Designing a State-Based Social Insurance Program for Long-Term Services and Supports
This chapter explores social insurance solutions to the growing challenge states face in meeting the long-term services and supports (LTSS) needs of their residents. There are other complementary or alternative approaches to enhancing access to LTSS, such as expanding Medicaid or improving the private insurance market, but this report focuses on social insurance strategies. It does not offer specific recommendations but instead identifies key design questions for states to consider in crafting a program, outlines a range of vetted approaches states could adopt, and describes the building blocks and tradeoffs associated with a wide variety of options. This analysis was developed during a year of deliberations by a Working Group of 16 experts in LTSS with a variety of perspectives. It is part of a larger Study Panel project on Universal Family Care. While addressed primarily to state policymakers, this report may also be of interest to providers, advocacy organizations, insurers, and administrators, as well as to any person interested in these issues.
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EXECUTIVE SUMMARY

Long-term services and supports (LTSS) needs are growing and for a variety of reasons families are becoming less able to meet them. One in two of those turning 65 today will need LTSS. Around 40 percent of those needing LTSS today are under 65; many will require lifelong services and supports. LTSS can be costly both for those needing care and for family caregivers. These costs often come at a time when individuals and their families are most vulnerable and in a context where they have had little opportunity to prefund or insure against such risks. Thus, the fundamental LTSS financing problem today is the absence of an effective insurance mechanism to protect people against these costs.

The majority of LTSS today is provided by family and friends, often to the detriment of their health and financial security. In the coming decades, most professional care will be paid for by families out of pocket. Most of the remainder of paid care will be covered by Medicaid, the primary public payer of LTSS. To qualify for Medicaid, however, a person must have low income and may not have assets above a certain level. Many middle-income people “spend down”—they use their assets to pay for care until they have very little left and qualify for Medicaid. Those who qualify for Medicaid (whether low- or middle-income) must contribute most of their income to their care costs, losing financial independence, and may be forced to enter a nursing home because they cannot access sufficient home- and community-based services or afford to remain at home.

States are grappling with the growing demand for LTSS as their Baby Boomers age. They already struggle to keep up with the growing need in the context of budget constraints. Social insurance could provide universal, affordable LTSS coverage. Indeed, Washington State enacted an LTSS social insurance program in 2019. As other states consider similar measures, policymakers need to be mindful of key design issues, including:

- **Program structure.** Who will be eligible for the program’s benefits? How will generational transition issues be addressed? Will front-end, back-end (catastrophic), or temporally unlimited coverage be offered?

- **Financing approach.** How will the program be financed? Will it be funded through a payroll tax, an income tax, or some other dedicated revenue source? And will it be financed on a pay-as-you-go or prefunded basis?

- **Program integration.** How will the new program interface with Medicaid LTSS and private long-term care insurance?

- **Program implementation strategy.** How will the program be administered, revenues collected and managed, eligibility determined, and program integrity ensured?

The chapter discusses tradeoffs among alternative approaches to these core design choices and compares the cost of different structural approaches by financing source. Also illustrated is how proactive policies could lessen the financial pressure on state Medicaid budgets, reduce care burdens on families, and also support significant job creation in one of the fastest-growing sectors of the economy—personal care and home health care.
Section I.

INTRODUCTION
Long-term services and supports can be costly both for those needing care and for family caregivers. Moreover, these costs often come at a time when individuals and their families are most vulnerable and in a context where they have had little opportunity to prefund or insure against such risks. The fundamental LTSS financing problem today is the absence of an effective insurance mechanism to protect people against these costs.

State policymakers could avail themselves of a number of viable social insurance policy options to make LTSS more affordable and accessible for their residents. Such options could enable those in need of care to remain at home longer and retain their autonomy. They would also give people the peace of mind of knowing that they will have access to the care they need as they age, without burdening their spouse or children. Proactive policies would also lessen the financial pressure on state Medicaid budgets and support significant job creation in one of the fastest-growing sectors of the economy—personal care and home health care.

Today’s Long-Term Care System Ill-Equipped to Cope with Growing Demand

Seventy percent of those turning 65 today are expected to need help with at least one activity of daily living (ADL) (bathing, dressing, toileting, continence, transferring, and eating) at some point in their remaining lifetime (Figure 1). More than half (52 percent) of those turning 65 today are expected to meet the commonly used threshold for requiring paid long-term services and supports, and, on average, they will need LTSS for nearly four years.

FIGURE 1: Majority Turning 65 Today Will Need LTSS
Among those turning 65 in 2015-19

80%
70%
60%
50%
40%
30%
20%
10%
0%

Will Have a Chronic Disability (2+ ADLs and/or severe cognitive impairment)

Source: Favreault, 2015; Favreault and Dey, 2016.
Note: ADLs = Activities of Daily Living: eating, bathing, dressing, transferring, toileting, and continence; IADLS = Instrumental Activities of Daily Living: e.g., shopping, housework, and meal preparation, which allow an individual to live independently in the community.

While about half of seniors will need LTSS, there is considerable variation in the nature of the risk. Some will need extensive LTSS at considerable cost. Many will need LTSS for less than a year, and roughly half will require none at all. This heterogeneity of the LTSS risk makes it well-suited to pooling through insurance. Since not everyone can afford or qualify for private long-term care insurance, there is a strong case for a social insurance approach to LTSS.3 (These issues will be discussed in more depth in Section III of this chapter.)

The disability threshold identified in the second column above, set forth in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), is defined as being unable to perform (without substantial assistance from another person) at least two ADLs for a period expected to last at least 90 days, or requiring substantial supervision to protect against threats to the individual’s health and safety, due to severe cognitive impairment.4 Since paid LTSS is most common among those who meet these HIPAA criteria,5 and since this report is concerned with policy options for financing paid LTSS, henceforth when we refer to people “needing LTSS” we mean those meeting this threshold.

In addition to older adults, millions of people with disabilities require LTSS. They may have an intellectual or developmental disability (IDD), a mental health disability, or a physical disability, and some have a lifelong need for LTSS. While reliable data on this heterogeneous population is scarce,6 it is estimated that today about 40 percent of those requiring LTSS are under age 65.7 It is important to understand the role that LTSS plays in the lives of those with disabilities. It enables them to have a meaningful life as part of a community, allows them to achieve or regain a certain degree of independence, and positions them to pursue greater economic self-sufficiency and give back to their community.

The aging population will increase the number of people needing LTSS so that, in the coming decades, the growth in LTSS needs will be particularly strong among older Americans. By 2050, the population 85 or older will more than triple (growing by 208 percent), while the population younger than 65 will increase by only 12 percent.8 The number of seniors needing LTSS is expected to rise from 6.3 million in 2015 to an estimated 15 million by 2050.

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By 2050, the population 85 or older will more than triple, while the population younger than 65 will increase by only 12 percent.

The increase in the demand for LTSS will strain the existing care infrastructure, which is already overburdened.9 Current trends suggest that the nation is headed toward a shortage of caregivers—paid and unpaid.

Today, for every person 80 or older there are about seven people age 45 to 64 (the peak caregiving age). By 2050, for every person 80 or older, there will be only three people of peak caregiving age.10 Already in the coming decade, this caregiver gap will begin to manifest itself. In a little over a decade—by 2030—there is projected to be a national shortage of 3.8 million unpaid family caregivers and 151,000 paid care workers. By 2040, the shortfall is expected to grow to 11 million family caregivers and 355,000 paid workers.11

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**Why Social Insurance?**

This report discusses considerations for the development of state long-term care programs that provide universal, affordable coverage and have dedicated financing. Broadly speaking, this means social insurance. Social insurance programs are universal, public insurance programs such as Social Security, Medicare Part A (Hospital Insurance), and Unemployment Insurance. They share the following characteristics:\(^\text{12}\)

- Social insurance programs are “social” in the sense that risk is pooled broadly across a population, often society as a whole. Virtually everyone contributes to a state or national insurance plan (typically a fixed percentage of their earnings), and everyone who contributes is eligible for benefits.

