, reduced labor force participation, caregiver strain, and unequal access depending on family availability. Reliance on informal care also has gender implications, since women have historically provided a disproportionate share of unpaid care.

This approach is especially relevant for the U.S., because the United States also relies heavily on unpaid family care. The difference is that the U.S. reliance is often implicit rather than openly designed. A sustainable LTSS financing system would need to recognize family care as part of the system rather than as a free residual.

V. Design choices in LTSS reform

The European cases reveal several recurring design choices. These choices matter more than country labels because they determine what public entitlement means in practice.

Public risk pooling versus private exposure

The first design choice is how much LTSS risk should be pooled publicly and how much should remain with individuals and families. Universal systems, both social insurance and tax-based systems, pool risk broadly but often provide only partial coverage of services, and as the German model illustrates, low-income individuals still rely on supplemental assistance. Means-tested systems limit public liability but expose households to large private costs. Mixed and decentralized systems may promise a public financial entitlement which can differ across the territory in some countries (e.g., Italy).

For the United States, a central question is whether a system of LTSS funding should aim for front-end coverage and provide catastrophic protection, or whether a hybrid model is more suitable. A catastrophic public insurance scheme may be more politically feasible than comprehensive coverage because it targets the risk most households cannot reasonably bear. But if the coverage is limited to very high-cost cases, it may fail to change the basic financial insecurity of the current system. The only recent U.S. advance in social insurance has been the program in the state of Washington that has front-end coverage and is strictly limited (Munnell, 2024).

Expansion of home- and community-based care

Across Europe, countries have tried to shift LTSS away from institutions and toward home- and community-based care. This shift reflects both preferences and fiscal incentives. Most older adults prefer to remain at home, and residential care is generally expensive. Although policies that promote aging in place can further social, clinical, and budgetary goals, home care is not automatically cheaper or easier to implement. If formal services are underfunded, the shift to home care may simply transfer responsibility to families, a form of *cost shifting*. If governments face fixed budgets, they may ration services directly or through needs tests and waiting lists, underpay providers, or rely on low-intensity care packages. If workforce supply is inadequate, home care expansion may produce delayed hospital discharge, unmet need, or heavy caregiver burden.

The Netherlands, Germany, Scotland, and Spain all illustrate this tension. Each expanded or restructured home-based supports, but the effects depended on workforce capacity, benefit design, and local implementation. The lesson is that HCBS expansion must be treated as infrastructure policy that is consistent with the increased demand for aging in place, not merely as a less expensive substitute for institutional care.

Cash benefits versus support services

A second recurring design choice is whether benefits should be provided as support services, cash allowances, or personal budgets. Cash benefits can support consumer

choice, enable care by family members, and help individuals arrange care where formal services are scarce. Germany, Spain, and the Netherlands all provide some form of cash or budget option.

Yet cash benefits are not neutral. They shape who delivers care and whether formal service markets develop. Spain's experience suggests that caregiver allowances can reinforce dependence on informal care and limit the expansion of formal services. Both Spain's and Germany's systems attempt to balance this by allowing choice while making cash benefits less generous than in-kind services because the costs of LTSS services tend to grow with a cash benefit. The Netherlands design includes personal budgets but regulates them and often values them below contracted services (Szenkurök, 2026).

For the United States, cash benefits are already a significant feature of many state Medicaid LTSS programs (AARP, 2024). They are politically attractive and administratively flexible, but treating them as a low-cost substitute for formal care infrastructure carries significant risks to quality and program integrity. If used, they should be paired with caregiver protections, quality safeguards, and investments in provider skills and training.

National standards versus local discretion

A third design choice concerns governance. Countries with more nationally standardized systems tend to provide more consistent entitlement across regions. However, decentralized systems can adapt to local needs, even though they can also produce geographic inequity unless funding is adjusted.

England's locally administered system is often criticized for place-based variation in access and generosity. Spain's national framework has also produced uneven regional implementation, and Italy's fragmented, region-based system produced regional differences. Poland shows substantial variation between municipalities and between urban and rural areas. The Netherlands offers a hybrid model, with intensive care organized nationally and community supports delegated to municipalities. This allows local tailoring but also exposes municipalities to budget pressures and incentives to contain costs.

