Long-term care (LTC) is one of the largest uninsured financial risks facing families in the U.S. today. LTC, sometimes referred to as long-term services and supports (LTSS), provides seniors and people with disabilities extended help with activities of daily living, such as eating and bathing. In a previous brief, we described how LTC is currently financed in the U.S., and the pressing need for alternatives that address the risk and financial insecurity that individuals and families face.

This brief explores recent national and state reforms, as well as LTC systems in other countries, that could serve as models for the U.S. As shown in Figure 1, Medicaid pays for the majority of formal, or paid, LTC in the U.S. This means-tested program is jointly funded by federal and state governments and pays for LTC in institutions and the home. Medicaid has strict income and asset criteria; as such, many individuals

![Figure 1. National LTC spending by payer, 2017.](source: Kaiser Family Foundation, Medicaid Home and Community-Based Services Enrollment and Spending (April 2019))

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Table 1. National Monthly Median LTC Costs (2019)

<table>
<thead>
<tr>
<th>IN-HOME CARE</th>
<th>COMMUNITY AND ASSISTED LIVING</th>
<th>NURSING HOME FACILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homemaker Services (e.g., cooking, cleaning, laundry)</td>
<td>Adult Day Health Care</td>
<td>Semi-Private Room</td>
</tr>
<tr>
<td>$4,290</td>
<td>$1,625</td>
<td>$7,513</td>
</tr>
<tr>
<td>Home Health Aide</td>
<td>Assisted Living Facility</td>
<td>Private Room</td>
</tr>
<tr>
<td>$4,385</td>
<td>$4,051</td>
<td>$8,517</td>
</tr>
</tbody>
</table>

Source: Genworth Cost of Care Survey 2019

only become eligible after “spending down” to qualify, essentially exhausting their personal resources. Private LTC insurance is available, but very few people buy it. Informal care, which is provided by family and friends usually without pay, remains critical to filling gaps in the system.

As we discuss policy options to finance formal LTC, it is important to keep in mind what those costs are, and the extent to which a program will cover them. Table 1 presents 2019 national monthly median costs for different forms of LTC.\(^2\)

In 2017, Hawaii became the first state to provide support (but not compensation) to informal caregivers of elderly people through its “Kapuna Caregivers Program.”\(^7\) Launched as a small pilot with $600,000 from the state budget, it provided family caregivers employed at least 30 hours a week with up to $70 per day to cover costs for in-kind support, including adult day care, chore services, home-delivered meals, homemaker services, personal care, respite care, or transportation. The funds (subject to availability) are paid directly to contracted service providers, not the caregiver. In FY 2019, the program served 110 caregivers. Subsequently, Hawaii amended the program to try to maximize its reach to the estimated 154,000 eligible caregivers.\(^8\) The state increased the appropriation to $1.5 million for FY 2019-20 but set a reduced maximum benefit of $210 per week. It also added coordination and case management to the list of services covered.

In 2018, Maine considered an ambitious proposal to establish a universal home care program.\(^9\) With the highest median age in the nation, nearly 20% of Maine’s population is age 65 and older, and the state ranks last in the nation on affordability of home care.\(^10\) The proposal, which appeared as a ballot measure in the 2018 midterm election, would have made home care services available to all residents, at no cost, regardless of income. It would have been financed by a 3.8% tax on income in excess of the cap on Social Security taxes ($128,400 in 2018), generating between $180 million and $310 million annually. While no one questioned the need for affordable home care, political opposition was fierce, and the proposal was ultimately rejected by 63% of voters.\(^11\)

In 2019, Washington became the first state to establish a public long-term care insurance program.\(^12\) Starting in 2025, eligible residents can receive an allowance of up to $100 per day, for help with activities of daily living and related services, with a lifetime cap of $36,500 (indexed to inflation). This benefit will be funded through a payroll tax of .58% that begins in 2022, which will generate about $1 billion per year. Self-employed people can opt in, and those with private LTC

STATE INITIATIVES

In the absence of a federal LTC plan, the onus of LTC coverage has remained with the states, and in recent years, several states have proposed or passed legislation to address LTC.