- Social insurance is distinct from social assistance or welfare programs (such as Medicaid, food stamps, or housing vouchers) in that benefits are paid only to those who have contributed to the program’s financing. Benefits from social insurance programs are therefore typically considered earned benefits. By contrast, in social assistance programs, benefit eligibility is based not on having contributed but simply on having a need (meeting certain financial, functional, and/or clinical criteria).

- Social insurance differs from social assistance programs further in that, for those who have contributed, benefits are universally available to all for whom the insured risk (e.g., the

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**Source:** Houser et al., 2018.

With the need for LTSS projected to rise and the availability of family caregivers projected to decline, there will be a growing need for paid long-term services and supports. Because of state budget constraints and other financial demands, state Medicaid programs—the primary public payers of LTSS—will face challenges paying for enough LTSS to meet the growing need. In light of all these trends, in this report we outline one possible solution to the LTSS financing challenge: the introduction of new state-based LTSS social insurance programs.

\[\text{FIGURE 3: Caregiver Gap Widening}\]

<table>
<thead>
<tr>
<th>Ratio of Population 45-64 to Population 80+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Ratio 2015: 7:1</td>
</tr>
<tr>
<td>Caregiver Ratio 2050: 3:1</td>
</tr>
</tbody>
</table>

Because of state budget constraints, state Medicaid programs—the primary public payers of LTSS—will face challenges paying for enough LTSS to meet the growing need. In light of all these trends, in this report we outline one possible solution to the LTSS financing challenge: the introduction of new state-based LTSS social insurance programs.

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need for long-term care) transpires. In social assistance programs, access to benefits is subject to a means test.

- Traditional social insurance programs are typically self-funded by contributions from participants and/or their employers; their finances are distinct and separate from those of the rest of the government. Assistance programs are typically funded out of general revenues.

- Traditional social insurance differs from private insurance in that there is no individual underwriting—no one can be excluded from the program because they have a high risk of needing the benefits provided. And social insurance is community rated: Everyone contributes at the same rate or level.

Some programs are hybrids, combining features of the traditional social insurance model and of either social assistance or private insurance. Medicare Parts B and D are funded by a combination of premiums (25 percent of program cost) and general revenues (75 percent). These parts of Medicare also charge higher premiums to those with higher incomes, so that contributions are progressive. Some social insurance programs have a role for private companies (within well-defined statutory requirements), which provide the insurance and/or administer the benefits, as in many Workers’ Compensation programs and all Medicare Advantage plans.

Social insurance represents a promising approach to meeting the challenges states face in ensuring broad access to LTSS.
A universal and affordable program is necessary to achieve broad coverage, which is particularly important given the nature of the LTSS risk. Many people will not have any need for LTSS, others will need it for a moderate duration, and a small number will face catastrophic expenses. As a result, the need for LTSS is difficult to plan for, threatens retirement security, and is well-suited to risk pooling. A social insurance program is an efficient way to mitigate the financial risk associated with LTSS. In addition, dedicated financing is an important feature at the state level, since many states have balanced budget requirements, which make funding a large new program out of general revenues challenging. States can choose from a variety of options in structuring a new social insurance program for long-term care. Those options will be discussed in detail in this report.

**Decision Points on the Path to Social Insurance Solutions to the LTSS Challenge**

States that decide to take action to help meet their residents' long-term care needs ultimately must address a range of considerations. To begin with, there are two critical first-order questions:

- Who is the program seeking to help—only the disabled elderly, or also children and working-age people with disabilities? Only those who start paying into the program now, or current retirees as well?

- How will the program be financed? Will it be funded through a payroll tax, an income tax, or some other dedicated revenue source?

Additional considerations follow from these two overarching questions; these include details about program structure, such as benefit amounts, benefit duration, and when benefits start and stop. Once the broad parameters of program eligibility, finance, and structure are determined, other issues can be considered, such as integration of the program with the current care delivery system, workforce and provider credentialing, and program implementation and sustainability.

The issues involved in LTSS financing are complex and require thoughtful deliberations involving a range of stakeholders. Therefore, while we are confident that the information in this report will be very helpful, we also believe...
policymakers would benefit from consulting long-term care experts and stakeholders in their states to determine the choices that best fit their needs and preferences. To make these choices easier to grasp, in the remainder of this report we discuss various alternative design features and highlight the considerations and implications related to them.

If a state implements an LTSS social insurance program, the success of that program should be measured against the objectives for which it is established. Some of the high-level criteria a state might use to assess program effectiveness include the following:

- **Improving access to LTSS.** To what extent does the additional money brought into the LTSS system by the new program allow the purchase of additional services?

- **Improving key outcomes for people with disabilities.** To what extent does greater access to paid LTSS improve the health and well-being of people with disabilities?

- **Reducing family out-of-pocket spending.** To what extent does the program relieve financial burdens on families?

- **Improving key outcomes for family caregivers.** To what extent does access to paid LTSS services make it possible for family caregivers who want to increase their labor force participation and income over the short and medium term to do so, and does the program support their improved well-being?

- **Reducing Medicaid spending.** To what extent does the program reduce budgetary pressure on Medicaid?
■ **Financial sustainability/stability.** Is the program sustainable? Can it be paid for over the long term in a stable manner?

■ **Political support and sustainability.** Is the program structured in a manner that will garner broad public support that is likely to persist over time?
Section II.

THE RATIONALE FOR STATE ACTION ON LTSS
Creating a new social insurance program with dedicated financing to address a state’s LTSS needs could provide relief on a number of fronts:

- **Enabling older adults to age in place, families to keep their loved ones at home, and younger people with disabilities to live in the community.** There are significant gaps in Medicaid’s coverage of LTSS today, for both older adults and younger people with disabilities. This is particularly true for home and community-based services (HCBS), which include adult day programs, home health aide services, personal care services, transportation, and rehabilitation services. For instance, under current arrangements, nearly 70 percent of the cost of HCBS for those turning 65 today will be paid out of pocket by families. A new LTSS social insurance program would make it much easier for those needing LTSS to access HCBS, enabling them to stay at home and avoid or delay institutionalization.

- **Relieving pressure on the state’s Medicaid budget.** As LTSS needs grow with the aging of the population, the increased demand for state Medicaid dollars could crowd out spending on other Medicaid benefits or reduce the state’s ability to meet LTSS needs, thus increasing unmet needs and putting greater burdens on families. Currently, the willingness to fund Medicaid spending growth appears limited, on both the state and the federal levels, as evidenced by recent attempts in Congress to permanently cap the federal contribution. Introducing benefits from a social insurance program, walled off from the existing state budget through new, dedicated financing, would inject hundreds of millions—or, in larger states, billions—of dollars into LTSS provision each year. If combined with a Medicaid waiver allowing the state to retain projected federal matching dollars (as discussed in Section VII of this chapter), a new social insurance program could reduce pressure on state Medicaid spending as social insurance dollars come to replace Medicaid dollars for the large and growing number of individuals who need LTSS. Additional state Medicaid savings could come from lower than projected Medicaid health spending, as a result of fewer individuals needing to spend down into poverty to become eligible for Medicaid.

- **Supporting the development and enhancing the quality of the state’s LTSS providers.** Today, care providers often struggle to generate sufficient revenue to make necessary capital investments or pay their workers adequately, leading to service gaps and uneven quality of care.

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particularly in rural areas. An infusion of new funding into a state’s system of LTSS provision could improve quality by facilitating capital investments, training, certification, and adequate compensation of workers.

- **Stimulating economic growth by increasing labor force participation and creating quality jobs.** The new program, by providing families with funds to hire paid LTSS workers, would both create LTSS jobs and make it easier for family members to remain in the labor force instead of staying home to care for loved ones. And if a state took steps to ensure the quality of new LTSS jobs, the positive economic impact would be magnified. In addition, since (unlike Medicaid) the new program would pay benefits to people with disabilities even if they earn significant wages, more such people are likely to work.