This issue is central for the United States because Medicaid already produces substantial state variation in LTSS eligibility, HCBS availability, waiting lists, provider payment, and service intensity. A federal LTSS reform that relies on state administration would need national minimum standards, transparent eligibility rules, and financing protections strong enough to prevent a new form of geographic inequity.

Universalism, cost-sharing, and partial coverage

Even countries viewed as generous rarely provide fully comprehensive public LTSS coverage. Most systems combine public entitlement with cost-sharing, asset tests, benefit caps, or exclusions for room and board. Public benefits often cover personal care, nursing care, or assistance with activities of daily living, while accommodation, meals, domestic help, and ancillary costs may remain the responsibility of users.

Germany illustrates explicit partial insurance. Coverage is universal, but benefits are capped, and many households face residual costs. Scotland provides free personal care but does not extend to non-personal supports. England relies heavily on means testing and self-funding. France adjusts benefits by income and needs. These examples show that universal entitlement can coexist with substantial private spending.

The key policy question is therefore not whether an LTSS system is formally universal. It is whether the system provides meaningful protection against the risks of LTSS costs. A narrow or capped benefit may be politically easier to enact, but it may leave affordability problems unresolved.

Informal care and the workforce

Informal care remains the backbone of many LTSS systems. European countries differ in how explicitly they recognize it. Germany's social insurance system provides cash options and caregiver pension protections. Spain's system mimics this model and provides a caregiver allowance as an alternative to a more general system of care supports. Poland relies heavily on unpaid care. Even more formalized systems such as the Netherlands and Scotland depend on families to supplement public services.

Reliance on informal care can reduce public spending, but it raises major concerns about gender equity, labor force participation, caregiver health, care quality, and household financial security. It also creates inequity between people with available family caregivers and those without them.

The formal care workforce presents a related challenge. Expanding access to LTSS requires enough direct care workers, adequate wages, training, supervision, and career ladders. Systems that promise more home care without addressing workforce supply are likely to encounter shortages, turnover, and unmet need. At the center of the U.S. LTSS workforce challenge are the nation's immigration policies (Watson, 2024).

VI. Lessons for U.S. reform

The European experience does not point to a single reform pathway that the United States could simply adopt. Instead, it offers a set of design lessons about how countries expand LTSS protection while managing fiscal, administrative, and political constraints.

1. LTSS reform requires explicit risk pooling, but public entitlement is rarely comprehensive and focuses on catastrophic risks.

Meaningful financial protection requires some mechanism for pooling LTSS risk across the population. Countries that rely primarily on individual savings, private insurance, or means-tested assistance commonly leave households exposed to large and unpredictable costs. European social insurance and tax-financed systems provide broader protection because they treat LTSS as a shared risk rather than a purely private contingency.

At the same time, European experience shows that public entitlement does not necessarily mean full coverage. Germany and Spain provide universal long-term care insurance, but benefits are capped, and copayments in Spain vary by income. Scotland provides free personal care, but not all supportive services are covered. England provides public support only after means testing, which is higher than Medicare entitlements in the U.S. (at £23,250 or \$31,000). Thus, the central distinction is not simply universal versus means-tested coverage. The more important question is whether the public system protects households against catastrophic LTSS costs.

For the United States, this suggests that politically feasible reform may be more likely to begin as a catastrophic or partial social insurance benefit than as a fully comprehensive entitlement. But the benefit must be large enough and designed clearly enough to provide real protection rather than simply adding another limited layer to the existing fragmented system.

2. Home- and community-based care must be financed as real infrastructure.

Nearly all systems are trying to shift care away from institutions and toward home- and community-based services. This shift is consistent with the preferences of many older adults and people with disabilities, and it may reduce reliance on high-cost institutional settings. But home care expansion can become a form of cost shifting if it is not accompanied by adequate workforce capacity, caregiver support, and coordination with health services.

The U.S. lesson is that expanding HCBS entitlement is necessary but not sufficient. It must be paired with investments in the direct care workforce, respite care, caregiver supports, and mechanisms to prevent state or local rationing. Otherwise, the result may be fewer institutional placements on paper but greater burden on families in practice.