\(^2\)Table BRIEF
\(^3\)Source: Genworth Cost of Care Survey 2019
\(^4\)The U.S. has a more than 30 year history of failed proposals to develop a national policy on LTC.\(^3\) The most recent attempt to establish a national LTC insurance program was the Community Living Assistance Services and Supports (CLASS) Act, a voluntary, federally-administered program that was included in the Affordable Care Act in 2010.\(^4\) After paying premiums for at least five years during their healthy, working years (and continuing to pay premiums thereafter), participants would receive a limited daily cash benefit (at least an average of $50 per day) to help defray the costs of needed LTC. However, the legislation required that the program be fully self-sustaining, with no federal subsidy, over a 75-year window. Citing actuarial estimates that the premium could be $235 to $391 a month, with significant adverse selection into the program, the Secretary of Health and Human Services declared the program financially unsound, and Congress repealed the CLASS Act in 2013.\(^5\) In its place, Congress established the Commission on Long-term Care to make policy recommendations, but in the Commission’s final report it was unable to come to a consensus on financing.\(^6\)
insurance can opt out. Eligible residents must have paid the tax for three consecutive years out of six, (or five consecutive years out of ten), and work at least 500 hours a year. Benefits are broadly defined: residents can use the money toward nursing home stays, but also in-home meals, home equipment, and more. Notably, benefits can also be paid to family caregivers, as long as they receive minimum levels of training. While the daily allowance and cap are insufficient to fund full-time L TC, legislators expect that it is enough for up to five years of respite care, one year of a part-time in-home care provider, 8-12 months of assisted living care, 6-8 months of adult family home care, and 4-6 months of care in a nursing facility. It is also expected to save the state $19 million in Medicaid spending in its first year.

INTERNATIONAL SYSTEMS

What lessons can we glean from the L TC systems of other high-income nations? Most OECD countries have had more success than the U.S. in developing and maintaining L TC financing systems, as they face many of the same issues. In 2017, the World Bank proposed a typology of L TC financing systems that is useful in international comparisons. It categorized L TC systems into four types: means-tested (tax-financed and available only to those meeting a high disability and low-income threshold); social insurance (financed by compulsory contributions and available to everyone meeting disability/age criteria); universal (tax-financed and available to everyone meeting disability/age criteria), and hybrid systems (a mix of features of other approaches). Within these types, programs differ on eligibility standards, financing, and benefits.

Means-tested systems

The U.S. and England are unusual, among high-income nations, in their reliance on means-tested programs, which are financed from general tax revenues. As detailed in a previous brief, the mean-tested system in the U.S. has left individuals in need of L TC facing large gaps in care. England is facing similar challenges; other than a small “attendance allowance” (about $75-$110 a week) for people over 65 who need full-time help with personal care, public support for “social care” is limited to those with extensive needs, after they have exhausted all but about $30,000 in income/assets. In effect, anyone owning a home is ineligible for public support. This is in sharp contrast to England’s National Health Service, where health care is fully tax-financed and free at the point of care. L TC has been a consistent target of reform in England; multiple white papers and independent commissions in the last 20 years have recognized that the system is broken, yet each successive government has been unable to meet the challenge of reform.

Targeting funds to the poor can limit the impact on public budgets, but it also creates inequities in access and health of vulnerable populations. Thresholds are arbitrary, and often leave out individuals not poor enough to qualify for public funding, yet not rich enough to pay for care costs or private insurance. It adds considerable administrative burden, requiring people to arrange income and assets to meet arbitrary eligibility thresholds and agencies to regulate what is “poor enough.” There is no private market for L TC insurance in England, and given the lack of success with private insurance markets for L TC elsewhere, little reason to believe that private insurance can fill the void. In light of the expected increase in demand for L TC in both the U.S. and England, means-tested systems will likely produce escalating burdens on families and high levels of unmet needs in an aging population. A recent OECD comparison found the cost of L TC for severe needs (either institutional care or full-time home care) is equal to or greater than the median disposable income for people over 65 in every country. Because of this cost, most other developed nations have used some form of public risk pooling to provide social protection to their residents, as discussed below.

Social insurance

In contrast to means-tested models, social insurance covers L TC for all or most of a defined population, typically through dedicated funding from payroll or income taxes. Because contributions are compulsory, social insurance allows governments to spread the L TC risk over a large population. Japan, the Netherlands, and Germany have forms of social insurance, and their experiences over time may be instructive to U.S. policymakers.

Japan created its mandatory social insurance program in 2000, in response to pressing demographic challenges, including high life expectancy, low
Germany enacted a mandatory social insurance program in 1994 to replace a means-tested system that required adult children to contribute to their parents’ LTC after parents had exhausted their own resources.