- **Providing state residents with peace of mind.** One of the greatest benefits of social insurance—like all insurance—is the knowledge that one is protected against a risk. Families worry about whether they and their loved ones will be taken care of if they need long-term services and supports. With the new program, they have the assurance that, if care is needed, benefits will be available to help pay for it. They will not have to impoverish themselves or spend down their assets to qualify for Medicaid, and they can receive quality care in the setting of their choice. Even when insurance is not used for many years, or never, a family benefits from having this peace of mind.

One of the greatest benefits of social insurance—like all insurance—is the knowledge that one is protected against a risk. Families worry about whether they and their loved ones will be taken care of if they need long-term services and supports. With the new program, they have the assurance that, if care is needed, benefits will be available to help pay for it.

As for why such programs could be established by the states, it is worth noting that the states have tremendous breadth of experience administering comprehensive LTSS. States have operated Medicaid LTSS programs for over 50 years and already perform functions such as defining and assessing benefit eligibility, certifying qualified providers, reimbursing providers, and managing a cash and counseling benefit. They also have an understanding of and familiarity with the local LTSS service delivery system. In short, states have a wealth of knowledge and experience that can be built on as a new LTSS program is designed and implemented.

States also have a solid track record in launching and running social insurance programs. For well over half a century, states have administered Workers’ Compensation and (jointly with the federal government) Unemployment Insurance. Four states—California, New Jersey, New York, and Rhode Island—also operate Paid Family and Medical Leave (PFML) social insurance programs,
and four more jurisdictions—Connecticut, the District of Columbia, Washington, and Massachusetts—have recently enacted PFML programs that are currently awaiting implementation.¹⁶

In LTSS, there has been a wave of state interest in adopting new programs in recent years:

**States have a solid track record in launching and running social insurance programs.**

- **Washington State** enacted the Long-Term Care Trust Act in 2019. It creates a public long-term care program that provides front-end coverage based on contributory social insurance. Front-end coverage pays benefits soon after a beneficiary is assessed as needing functional supports, but it pays only up to a fixed maximum amount—in the case of Washington State, no more than $36,500 over a beneficiary’s lifetime. The program will reimburse beneficiaries for the cost of LTSS services received at home, in the community, or in a facility, up to $100 per day. The program is funded by an employee contribution of 0.58 percent of wages (without a cap). Independent contractors can opt into the program by paying the same contribution rate on their earnings. Workers become eligible for benefits after a vesting period of a total of 10 years (without any interruption lasting five or more consecutive years) or three of the past six years. Contributions begin January 1, 2022, and benefits will be payable to eligible persons starting January 1, 2025.¹⁷

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¹⁶ For in-depth descriptions of these programs, see Chapter 2 of this report.
Maine residents considered a ballot initiative to create a new LTSS program in 2018. While not a traditional social insurance program, it was designed to provide a universal benefit to help people needing LTSS receive home care and remain living in their homes for as long as possible. The ballot initiative did not pass.

Hawaii enacted the Kūpuna (Elders) Caregivers Program in 2017 to help family caregivers stay in the workforce. For family caregivers who work at least 30 hours a week, the program pays up to $210 per week for LTSS services for a loved one living at home (60 or older and not covered by Medicaid or private long-term care insurance). It is not a social insurance program and is funded by general revenues; availability of benefits is subject to funding. In 2018 and 2019, the number of eligible applicants exceeded funding capacity and some applicants were put on a waitlist.

Hawaii enacted the Kūpuna Care Program in 2008. It makes limited LTSS available to non-Medicaid-eligible residents 60 or older, supporting them to continue living at home or in the community. Covered services include adult day care, personal care, and transportation. This is not a social insurance program, because benefit eligibility is not conditioned on having contributed and funding comes from an excise tax on businesses. In addition to Hawaii, a number of other states have programs, mostly several decades old, designed to target LTSS benefits to the near-Medicaid-eligible population.

Establishing a state-based program does present some unique challenges that will need to be addressed. Among the most prominent are defining program obligations in the context of interstate mobility among residents, having sufficient vesting requirements to assure that states are not selected against by attracting people more likely to need benefits, and integration and transition issues that could arise should the federal government implement a new program.

Washington State enacted the Long-Term Care Trust Act in 2019. It creates a public long-term care program that provides front-end coverage based on contributory social insurance.

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Section III.

THE CURRENT STATE OF LTSS FINANCING: HOW CAN SOCIAL INSURANCE ADDRESS THE NEED?
In this section we examine the existing financing sources for LTSS and illustrate how social insurance can help address current and future unmet needs.

The majority of the nation’s LTSS is provided by family and friends. The economic value of such unpaid care has been estimated at nearly $470 billion in 2013.

With regard to paid care, today about half is financed by Medicaid (51 percent of aggregate costs), while the rest comes out of the pockets of families (household savings or income) (19 percent), private long-term care insurance (8 percent), and a range of other public programs (21 percent). (See Figure 4)

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21 In some cases family and friends can be compensated for care they provide. (Medicaid.gov, “Self-Directed Services,” https://www.medicaid.gov/medicaid/ltss/self-directed/index.html.)

22 These National Health Expenditure data are likely to underreport out-of-pocket expenditures vis-à-vis other payers of LTSS due to difficulties documenting such expenditures.

23 Erica L. Reaves and MaryBeth Musumeci, “Medicaid and Long-Term Services and Supports: A Primer,” KFF, December 15, 2015, using Kaiser Commission on Medicaid and the Uninsured estimates based on Centers for Medicare and Medicaid Services National Health Expenditure Accounts data for 2013. Note: Total LTSS expenditures include spending on residential care facilities, nursing homes, home health services, and home and community-based waiver services. Expenditures also include spending on ambulance providers and some post-acute care. This chart does not include Medicare spending on post-acute care ($74.1 billion in 2013). All home-and community-based waiver services are attributed to Medicaid.
As the Baby Boomer population ages, demand for LTSS will increase sharply, and states will struggle to keep up with the growing need in the context of budget constraints. Consequently, in the coming decades families will be left paying a much larger share of costs. For those turning 65 today, the out-of-pocket share of aggregate LTSS costs is projected to amount to 52 percent, with Medicaid picking up only a third (34.3 percent) and private insurance only 3 percent. Medicare is projected to pay only 10 percent (primarily when LTSS overlaps with medical care).\textsuperscript{24,25}

Moreover, as important as Medicaid and (to a far lesser extent) private long-term care insurance are in providing access to LTSS for millions of Americans, they leave the broad middle class largely exposed to the risk of not being able to afford the care they need and/or maintain their family’s living standards when they do need care. They also have other limitations, as we will see in this section.

\textsuperscript{24} Several important recent developments have paved the way for Medicare to provide non-medical benefits and to better integrate and coordinate medical care and LTSS. First, in 2015 Medicare began covering chronic care management (CCM) services for beneficiaries who have two or more serious chronic conditions expected to last at least one year or until death. These services are limited to the management and coordination of clinical care and do not include the provision of LTSS. (Centers for Medicare and Medicaid Services, “Chronic Care Management Services,” December 2016, https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/ChronicCareManagement.pdf.) Second, in February 2018 Congress passed the Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act, which seeks to facilitate integrated, person-centered care for adults with complex care and support needs. The Act gives Medicare Advantage (MA) plans greater flexibility to provide—at no extra cost—non-medical benefits for identified high-need/high-risk members. These benefits can pay for such items as bathroom grab bars, wheelchair ramps, transportation, or home meals. (Anne Tumlinson, Megan Burke, and Gretchen Alkema, “The CHRONIC Care Act of 2018: Advancing Care for Adults with Complex Needs,” The SCAN Foundation, March 7, 2018, https://www.thescanfoundation.org/chronic-care-act-2018-advancing-care-adults-complex-needs.) Third, the Department of Health and Human Services has adopted regulations that allow MA plans to provide certain non-medical benefits, including payment for supportive services such as in-home assistance with activities like dressing, bathing, and managing medications. It is too soon to determine the degree to which MA plans will offer LTSS benefits in the coming years and whether the amount of the benefits (such as the number of hours of in-home assistance covered) will be sufficient to address LTSS needs in a significant way. (Howard Gleckman, “What a Medicare Advantage Personal Care Benefit Looks Like,” Forbes, October 5, 2018, https://www.forbes.com/sites/howardgleckman/2018/10/05/what-a-medicare-advantage-personal-services-benefit-looks-like/#5c302c2d6066.)