3. Cash benefits should support choice, but substitution for formal services must be carefully pursued.

Cash benefits can increase autonomy and support family caregiving, especially where formal provider networks are thin. But they also shape the care economy. If cash benefits are too generous relative to formal services, or if formal services are underdeveloped, they can reinforce dependence on unpaid or underpaid family care.

For the United States, cash benefits should be calibrated carefully. They can be valuable when they support genuine choice, but they should not be used as a low-cost alternative to building formal service capacity. Cash benefits should be paired with quality protections, caregiver supports, and investments in workforce development.

4. Federal standards are needed to promote geographic fairness.

Decentralized systems often produce territorial variation in access, generosity, and quality. This is a central concern for the United States because Medicaid already produces large state differences in LTSS access. A federal reform that relies on states for administration would need national minimum standards, transparent eligibility rules, and

financing protections. Without these safeguards, a new LTSS benefit could reproduce the same geographic inequities that characterize the current Medicaid-based system.

5. Informal care must be treated as part of the system.

Informal care is never absent from LTSS policy. It is either explicitly supported, implicitly assumed, or substituted for formal underinvestment. A sustainable U.S. system should therefore include caregiver assessment, respite, training, paid leave or wage replacement, and retirement protections for intensive caregivers. Otherwise, public reform may reduce some financial risk while leaving the practical burden of care largely unchanged.

6. Durable reform requires a credible financing mechanism.

LTSS reform is easier to announce than to finance over time. Spain's SAAD expansion was followed by fiscal pressure amidst the Great Recession spending cuts in Europe, and more recently the development of waiting lists and constraints on benefits. England has repeatedly debated more generous reform, including caps on lifetime care costs, but implementation has been delayed. Germany has expanded eligibility and benefits while also raising contribution rates (Gruber & McGarry, 2025).

The U.S. implication is that LTSS reform cannot be designed only as a benefit expansion. It must also be designed as a financing institution. Whether the mechanism is a payroll contribution, a Medicare-linked benefit, federal-state financing, a catastrophic public benefit, or a hybrid public-private structure, the financing source must be durable enough to survive demographic pressure and economic downturns.

VII. Conclusion

The United States has made some meaningful but incomplete progress in long-term services and supports policy. It has expanded home- and community-based services, strengthened nursing home oversight, improved data and quality measurement, and begun to recognize the role of family caregivers. But it has not created a comprehensive financing system for LTSS. The result is a residual structure in which catastrophic care costs fall unpredictably on individuals, families, and Medicaid.

European experience shows that broader public protection is possible, but always with hard trade-offs. Social insurance improves risk pooling but often provides only partial benefits. Tax-funded systems can expand access but may rely on means testing and local rationing. Cash benefits increase flexibility but may reinforce informal care and may suffer from quality problems and create labor market challenges, especially for women. Home care expansion is desirable but requires workforce and infrastructure. Public entitlement can reduce insecurity, but only if paired with a sustainable financing base.

The most realistic lesson for the United States is therefore not to copy any single European model. It is to move beyond the current fragmented system by creating a federal LTSS framework that pools catastrophic risk, establishes national minimum protections,

supports home- and community-based care, recognizes family caregivers, and permits supplemental private coverage. Such a model would not eliminate all private responsibility, nor would it replicate full European universalism. But it would acknowledge what the current system obscures: LTSS need is a predictable social risk, not an exceptional private misfortune.

Absent such reform, the United States is likely to remain in its current equilibrium. Medicaid will continue to serve as the default payer after impoverishment. Families will continue to provide unpaid care with limited support, even though demographic trends will make that less and less possible over time. Private insurance will remain marginal. State variation will persist. And catastrophic LTSS costs will continue to threaten household financial security and compromise the retirement years of many middle-income Americans. Demographic pressures will continue to heighten these problems. The policy choice is whether to respond through deliberate risk pooling and system design, or to continue relying on a fragmented arrangement that was never designed to meet the scale of future need.