The Netherlands began its social insurance program in 1967, covering mostly nursing home and institutionalized care for the “mentally handicapped”; subsequently, it expanded to cover home health care (1980), social assistance in case of frailty, and residential care for the elderly (1997). The program covered a wide range of residential, domiciliary, and support services, funded by mandatory social security contributions and general government revenues. Just 8% of total costs were financed through cost sharing, with copayments varying by wealth and capped for the poor. Because of an aging population and over-reliance on institutionalization, LTC costs and premiums escalated over time, and the Dutch enacted significant reforms in 2015. These reforms sought to curb spending by restricting overall budgets, transferring community nursing services to the mandatory health insurance program, and devolving control over custodial home care and social supports to municipalities. The national government retained control over institutional care and intensive home health care, but tightened up admission criteria. People can choose to receive benefits in-kind or as cash. Municipal governments receive funding for social supports in the form of block grants. Overall, the reforms were designed to refocus care on the most in-need beneficiaries, while encouraging local control and use of personal social networks for domiciliary and social support—the lowest levels of need. The reforms were meant to provide incentives for efficiencies across the national, regional, and municipal governments, but coordination problems and strategic cost-shifting could jeopardize its potential success. In a study of the pros and cons of the LTC reform, the Netherlands Bureau of Economic Policy Analysis pointed out several problems in the coordination of care between municipalities and health care insurers [12]. Early evaluation of the reforms found an increased trend of aging-in-place and a lower growth of public LTC spending [10].

Unlike the Japanese system, Germany’s program has several elements that encourage reliance on informal caregivers. Because there are no regulations around how the cash is used, beneficiaries may choose to accept the cash benefit, but continue relying on unpaid informal care. Additionally, the German government covers social security premiums and respite care for family members who provide at least 14 hours of care a week. 

Germany enacted a mandatory social insurance program in 1994 to replace a means-tested system that required adult children to contribute to their parents’ LTC after parents had exhausted their own resources.
Social insurance prompts fewer concerns about inequities than means-tested programs, but it is obviously more expensive for public budgets. Benefits may tend to expand over time, if people reduce informal care by family and friends once they have the option to do so, but that is arguably a sign of a program meeting a latent need. Social insurance allows risk to spread over the entire population and across generations, as employees pay for a defined set of benefits they might need in the future. Having a dedicated funding stream and universal benefits can increase transparency and support for the program in the long term as the population sees the direct benefits of their contributions.

Universal systems
The Nordic countries (Denmark, Finland, Sweden), are examples of countries with universal, tax-based LTC programs. Universal systems differ from social insurance in that they are funded from general tax revenues, rather than a dedicated LTC fund into which all workers contribute. They could otherwise be identical in benefits and eligibility design. Denmark has one of the most comprehensive LTC systems, with services provided to all elderly free of charge. All people over 75, (and at-risk people 65-74) are offered a home visit that focuses on their functional, psychological, medical, and social resources and challenges. People over 80 are offered a yearly home visit. LTC services include preventative measures, rehabilitation, home help, special homes for the elderly, and other measures, including personal assistance and food services. LTC services are funded and organized locally through 98 municipalities using block grants from the federal government and local taxes. A municipal case worker assesses the level help needed, and reassesses after rehabilitation services. While municipalities differ in their approach, many use five levels of functioning to assign home help. Denmark is unusual in its emphasis on home visits, preventative services, and rehabilitation to meet low-level needs. On average, eligible elderly people receive 5.8 hours of personal care and 0.7 hours of practical help each week. As a result, levels of informal care are relatively low. Denmark has a strong preference toward deinstitutionalization, with higher levels of care delivered through elder-specific dwellings where residents pay rent and needed services (including nursing care) are available at no charge.

In general, universal LTC systems in Europe enjoy a broader tax base than those that are labeled social insurance because general tax revenues are levied on wealth as well as income. These programs tend to have expansive benefits and little cost sharing. Programs like those in Denmark are most likely to avoid the problem of creating insecurity for future generations, who struggle to support today's LTC costs for loved ones.

Hybrid systems
Hybrid approaches blend design and delivery features of other program types and rely on a mixture of public funding and means-tested strategies. To the extent a hybrid system fills in fewer gaps, informal care remains an important part. Even if eligibility is universal, hybrid systems in place now generally do not cover LTC costs in their entirety but instead vary subsidy levels and personal contribution by income and assets of the care recipient.

In France, for example, mandatory social insurance provides public benefits to people age 60 and older, but amounts are income-adjusted and vary according to disability severity. Benefits are paid in cash through a “Personal Autonomy Allowance” created in 2001 and expanded in 2015. The allowance is a partial subsidy of the costs of personal services in the home (nursing care is covered by National Health Insurance) or services received in institutions (room and board not included). Depending on the level of assessed disability, the allowance ranges from about $700-$1,900 a month, but the benefit is means-tested. Recipients at the highest income level pay a 90% coinsurance, while the poorest have no cost-sharing requirements. Relatives (except for spouses) can be paid from the allowance for personal care services in the home. There are also tax incentives for families paying for the cost of care, allowing deductions of 50% of the cost of personal and domestic staff from tax contributions and up to 25% of residential care costs.
Private LTC insurance in France is often purchased to cover gaps in public coverage created by this income-adjusted design, similar to the relationship between Medigap supplemental insurance and Medicare. Unlike the U.S., France has a large and growing private LTC insurance market. Most growth is attributable to group (employer-based) products, which account for 75% of policies sold. Private LTC insurance options in France differ from those in the U.S. in that they tend to offer less coverage, even though the U.S. policies are far from generous, and the French policies are subsequently cheaper. [46]