\textbf{Medicaid}

Medicaid pays for health care and LTSS for eligible low-income people. Medicaid is administered by the states, according to federal requirements. It is funded jointly by the states and the federal government.\textsuperscript{26} To qualify for Medicaid, individuals must meet certain categorical, financial, and functional or clinical requirements.
Categorical eligibility criteria. Being categorically eligible for Medicaid means belonging to a covered population group (such as children, pregnant women, elderly adults, and people with disabilities). To be categorically eligible based on being elderly or disabled (the majority of LTSS users), individuals must be over the age of 65, have a disability, or have one of several specified medical diagnoses. Other categorical eligibility criteria include U.S. citizenship or legal immigration status and state residency.

Financial eligibility criteria. Medicaid is means-tested—to qualify, a person must have low income. In addition, those qualifying on the basis of disability or age may not have assets (resources) above a certain level. Many middle-income people “spend down”—they spend their assets on care until they have very little left, qualify for Medicaid, and then, while on Medicaid, must spend most of their income on care. This of course means that financial independence is lost. (Financial eligibility rules vary somewhat by state, within federal guidelines. For a more detailed discussion, see Appendix II.)

Functional/clinical eligibility criteria. Functional eligibility criteria can include an individual’s inability to perform Activities of Daily Living (ADLs: eating, bathing, dressing, transferring, toileting, and continence) or certain Instrumental Activities of Daily Living (IADLs, such as shopping, housework, and meal preparation) that allow an individual to live independently in the community. Some states may use clinical, level-of-care criteria (diagnosis of an illness, injury, disability, or other medical condition, treatment and medications, and cognitive status). Most states use a combination of functional and clinical criteria in defining the need for LTSS. For certain programs within Medicaid (including the most important vehicles for the delivery of LTSS, 1915(c) waivers), the clinical criteria that individuals must meet are the same as for an institutional level of care.

The difficulty in accessing HCBS coverage

While federal law stipulates that states must cover nursing home care and home health services, HCBS and personal care benefits are optional for states. The majority of states offer personal care and similar services through their state plans, but the criteria used for access to these services (as well as the amount, duration, and scope of these services) vary widely. In addition, all states offer HCBS through a Medicaid authority called a waiver. Waivers are often targeted toward specific populations, and there is wide variation in the

27 Categorical eligibility for Medicaid coverage due to disability can be based on physical conditions (e.g., quadriplegia), intellectual and developmental disabilities (e.g., Down syndrome), and/or severe behavioral or mental illnesses (e.g., schizophrenia). (Medicaid and CHIP Payment and Access Commission, “Medicaid and Persons with Disabilities,” Report to the Congress on Medicaid and CHIP, March 2012, https://www.macpac.gov/wp-content/uploads/2015/01/Medicaid_and_Persons_with_Disabilities.pdf.)

28 Some individuals transfer their assets to family members in order to qualify for Medicaid, although the magnitude of this activity is subject to debate and is generally thought to be relatively modest.


30 Most states use 1915(c) HCBS waivers, although an increasing number are including HCBS as a part of 1115 demonstration programs. See “State Waivers List,” Medicaid.gov, https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html.
types of benefits offered. What this means for state residents is that even those who meet all the normal eligibility criteria for Medicaid LTSS may not have access to HCBS coverage. States can seek to contain costs by utilizing additional restrictive financial and functional eligibility standards, enrollment caps, service unit limits, or waiting lists. Figure 5 presents a stylized schematic of the hurdles a disabled individual must clear in order to get access to HCBS through the Medicaid program.

In 2016 there were 656,195 individuals in 39 states on a Section 1915(c) waiver waiting list. It also is important to note that there is tremendous heterogeneity both in the HCBS waiting list population and in state HCBS waiting list policies. And states vary greatly in terms of their level of investment in HCBS, as shown in Figure 6.

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31 This compares to 1.6 million individuals receiving services through Section 1915(c) programs in 2014 (the latest data available). (Kaiser Family Foundation, “Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers, 2016,” State Health Facts, https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D.)

32 Four states—Texas, Louisiana, Florida, and Ohio—account for two-thirds of the waiting list population nationally. The waiting list population includes different types of disability: nearly two-thirds are people with intellectual/developmental disabilities, 28 percent are seniors or adults with physical disabilities, and 8 percent are other populations (such as children who are medically fragile or technology-dependent, people with HIV/AIDS, people with mental health needs, or people with traumatic brain or spinal cord injuries). About half of state HCBS waiver programs do not screen individuals for HCBS eligibility until they have cleared the waiting list. People on HCBS waiting lists may be receiving other Medicaid LTSS services if such services are included in the state’s Medicaid plan. (Ibid.)
FIGURE 5: Barriers to Access to Home and Community-Based Services (HCBS) under Medicaid

**Categorical Eligibility Requirements**

- Do I meet the categorical eligibility requirements for Medicaid?
  - **No**
    - Not eligible
  - **Yes**
    - Do I meet the financial eligibility requirements for Medicaid?

**Federal Requirements**

- Am I age 65+, disabled, medically needy*, or do I have other specified medical conditions?
  - **No**
    - Not eligible
  - **Yes**
    - Do I meet the financial eligibility requirements for Medicaid?

**State Requirements**

- Do I meet the financial eligibility requirements for Medicaid?
  - **No**
    - I may or may not be eligible depending on my eligibility pathway.
  - **Yes**
    - Do I receive SSI? Or did I formerly receive SSI but become ineligible due to increased earnings or age?

**Financial Eligibility Requirements**

- Do I receive SSI? Or did I formerly receive SSI but become ineligible due to increased earnings or age?
  - **No**
    - Not eligible
  - **Yes**
    - Does my state have more restrictive financial eligibility requirements?

**State Requirements**

- Does my state have more restrictive financial eligibility requirements?
  - **No**
    - I meet clinical level of care criteria.
  - **Yes**
    - Do I meet the functional eligibility requirements for Medicaid?

**Functional Eligibility Requirements**

- Do I meet the functional eligibility requirements for Medicaid?
  - **No**
    - Not eligible
  - **Yes**
    - Do I meet the level of care requirements (e.g., ADLs)?

**Federal Requirements**

- Do I meet the level of care requirements (e.g., ADLs)?
  - **No**
    - Not eligible, unless my state has a buy-in option.
  - **Yes**
    - Are the services that I need covered under my state’s 1915(c) waiver (or, in rare cases, 1115 waiver) for HCBS?

**State Requirements**

- Are the services that I need covered under my state’s 1915(c) waiver (or, in rare cases, 1115 waiver) for HCBS?
  - **No**
    - Not applicable to my care needs.
  - **Yes**
    - Depending on my position on the wait list, I may or may not get Medicaid HCBS coverage.

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*Note: Medicaid eligibility rules vary by state and can be complex.**
State Medicaid coverage and funding can also change over time. Therefore, it is very risky for someone to rely on receiving Medicaid LTSS in a home-and-community-based setting, or to make that a cornerstone of their LTSS planning. Most people realize this and do not see reliance on Medicaid as a desirable strategy for coping with their long-term care needs. In a Society of Actuaries survey of adults ages 35 to 55, nearly two-thirds agreed that “someone on Medicaid has less choice about care options.” And in a survey of California adults ages 40 to 69, 73 percent said that they “never want to have to rely on Medi-Cal [California Medicaid] to pay for their long-term care needs.”

State Medicaid coverage and funding can also change over time. Therefore, it is very risky for someone to rely on receiving Medicaid LTSS in a home-and-community-based setting, or to make that a cornerstone of their LTSS planning.