References

- AARP. (2024). *Medicaid self-directed services and supports*. AARP Public Policy Institute.
- American Association for Long-Term Care Insurance. (n.d.). *Who is likely to need paid long-term care*. <https://www.aaltci.org/long-term-care-need/>
- Bakx, P., Van Doorslaer, E., & Wouterse, B. (2025). Long-term care in the Netherlands. In J. Gruber & K. McGarry (Eds.), *Long-term care around the world*. University of Chicago Press.
- Banks, J., McCauley, J., & French, E. (2025). Long-term care in England. In J. Gruber & K. McGarry (Eds.), *Long-term care around the world*. University of Chicago Press.
- Bhaumik, D., & Grabowski, D. C. (2025). Long-term services and supports in supplemental benefits in Medicare Advantage plans. *JAMA Network Open*, 8(8), e2526406. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2837375#google_vignette
- Brugiavini, A., Carrino, L., & Pasini, G. (2025). Long-term care in Italy. In J. Gruber & K. McGarry (Eds.), *Long-term care around the world* (Chap. 5). University of Chicago Press.
- Centers for Medicare & Medicaid Services. (n.d.-a). *Community First Choice (CFC) 1915(k)*. U.S. Department of Health and Human Services. <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k>
- Centers for Medicare & Medicaid Services. (n.d.-b). Balancing Incentive Program. U.S. Department of Health and Human Services. <https://www.medicaid.gov/medicaid/long-term-services-supports/balancing-long-term-services-supports/balancing-incentive-program>
- Centers for Medicare & Medicaid Services. (n.d.-c). *IMPACT Act of 2014 data standardization & cross setting measures*. U.S. Department of Health and Human Services. <https://www.cms.gov/medicare/quality/initiatives/pac-quality-initiatives/impact-act-2014-data-standardization-cross-setting-measures>
- Centers for Medicare & Medicaid Services. (n.d.-d). *Independence at Home Demonstration*. U.S. Department of Health and Human Services. <https://www.cms.gov/priorities/innovation/innovation-models/independence-at-home>
- Centers for Medicare & Medicaid Services. (n.d.-e). *GUIDE (Guiding an Improved Dementia Experience) Model*. U.S. Department of Health and Human Services. <https://www.cms.gov/priorities/innovation/innovation-models/guide>
- Centers for Medicare & Medicaid Services. (2014). *Medicaid program; State plan home and community-based services, 5-year period for waivers, provider payment reassignment, and home and community-based setting requirements for Community First Choice and home and community-based services (HCBS) waivers*. Federal Register. <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>
- Centers for Medicare & Medicaid Services. (2022). *QSO-22-19-NH: Revised long-term care surveyor guidance*. U.S. Department of Health and Human Services. <https://www.cms.gov/files/document/qso-22-19-nh-revised-long-term-care-surveyor-guidance.pdf>