While these systems often provide coverage to those with the greatest need, they can still leave a significant share of costs to be paid out-of-pocket by beneficiaries and families. Fragmentation in benefits, eligibility, and financing can make it difficult to navigate the LTC system in these countries, and also make it difficult to quantify the benefits received by beneficiaries relative to the cost incurred. [20]

France is now considering another round of reforms to replace the personal autonomy allowance with a more comprehensive home care cash benefit that would include respite for caregivers and merging health care and social care in institutions to reduce families’ out-of-pocket costs. [37]

**POLICY CHOICES**

This review of international (and U.S. state) LTC programs provides U.S. policymakers a range of options on how to structure programs to achieve certain goals. Policy choices will vary, depending on whether the goals are to encourage reliance on family caregiving, support aging-in-place, provide family income security, or to support employed caregivers. Key design choices include:

- **Eligibility criteria.** This question includes whether to limit the benefit to the older population or to make it available to anyone with long-term care needs. It also includes whether to make programs universal or means-tested.

- **Cash benefits vs. in-kind services.** If both benefits are offered, the ratio of one to the other will shape incentives about which to select.

- **Payment for family caregivers.** Policymakers have to determine whether to allow it and, if yes, on what to base the rate of payment and how many hours to allow.

- **Scope of benefits.** Policies can be designed to address the full range of preventive and critical needs, as in Denmark, or many layers short of that, as in most other places. They can also be designed to cover all, or some, of the total costs of supports.

The answers to these types of questions reflect how seriously policymakers take protecting American families against the insecurity they currently face as they fill in the gaps left by a void of LTC policy in the U.S. The answers determine to what extent LTC social protection will alleviate the burdens families currently shoulder on their own, and to what extent they will be required to continue to do so.

Policymakers in U.S. states differ in how they designed their LTC programs, reflecting different emphases and fiscal realities. Hawaii’s program reflects a strong cultural tradition of family caregiving for elders; policymakers chose to provide a small universal benefit that targeted working families and would help caregivers maintain their employment. Maine’s ballot measure was geared toward allowing elderly people and disabled people to stay in their homes; it would have involved no means testing or cost sharing, although details of the range and scope of benefits were left to a Trust Fund Board to be named later. Washington state made some strategic fiscal decisions about eligibility and scope of benefits, choosing to provide a modest, flexible benefit that could be applied across settings and could be used to pay a family caregiver. The plan was not universal; employees had to pay into for a certain number of years to be eligible, and it excluded current retirees and children with disabilities.

**CONCLUSION**

This brief has laid out a wide range of options for policymakers to consider for future LTC reforms, based on the programs adopted by peer nations. Without intervention, the LTC crisis in the U.S. will intensify with time and will slowly erode the security of American families. Demographic changes point to a dramatic increase in the
demand for LTC; the elderly population is projected to nearly double from 48 million in 2013 to 83 million in 2040. With the increase in the older population, various models have also projected large increases in the number of people with disabilities who require LTC. Changing family structures and societal norms, such as more women working full-time, suggest that there will be a decrease in the availability of informal caregivers, who are the backbone of our current flawed system, and that those people who provide informal care are likely to incur significant costs, both financial and physical..

Proposals that address LTC financing have emerged during the 2020 presidential campaign. They include one or more of the following strategies:

- Creating a universal system for home- and community-based care as part of a new national health insurance plan. Although the details are not clear, the financing of the new plan would likely be modeled on social insurance, with a dedicated funding stream from payroll or income taxes.
- Providing tax credits to incentivize purchase of private LTC insurance. These credits would effectively lower the purchase price for a plan, inducing some level of demand.
- Providing tax credits to support family caregivers or to people needing LTC to offset some of their costs across settings.
- Providing a daily cash benefit to help cover LTC, similar in range to England’s "attendance allowance."
- Increasing Medicaid income threshold and allowable assets. Families would be a little less impoverished after they spend down to get Medicaid coverage.
- Expanding Medicare coverage for Alzheimer’s disease, which might include LTC services not usually covered under Medicare, such as respite care and in-home assistance.

These proposals vary in the extent to which they offer social protection for LTC services. Most peer nations have chosen some form of public risk pooling to protect families against catastrophically high-cost LTC, as well as to support families in financing lower-level LTC, either through direct payment or by providing formal services. While the breadth and depth of public coverage varies, most peer nations have found sustainable ways to finance a level of social protection for LTC costs.

U.S. policymakers can draw on the experiences of these nations in developing an alternative to our present system that internalizes these costs to individual families, and leaves large and inequitable gaps in access to needed LTC services.
REFERENCES