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Individual Savings

Individuals with savings that significantly exceed their retirement income needs may, depending on the duration of their care, be able to pay for their LTSS out of their savings. However, this is not possible for the majority of the population. Half of today’s working-age households are projected to be unable to save enough to maintain their pre-retirement standard of living, much less finance their health and long-term care expenses in retirement. This is true even if at age 65 they were to take out a reverse mortgage on their home and annuitize all their assets. The typical household approaching retirement (age 55-64) has about $10,000 in retirement (401(k)/IRA) savings. If one considers only the 58 percent of households with some retirement savings, the median amount of their holdings is $108,000. Among the roughly half of Americans 65 and over who will have significant LTC needs, the average cost for their care will be $266,000 in today’s dollars, and a little more than half of that will need to be paid out of pocket.

Relying on savings is also an inefficient approach to financing long-term care needs, given the nature and distribution of the risk. Roughly half of individuals turning 65 today are expected to die without incurring a substantial LTSS expense, while a small percentage (15 percent) are expected to incur several hundred thousands of dollars in costs. The distribution of the need and the potentially high cost make saving individually for LTSS needs imprudent for most people. It makes as much sense as saving for the possibility your home might burn down or you might need major surgery. It makes more sense to rely instead on risk-pooling through insurance—but not everyone can afford or qualify for private LTC insurance.

Private Insurance

While private long-term care insurance (LTCI) policies have served well those who have had them over the years, these products do not hold the potential to be a broad-based solution to the country’s LTSS needs, for several reasons. Just as most families lack the assets to pay for their potential LTSS needs out of pocket, many also lack the disposable income to purchase LTCI. Even those who might be able to afford LTCI prioritize more immediate expenses (e.g., student loan debt, mortgage, child care, or college expenses) over protecting against an

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38 Ibid.
uncertain and very distant potential liability.\textsuperscript{39} Only about seven percent of adults age 50 or older have private LTCI today.\textsuperscript{40,41}

Another reason why LTCI has not grown to cover a significant share of the population is that it is voluntary, and many families who could afford to buy it choose not to do so. They are unclear about their future risk and tend to underestimate it, believe they may be covered by other programs, or find LTCI products complex and hard to understand.

Another obstacle is that many people do not qualify for LTCI. Various estimates suggest that upwards of 30 percent of the public age 50 and over would not meet insurers’ underwriting criteria.\textsuperscript{42}

In addition to limited consumer demand for LTCI, there are a variety of issues related to the supply of these products that have caused the LTCI market to contract significantly over the last 15 years. First, private insurers are no longer willing to


\textsuperscript{40} A growing number of consumers are buying products that combine life insurance or an annuity with long-term care benefits; these are considerably more expensive than traditional LTCI and thus are available only to a more limited upper-income market segment.


\textsuperscript{42} Portia Cornell, David Grabowski, Marc Cohen, Xiaomei Shi, and David Stevenson, “Medical Underwriting in Long-Term Care Insurance: Market Conditions Limit Options for Higher-Risk Consumers,” \textit{Health Affairs}, Vol. 35, No. 8, August 2016.
provide policies that pay benefits indefinitely, potentially covering many years of LTC need. Second, most companies have been unable to generate a profit because of certain macro-economic events that have been outside of their control but affect the entire industry. These include operating in a very low interest rate environment, changes in both mortality and morbidity trends across the population, and high marketing costs to overcome demand issues. Consequently, while there were more than 100 companies selling LTCI at the turn of the 21st century, today fewer than a dozen sell a meaningful number of policies. All of these factors have led to higher prices and have made premiums less affordable to middle-income Americans.

**Only about seven percent of adults age 50 or older have private long-term care insurance today.**

**Social Insurance Can Address Many Shortcomings in the Current System**

Under the current system, those with high incomes can pay for LTSS out of their savings or with private insurance benefits. But those in the broad middle class either forgo paid care (relying on family members) or pay for it out of limited income and savings until they deplete their assets and qualify for Medicaid. And those who qualify for Medicaid (whether low- or middle-income) must contribute most of their income to their care costs and may be forced to enter a nursing home because they cannot access sufficient home- and community-based services or afford to remain at home.

A social insurance approach to financing LTSS could go far in efficiently and affordably addressing these coverage gaps. Social insurance contributions are generally more affordable than private insurance premiums, for a number of reasons. Social insurance pools risk across the entire workforce. Contributions are generally paid into a social insurance program for much longer than premiums are paid to an insurance company—they can be collected as payroll deductions for a person’s entire working life. Also, a significant part of the private insurance premium goes to cover marketing and sales expenses (including agent commissions), which is largely unnecessary in a traditional social insurance program. Existing social insurance programs (such as Social Security and Medicare) have had much lower administrative costs than their private-sector counterparts, accounting for only

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about one percent of expenditures. Finally, with social insurance the considerable cost of underwriting is eliminated; there is no need to assess and filter out high-risk applicants, since coverage is typically mandatory and extended to large populations with diverse risks (like the entire workforce). For these reasons, overall costs and hence contributions can be lower and more predictable.

State adoption of a social insurance program for LTSS could also spur growth in the private insurance market, since it is unlikely that such a program would pay for all LTSS costs for all people. The program would likely cap benefits at a certain daily or monthly dollar amount, and this potential gap in coverage would create a market for a supplemental private benefit similar to Medigap insurance. Moreover, if a social insurance program offered only front-end or back-end coverage, this would limit the risk against which a private insurance product could protect beneficiaries. In other words, introducing a social insurance program for LTSS in a state could actually spur growth in the private market, both because of gap-filling opportunities and because tastes for and awareness of the need for insurance would likely change. Clear definitions about public and private responsibilities would eliminate current confusion about what is and is not covered and clarify for people the need for private insurance to cover the portion of

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the risk that a social insurance program left unaddressed. In short, given that neither individual savings nor private insurance offers broad-based solutions to the LTSS needs of the population, social insurance is worthy of consideration by policymakers.

State adoption of a social insurance program for LTSS could spur growth in the private insurance market, since it is unlikely that such a program would pay for all LTSS costs for all people.

When introducing a social insurance program to address the LTSS needs of residents, state policymakers need to be mindful of four core design issues:

- **Program structure.** This refers to who will be eligible for the program’s benefits, how generational transition issues will be dealt with, and the timing and duration of coverage.

- **Financing approach.** This encompasses two broad and critical issues. One has to do with the source or sources of funding for the program (e.g., payroll tax, income tax, or other options). The other question is whether the program is financed on a pay-as-you-go or prefunded basis.

- **Program integration.** This refers to how the new program interfaces with the existing LTSS financing and service delivery systems. Integration is particularly important for ensuring that benefits are paid appropriately, consumers do not face discontinuities in coverage, and program accounting and financial forecasting can be completed accurately.

- **Program implementation strategy.** This addresses the strategies and tactics for program administration, collection of revenues, eligibility determination, ongoing program management, program integrity, and evaluation.

These issues are discussed in the following sections.
Section IV.

PROGRAM STRUCTURE: NEW COVERAGE OPTIONS AND BENEFIT DESIGN
While there are many components to be determined in designing a program, this section focuses on the three most critical: **eligible population, generational transition issues,** and **coverage durations and start times.** Additional considerations—such as the criteria for becoming eligible for benefits (benefit triggers), the amount of the benefit payment, and whether benefits are paid in the form of cash or as a reimbursement for services received—are discussed in Appendix I.

**Eligible Population**

People needing LTSS include elderly and non-elderly people with intellectual and developmental disabilities, physical disabilities, behavioral health diagnoses (such as dementia), spinal cord or traumatic brain injuries, and/or disabling chronic conditions. A person’s age, gender, socioeconomic status, living arrangement, and access to information about care options, in addition to their health and disability status, can influence the types and amounts of LTSS utilized and the duration of care. ⁴⁶ People with disabilities may need LTSS at a relatively young age as a result of illness or injury, and in some cases throughout their entire lives. LTSS can facilitate a meaningful life as part of a community and provide modest support to a family to support the individual in need.