- Centers for Medicare & Medicaid Services. (2023). *Medicare and Medicaid programs; Disclosures of ownership and additional disclosable parties information for skilled nursing facilities and nursing facilities, and transparency of nursing facility ownership*. Federal Register. <https://www.federalregister.gov/documents/2023/11/17/2023-25408/medicare-and-medicaid-programs-disclosures-of-ownership-and-additional-disclosable-parties>
- Centers for Medicare & Medicaid Services. (2024). *Medicare and Medicaid programs; Minimum staffing standards for long-term care facilities and Medicaid institutional payment transparency reporting*. Federal Register. <https://www.federalregister.gov/documents/2024/05/10/2024-08273/medicare-and-medicaid-programs-minimum-staffing-standards-for-long-term-care-facilities-and-medicaid>
- Cohen, M. A., Kaur, R., & Darnell, B. (2013). *Exiting the market: Understanding the factors behind carriers' decision to leave the long-term care insurance market*. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. <https://aspe.hhs.gov/reports/exiting-market-understanding-factors-behind-carriers-decision-leave-long-term-care-insurance-market>
- Colello, K. J. (2025). *Who pays for long-term services and supports?* (CRS In Focus No. IF10343). Congressional Research Service. https://www.congress.gov/crs_external_products/IF/PDF/IF10343/IF10343.13.pdf
- Costa-Font, J. (2010). Family ties and the crowding out of long-term care insurance. *Oxford Review of Economic Policy*, 26(4), 691–712.
- Costa-Font, J., & Vilaplana-Prieto, C. (2017). Does the expansion of public long-term care funding affect saving behaviour? *Fiscal Studies*, 38(3), 417–443.
- Costa-Font, J., D'Amico, F., & Vilaplana-Prieto, C. (2023). Caring for carers? The effect of public subsidies on the well-being of unpaid carers. *American Journal of Health Economics*, 9(4), 487–522.
- Costa-Font, J., Jiménez-Martín, S., Vilaplana-Prieto, C., & Viola, A. (2025a). Universalizing the access to long-term care: Evidence from Spain. In J. Gruber & K. McGarry (Eds.), *Long-term care around the world* (Chap. 9). University of Chicago Press. (NBER Working Paper No. 31825)
- Costa-Font, J., & Vilaplana-Prieto, C. (2025b). The hidden value of adult informal care in Europe. *Health Economics*, 34(4), 791–812.
- Da Roit, B., & Le Bihan, B. (2010). Similar and yet so different: Cash-for-care in six European countries' long-term care policies. *The Milbank Quarterly*, 88(3), 286–309.
- European Commission. (2007). *Health and long-term care in the European Union* (Special Eurobarometer 283/Wave 67.3). Directorate-General for Employment, Social Affairs and Equal Opportunities.
- European Commission, Directorate-General for Employment, Social Affairs and Inclusion. (2021). *Long-term care report: Trends, challenges and opportunities in an ageing society: Vol. II. Country profiles*. Publications Office of the European Union. <https://doi.org/10.2767/183997>
- European Commission. (2023). *Social Europe* (Special Eurobarometer). Directorate-General for Employment, Social Affairs and Inclusion.
- European Commission. (2026). *Standard of living expectations* [Eurobarometer survey]. Reported in V. Genovese & J. Janas, *Euronews*. <https://www.euronews.com/2026/07/01/almost-one-in-three-europeans-expect-standard-of-living-to-decline-survey-says>

- Federal Government of Germany. (2023). *Long-term care reform: More benefits and stable finances*. <https://www.bundesregierung.de/>
- Genworth Financial. (2019). *Cost of care survey 2019*.
- Geyer, J., Börsch-Supan, A., Haan, P., & Perdrix, E. (2025). Long-term care in Germany. In J. Gruber & K. McGarry (Eds.), *Long-term care around the world* (pp. 141–176). University of Chicago Press.
- Ghailani, D., Durri, I., Merler, A., Peña-Casas, R., Spasova, S., & Konstantinidou, D. (2026). *Long-term care settings for older people in Europe: An analysis covering 38 European countries*. European Social Policy Analysis Network, Publications Office of the European Union. <https://op.europa.eu/en/publication-detail/-/publication/b0f9d445-21eb-11f1-8c3a-01aa75ed71a1/language-en>
- Golinowska, S., & Sowa-Kofta, A. (2017). *Quality and cost-effectiveness in long-term care and dependency prevention: The Polish policy landscape* (CASE Reports No. 489). Center for Social and Economic Research.
- Gruber, J. and McGarry, K.M. (2025) *Long-term care in the United States*. In J. Gruber & K. McGarry (Eds.), *Long-term care around the world*. University of Chicago Press. NBER Working Paper No. 31881. Cambridge, MA: National Bureau of Economic Research. <https://www.nber.org/papers/w31881>
- Hamel, L., & Montero, A. (2023). *The affordability of long-term care and support services: Findings from a KFF Survey*. KFF. <https://www.kff.org/health-costs/the-affordability-of-long-term-care-and-support-services/>
- Ilinca, S., & Simmons, C. (2022). *The time to care about care: Responding to changing attitudes, expectations and preferences on long-term care in Europe* (InCARE Policy Brief No. 2). European Centre for Social Welfare Policy and Research. https://incare.euro.centre.org/wp-content/uploads/2023/10/InCARE-Policy-Brief-2_The-time-to-care-about-care_261023_WP1.pdf
- Johnson, R. W. (2019). *What is the lifetime risk of needing and receiving long-term services and supports?* Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. <https://aspe.hhs.gov/reports/what-lifetime-risk-needing-receiving-long-term-services-supports-0>
- Karagiannidou, M., & Wittenberg, R. (2022). Social insurance for long-term care. *Journal of Population Ageing*, 15(2), 557–575.
- Kesternich, I., Romahn, A., Van Biesebroeck, J., & Van Damme, M. (2025). *Cash or care? Insights from the German long-term care system* (Research Paper No. 31). Hamburg Center for Health Economics. <https://www.hche.de>
- KFF. (2023). *Long-term care insurance: Trends and market developments*. Kaiser Family Foundation.
- Lamberts, E., & Schutt, C. (2020). *Long-term care insurance: The market's challenges and future*. Society of Actuaries.
- LeadingAge. (2023). *Comments on the CMS home and community-based services settings rule and dementia care*.
- Le Bihan, B., & Martin, C. (2010). Reforming long-term care policy in France. *Social Policy & Administration*, 44(3), 286–303.