How or whether to include people with disabilities in a social insurance program can have a major impact on program costs, the feasibility and suitability of specific program designs, and options for how the program is to be financed. The decision also has important implications for public support for the program as a broader constituency of individuals with LTSS need would benefit from the program. For the most part, inclusion of those under 65 with LTSS need would result in higher costs compared to a program designed exclusively as a retirement benefit; this is because, everything else held constant, there is less time to prefund (collect and invest contributions to pay for future benefits). Furthermore, if there is no vesting requirement, the funds needed to pay claims will be higher, given that there will be an immediate need on the day the program becomes operational. Finally, the lifetime service costs for people with lifelong LTSS need tend to be higher than for those who become disabled after 65. ⁴⁷

On the other hand, including this population ensures that the program is completely universal and focused on the need for LTSS rather than the cause of the need. It would ensure that individuals with similar needs would receive the same coverage, regardless of age.

**Generational Transition Issues**

When instituting a new LTSS social insurance program, policymakers must make a choice. The program could cover only those who start paying in now, and only some years from now, after they have vested in the program (paid in long enough to earn benefit eligibility). In such a prefunded system, current contributions are invested

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⁴⁷ It should also be noted that, through the ABLE Act of 2014, 39 states now have programs to assist families caring for individuals whose disabilities emerged before age 26 by enhancing their ability to save and pay for LTSS on a tax-advantaged basis. (For more on ABLE accounts see the ABLE National Resource Center, http://ablenrc.org.)
to pay for future needs. Alternatively, the program could cover everyone essentially from the start, including those who are already retired or disabled. In such a pay-as-you-go (PAYGO) system, current contributions pay for the benefits of those who need them now. The financial implications of this choice will be examined in the next section of this chapter, which is devoted to financing issues; here we will discuss more general issues.

While prefunded systems require vesting and so would exclude Baby Boomers and most people with lifelong disabilities, PAYGO systems can cover everyone immediately, typically making them a politically more viable approach (particularly given that seniors are more likely to vote than other age groups). For this reason, the vast majority of public long-term care systems around the world operate on a PAYGO basis.

One approach is to adopt a prefunded social insurance program to provide for future LTSS needs while relying on a separate system funded by general revenues to cover those already disabled today as well as the transition cohorts (those too old to become vested under the prefunded system). The second of these components already exists in the form of Medicaid LTSS, so policymakers could choose to introduce a prefunded system and rely on Medicaid to serve transition cohorts. The downsides of this approach are, as we have seen, that under Medicaid LTSS in its current form, individuals must deplete their assets and access to HCBS can be limited. However, a state adopting a prefunded social insurance program for future LTSS needs might be able to obtain a waiver to enhance its Medicaid LTSS program during the transition period. This could provide broader coverage to people who have already retired and so are unable to earn vesting in the new program. Hybrid approaches between a prefunded and PAYGO system are possible as well. One such approach is to collect contributions
for several years before benefit payouts begin, allowing the system to accumulate some level of assets. Another is to cover everyone from the start, but set aside part of the payroll contributions in a “buffer fund” to pay for future cohorts. Germany’s 2015 reform package, for example, increased the contribution rate for its social insurance program and stipulated that part of the money would go to a trust fund that could only be used to pay benefits from 2035 onward. This approach helps equalize the burden of funding the cost of demographic transition across generational cohorts, and also stabilizes the rate of payroll contributions needed to fund benefits over the long term.

Universal LTSS programs—whether prefunded or PAYGO—require young people to pay into a system that does not usually pay benefits until far into the future (unless a beneficiary is or becomes disabled before retirement age). This can be politically problematic, particularly as many young people may have difficulty imagining that they will ever need long-term care. One way to address this—as Japan has done—is to require participation and contributions only from people 40 and older, who are likely to be more aware of their own long-term care risks and of those of their aging parents. However, restricting the program’s tax base in this way requires an increase in contribution levels, a reduction in benefits, or restrictions on beneficiaries. (For instance, Japan’s system pays benefits only to those with aging-related disabilities.)

**Coverage Durations and Start Times**

Policymakers have to choose among three basic structures:

- **Front-end coverage.** Benefits begin to be paid as soon as someone becomes disabled (or after a brief waiting period of, for example, 30 or 90 days), but they last only for a limited time (such as a year or two) or only up to a total dollar amount.

- **Back-end (catastrophic) coverage.** Benefits begin only after someone has been disabled for an extended period (such as two or three years).

- **Comprehensive coverage.** Benefits are paid during the entire period of need.

Once the basic structure is set, there are other choices. For front-end coverage, one must decide how long benefits will last or what the maximum dollar amount will be. For back-end coverage, one must decide how long a person must be disabled before benefits begin, and whether benefits will last as long as care is needed or be subject to a time or dollar limit. In the front-end approach, everyone who becomes disabled receives some benefits, but those who need care for a long time must pay their own expenses if care needs extend beyond the coverage duration. The back-end approach ensures that participants

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are protected against catastrophic costs, but everyone must cover their own expenses for an initial period. Back-end coverage has the advantage of meeting a need not addressed by currently available private insurance products (which do not cover catastrophic costs). On the other hand, having to pay expenses for an initial period may be a hardship for low-income people, although presumably many would qualify for Medicaid LTSS. For most people, family members would likely provide most needed care until a back-end benefit kicked in. In a back-end system, those who need LTSS for only a limited time will receive no financial benefits at all.

A front-end program typically serves more people but pays them less, while a back-end program serves fewer people but pays them more. If overall program cost is held constant, beneficiaries in a back-end system receive more on average than those in a front-end system. This is because the care needs of those who have required LTSS for a long time are typically greater than those who have recently developed an impairment, and the length of time they receive benefits is open-ended.

Closer examination of the impact of program structures on the older adults reveal some of the differences. Figure 7 shows that a little more than half (52.3 percent) of those turning 65 today will, at some point in their lifetime, require significant LTSS (because of the inability to perform at least two ADLs and/or a severe cognitive impairment). The other half of seniors would receive no benefits from any type of LTSS program, since they will have no need. Figure 8 focuses on those who will have a need, showing how many need LTSS for different durations; this enables us to see who will benefit from different program structures. A front-end program that provides coverage for the first two years of LTSS need would cover the entire duration of care of the 51 percent of seniors who will need care for less than two years. For the other 49 percent, it would cover the first two years, after which they would be on their own. Thus, 100 percent of those in need would receive some benefit from this front-end program, and about half would receive benefits for the whole time they needed LTSS. In contrast, a back-end program beginning with the third year of LTSS need would cover 49 percent of seniors with LTSS needs; the other 51 percent would receive no benefits. A comprehensive program would cover the entire period of need for everyone with significant LTSS needs regardless of how long that need persisted.

A front-end program typically serves more people but pays them less, while a back-end program serves fewer people but pays them more.
For either a front-end or a back-end program, a decision must be made about the maximum duration of benefits or the maximum dollar amount of benefits. This will be a key factor in both the generosity of coverage and the program cost. A front-end program might pay benefits for one or two years, or it might set a dollar maximum based on one or two years. (For instance, the maximum might be based on a daily benefit of $100 for two years—that is, $73,000, the product of $100 x 365 x 2). A pure back-end program would have no limit on duration or total amount of benefits, but a back-end program could be designed with such limits. In a comprehensive program, policymakers could consider paying a lower benefit in the early years of LTSS need and a higher benefit after a certain number of years. This could be cost-neutral, but it would address the fact that a person’s care costs often go up the longer they need care (as impairments become more severe and unpaid caregivers become less available), and their ability to pay declines as savings are depleted.

Any new public program would likely leave a role for personal savings and supplemental private insurance, which would fill gaps and
meet certain consumer needs and wants. Whether and how the private market could be expected to offer products to supplement a social insurance program is one of many considerations states face. Private insurers are no longer willing to cover LTSS needs for an indefinite period (the back-end, catastrophic risk), but they are interested in covering the front-end risk. A back-end public program thus seems more likely to attract private insurers offering wrap-around or supplemental policies. A back-end public program also provides a clear delineation between when private coverage ends and public coverage begins. With a front-end program, private insurers might be willing to offer additional coverage, but with a limit on duration. With a comprehensive public program, which is likely to have a lower daily benefit in order to contain costs, private coverage might “top up” the benefit amount for those who are willing and able to afford more coverage. Table 1 summarizes some of the key differences among program structures.

Any new public program would likely leave a role for personal savings and supplemental private insurance, which would fill gaps and meet certain consumer needs and wants.

| TABLE 1: Comparison of Front-end, Back-end, and Comprehensive LTSS Coverage |
|---------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|
| **Who is covered?**                                           | **Back-end (Catastrophic)**                                   | **Comprehensive**                                             |
| Everyone with an LTSS need receives some benefits.            | Targets funding to those with the greatest LTSS needs (longest duration). | Everyone with an LTSS need receives benefits.                 |
| **Program costs**                                             |                                                               |                                                               |
| More predictable program costs and more affordable premiums,  | Costs may be more unpredictable, as life span increases over time or as duration of morbidity increases. | Most expensive (all else being equal) because both front- and back-end needs are covered and duration of needs is unpredictable. Costs also may be unpredictable as life span increases or as duration of morbidity increases. |
| all else equal.                                                |                                                               |                                                               |
| **Impact on family caregivers**                               |                                                               |                                                               |
| Helps all families cope with initial period of care need, giving them time to identify appropriate planning and resources for continuing to meet needs (e.g., apply for Medicaid if needed to cover longer-term need). | Reduces need for family care during phase when family care resources are “burnt out” or high-level care needs at longer care durations exceed what family can support. | Reduces family care burden throughout duration of need. |
| **Private market gap-filling**                                |                                                               |                                                               |
| More difficult for private market to supplement because private market unlikely to cover catastrophic, back-end risk. | Easier for private market to gap-fill with affordable front-end coverage for those who want it. | Private market might gap-fill with a benefit that adds to the daily benefit amount. |
Section V.

SOCIAL INSURANCE FINANCING OPTIONS
Nearly all states are required to balance their budgets, either by constitution or by statute. Hence a new LTSS program will need to be fully paid for. This section identifies the conventional approaches used to finance social insurance programs and also puts forward other potential funding sources. The panel recognizes that each state’s tax system and culture are unique. For example, not all states have an income, sales, or estate tax. Moreover, some states will prefer a program with higher benefits and funding levels, while others will prefer a more modest program.

Before discussing revenue sources, it should be noted that our LTSS system today is already asking people with disabilities and their families to pay for LTSS, but in an inefficient manner. The primary source of all LTSS today—if one considers both compensated and uncompensated care—is out-of-pocket costs paid by individuals needing care and the support-related costs of their family caregivers. These costs include cash payments to those providing paid LTSS as well as income lost by family caregivers having to work less. These costs occur with no risk pooling or prefunding and often come at a time when individuals and their families are most vulnerable. The fundamental LTSS financing problem today is the absence of an effective insurance mechanism to protect people against these costs.51

A new LTSS social insurance program could be financed through dedicated payroll taxes (as for Social Security or Medicare), income or sales surtaxes, estate or property taxes, other earmarked taxes, provider fees, a combination of these, or general revenues. Beneficiaries could also be charged premiums, as for Medicare Parts B and D. For a tax-based approach, one needs to consider the base over which the tax is applied (e.g., wages, total income, adjusted gross income), the distribution of the tax burden across different income and age groups, the period over which the tax is collected, and how the tax base is likely to change over time. The financial adequacy and political feasibility of funding sources vary, and in making choices states will need to both ensure fiscal sustainability and garner political support.

**Financing Sources for Federal Social Insurance Programs**

Existing large-scale social insurance programs in the United States include Social Security, Medicare, Workers’ Compensation, Unemployment Insurance, and Paid Family and Medical leave. How are federal social insurance programs funded?

- **Social Security** levies a payroll tax on all earned income, up to an annual cap ($132,900 in 2019, indexed to wage inflation). This is paid by both workers and


employers, but an LTSS tax could be paid by workers alone. There are many ways a new LTSS program could adapt the Social Security approach. Possibilities include: (1) levy a tax on the Social Security tax base (earned income up to the Social Security tax cap); (2) levy a tax on earned income without a cap; or (3) levy a tax only on earned income above the cap.

- **Medicare Part A** also levies a payroll tax on earnings, paid by workers and employers, but without an annual cap. Also, an Additional Medicare Tax is levied on earnings above certain thresholds ($200,000 for an individual, $250,000 for a couple).52

- **Medicare Parts B and D.** Roughly three-quarters of funding comes from general revenues, and most of the rest comes from premiums paid by beneficiaries. Higher-income enrollees (those earning more than $85,000 for individuals and $170,000 for couples) pay premiums that are 40 to 240 percent higher.53

- **Medicare Net Investment Income Tax.** This is a tax on unearned (investment) income levied on households with modified adjusted gross income above $200,000 for individuals or $250,000 for couples (thresholds not indexed for inflation). The funds raised do not go into the Medicare trust fund but rather to general revenues.

If a new LTSS program is financed by a payroll contribution (i.e., a tax on wages), it must address the issue of whether and/or how people who are not in the labor force would be eligible to participate, and current Social Security regulations may offer a guideline in this regard.

**Financing Sources for State Social Insurance Programs**

State governments also administer social insurance programs, and these employ additional financing approaches that would be possible for an LTSS program:

- **Workers’ Compensation.** Employers pay premiums for their workers; employers may also (where it is permitted and provided that they meet certain financial requirements) self-insure the risk (pay claims out of their own resources). Premiums are paid either to a state-run insurance program or to a private insurance company. Premiums vary based on a variety of factors, including expected risk and an employer’s past record of on-the-job illness and injury (experience rating).54

- **Unemployment Insurance** is funded by a federal tax paid by employers and by employers’ state contributions. As with Workers’ Compensation, contribution rates vary based on several factors, including an employer’s past experience with layoffs.55

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54 Ibid.

55 Ibid.
Paid Family and Medical Leave. There are four states with paid family and medical leave programs, one state with a paid medical leave program, and three states and the District of Columbia in the process of implementing recently enacted PFML. Most of these programs are funded through payroll contributions by workers and/or employers, although in some cases employers pay premiums to private insurance companies.\footnote{Sarah Jane Glynn, Alexandra L. Bradley, and Benjamin W. Veghte, “Paid Family and Medical Leave Programs: State Pathways and Design Options,” National Academy of Social Insurance, September 2017, https://www.nasi.org/sites/default/files/research/NASI%20PFML%20brief%202017-%20Final.pdf.}

Having administered these programs in some cases for three-quarters of a century or more, states have a proven track record in collecting payroll taxes and/or premiums from employees and/or employers, and in administering the payment of benefits. That said, there may be greater complexities in administering an LTSS program, particularly in long-term actuarial planning and—if a prefunded program is adopted—asset accumulation. This is because Workers’ Compensation, Unemployment Insurance, and Paid Family and Medical leave claims are typically not of long duration, whereas LTSS claims typically are. Furthermore, LTSS program costs and the timing of those costs are heavily influenced by demographic trends.

States have a proven track record in collecting payroll taxes and/or premiums from employees and/or employers, and in administering the payment of benefits.

Additional Potential Funding Sources

Income surtax. States could levy a surtax on their income tax base and dedicate this to the new LTSS program. State income tax bases differ by state, while seven states—Alaska, Florida, Nevada, South Dakota, Texas, Washington, and Wyoming—have no income tax whatsoever. Residents of New Hampshire and Tennessee pay taxes only on dividends and other income from investments.
Sales surtax. A sales tax is a tax on the sale of goods and services. Forty-five states and the District of Columbia have a sales tax, and five—Alaska, Delaware, Montana, New Hampshire, and Oregon—do not. Many states have lower sales tax rates or no tax at all on some food, other goods, and many services such as medical care, education, and most professional services. This renders the sales tax base narrow in most states.