- Le Bihan, B., Da Roit, B., & Sopadzhyan, A. (2019). The turn to optional familialism through the market: Long-term care, cash-for-care, and caregiving policies in Europe. *Social Policy & Administration*, 53(4), 579–595.
- MetLife Mature Market Institute. (2012). *Market survey of long-term care costs*.
- Munnell, A. H. (2024). *Washington State establishes a long-term care program*. Center for Retirement Research at Boston College. <https://crr.bc.edu/washington-state-establishes-a-long-term-care-program/>
- Parker, K., Morin, R., & Horowitz, J. M. (2019). *Retirement, Social Security and long-term care*. Pew Research Center. <https://www.pewresearch.org/social-trends/2019/03/21/retirement-social-security-and-long-term-care/>
- Parker, K. (2026). *What policies would Americans support to help family caregivers?* Pew Research Center. <https://www.pewresearch.org/social-trends/2026/02/26/what-policies-would-americans-support-to-help-family-caregivers/>
- Rau, J., & Aleccia, J. (2023). *Why long-term care insurance falls short for so many*. KFF Health News. <https://kffhealthnews.org/aging/dying-broke-why-long-term-care-insurance-falls-short/>
- Swartz, K., & Feder, J. (2021). The future of long-term care in the United States. In P. Villalobos Dintrans (Ed.), *The future of long-term care* (Chap. 3). Nova Science Publishers.
- Szenkurök, V. (2026). Cash-for-care and its impact on older adults' informal and formal long-term care use: Evidence from continental European countries. *European Journal of Health Economics*. <https://doi.org/10.1007/s10198-026-01901-y>
- Tediosi, F., & Gabriele, S. (2010). Long-term care in Italy. In *Social protection for long-term care: Need, costs and financing*. Organisation for Economic Co-operation and Development.
- U.S. Department of Health and Human Services. (2016). *The use of 1915(i) Medicaid plan option for individuals with mental health and substance use disorders*. Office of the Assistant Secretary for Planning and Evaluation. <https://aspe.hhs.gov/reports/use-1915i-medicaid-plan-option-individuals-mental-health-substance-use-disorders>
- Veghte, B. W. (2025). *Promising policy innovations to make aging in the community affordable for all: Lessons from the Netherlands*. National Academy of Social Insurance. <https://www.nasi.org/wp-content/uploads/2025/01/Promising-Dutch-Long-Term-Care-Innovations.pdf>
- Watson, T. (2024). *How immigration reforms could bolster Social Security and Medicare solvency and address direct care workforce issues*. Brookings Institution. <https://www.brookings.edu/articles/how-immigration-reforms-could-bolster-social-security-and-medicare-solvency-and-address-direct-care-workforce-issues/>
- Wiener, J. M. (2012). The CLASS Act: Is it dead or just sleeping? *Journal of Aging & Social Policy*, 24(2), 118–135.
- Wiener, J. M., Khatutsky, G., Thach, N., Greene, A. M., Allaire, B., Brown, D., Lamont, H., Marton, W., & Shipley, S. (2015). *Findings from the Survey of Long-Term Care Awareness and Planning: Research brief*. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. <https://aspe.hhs.gov/reports/findings-survey-long-term-care-awareness-planning-research-brief-0>

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