Other dedicated taxes. Dedicated taxes produce revenue streams that are earmarked for a particular purpose and therefore not available for general budgeting to support the full range of agencies, programs, and services provided by the government. Dedicated financing may be conducive to the fiscal sustainability of a new LTSS program given state balanced budget requirements, which make funding a large new program out of general revenue challenging. However, statutory earmarks can be overridden by changes in the law, and they are even ignored in some cases, which makes meeting the challenge of fiscal sustainability more difficult.

Provider fees: Fees from care providers—hospitals, nursing homes, managed care plans, and health facilities—are currently a revenue source for 49 state Medicaid programs. States could charge LTSS providers a percentage of payments made to them for services and earmark this revenue for the new LTSS program. However, it should be noted that the LTSS service infrastructure is not yet developed enough to meet current needs, so that imposition of a provider fee may prove very difficult in many states.

Estate Tax. Estate taxes are levies on the net value of the assets of a deceased person prior to their distribution to heirs. Thirteen states currently have an estate tax. However, these states exempt between $1 million and $11.2 million in assets from

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their estate tax, so that the vast majority of estates are not subject to this tax. Moreover, those that are subject to it pay the rate (often gradually increasing with asset size, up to a maximum rate in some states of 20 percent) only on the value of assets above the exemption threshold. Estate taxes have been rolled back significantly since 2001, both on the state and federal levels, and they can be fairly easily avoided.\footnote{The Urban Institute, “Estate and Inheritance Taxes, 2018” (State and Local Backgrounders), https://www.urban.org/policy-centers/cross-center-initiatives/state-local-finance-initiative/state-and-local-backgrounders/estate-and-inheritance-taxes; Chye-Ching Huang and Chloe Cho, “Ten Facts You Should Know about the Federal Estate Tax,” Center on Budget and Policy Priorities, October 30, 2017, https://www.cbpp.org/research/federal-tax/ten-facts-you-should-know-about-the-federal-estate-tax.}

- **Property surtax.** A property tax is a tax on real property (land and buildings) or personal property (e.g., business equipment or noncommercial motor vehicles). All states have property taxes, but the tax is primarily levied by cities, counties, and school districts rather than by states. Hence property taxes are, typically, not a major source of state revenue (New Hampshire being a notable exception).\footnote{The Urban Institute, “Property Taxes” (State and Local Backgrounders), https://www.urban.org/policy-centers/cross-center-initiatives/state-local-finance-initiative/projects/state-and-local-backgrounders/property-taxes.} Moreover, 44 states have either a statutory or constitutional limit on property taxes.\footnote{Iris J. Lav and Michael Leachman, “State Limits on Property Taxes Hamstring Local Services and Should Be Relaxed or Repealed,” Center on Budget and Policy Priorities, July 18, 2018, https://www.cbpp.org/research/state-budget-and-tax/state-limits-on-property-taxes-hamstring-local-services-and-should-be.}

- **General revenues:** General revenues are revenues raised by government from all sources not earmarked for specific purposes. They may include revenues from a state income tax, corporate income tax, sales tax, or excise taxes (although not all states have each of these). Medicaid, the main public program paying for LTSS in the U.S. today, is funded (jointly by states and the federal government) predominantly from general revenues. Its funding is based on a federal formula that pays states a percentage of their qualifying expenditures; that percentage varies by state (with states having lower per capita income receiving more).

### Funding Considerations

Several criteria should be considered in choosing one or more revenue sources to fund a new LTSS program.

- **Size of tax base.** The smaller the base of the revenue source chosen, the higher the rate will need to be. At the state level, among the taxes available to policymakers, income taxes (where applicable) have the largest base, followed by payroll taxes.
Fiscal sustainability. In LTSS programs, a long time typically elapses between when individuals begin making contributions and when they receive benefits. One of the goals of a program is to provide plan participants with peace of mind during this period, and if a program is fiscally sustainable, participants have the assurance that promised benefits will be there when they need them. Ideally, revenues should be set to meet projected benefit costs over at least a 75-year window, with experience reviews at specified intervals (e.g., every five years). Under a new program, states will face a choice between committing to certain benefit levels and, if necessary, adjusting revenue to fund those levels, or setting revenue and adjusting benefits to match the available funds. Using multiple and diverse financing sources can make a program’s revenue stream more stable, while also making each revenue component smaller. On the other hand, using only one revenue source simplifies the financial management and administration of the program. A combination of dedicated funds and general revenues might be used. If the earmarked funds are sufficient for benefits, they can be the sole source of financing. If they are insufficient, general funds can be used to cover the deficit while the earmarked funding is adjusted. General revenues could also be used to make up shortfalls in projected income from fund investment returns, or to subsidize the contributions of low-income participants or those who are outside the workforce.

Political sustainability. Contributory social insurance programs have proven far more politically resilient than programs funded out of general revenues. Their funds are strictly separated from government budgets and cannot easily be used for other purposes. In contrast, general revenues may be used for any purpose, and funds for any specific need, such as an LTSS program, would be subject to reallocation each year in the annual appropriations process. In addition, in a social insurance program, contributors tend to feel that they have earned a right to benefits if the insured risk transpires, creating a strong constituency to sustain the program. However, Medicaid is an example of a general revenue-funded program that has proven remarkably resilient; since its enactment, it has seen major expansions to children and (in many states) childless adults. Still, it was one vote short of being significantly cut in 2017, highlighting the political vulnerability of social programs funded by general revenues.

Affordability. A universal program needs to be affordable even for low-income participants. Otherwise, it will contribute to their financial hardship. A modest payroll tax, whereby workers contribute a fixed percentage of their earnings, can by definition not exceed a small fraction of a worker’s income. Some social insurance programs provide subsidies funded from general revenues for those who cannot afford contribution payments.

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Connection with program benefits. People tend to be more willing to pay particular taxes if the money goes to a particular purpose they find worthwhile—see, for example, the popular acceptance of Social Security and Medicare taxes. Having a revenue stream (whether from a payroll tax or some other source) dedicated to a new LTSS program would likely increase buy-in for the program and the taxes used to fund it. Buy-in can also be enhanced if a revenue source is related in some way to the purpose it is used for, and several types of sources are connected to LTSS. For example, provider fees on businesses supplying LTSS services, which would benefit from an increase in revenue from the new program, would fit this criterion. So would a tax on the value of a home to help finance LTSS services so that people could age in place.

A conceptual case can be made for using an estate tax to fund LTSS benefits. It would allow people to protect part of their estate from the largest unfunded liability threatening it—major LTSS costs. Today, many people tap into their assets—by withdrawing from their 401(k), selling their home, or taking out a reverse mortgage—to pay for LTSS. Some completely exhaust their assets. For example, one study found that among nursing home entrants, housing wealth steadily declined over a six-year period, resulting in a median housing wealth of zero within six years after entry. In other cases, after a person has received Medicaid LTSS benefits, a state may put a lien on their estate and reclaim the cost of some of those benefits after their death. If a modest estate tax were enacted with a low threshold, it could ensure that a broad range of households contribute to LTSS from their assets, while rendering it extremely unlikely that anyone—even someone with high LTSS needs—would deplete all their assets paying for LTSS.

Other possible funding sources, not discussed here, include excise taxes (e.g., state taxes on alcohol and tobacco, which are sometimes used to fund health care and education spending), taxes on business income and tourism (which fund Hawaii’s Kūpuna Caregivers program), and lottery funding (used by Florida to address nursing home liability issues). “Sin” and lottery taxes are highly regressive.

**A modest estate tax could ensure that a broad range of households contribute to LTSS from their assets, while making it extremely unlikely that anyone would deplete all of their assets to pay for LTSS.**

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**Pay-As-You-Go vs. Prefunding**

As noted earlier, a key decision is whether a new program is to be financed on a PAYGO basis or prefunded. A **prefunded system** invests the contributions of current workers and pays future benefits out of the assets generated. Therefore, it cannot immediately pay out benefits for currently eligible individuals, but rather must accumulate monies for many years before benefits can be paid. This leaves workers who are above a certain age when a program is first implemented (transition cohorts) excluded from the benefits of the program. On the other hand, prefunding future benefits lowers the tax burden on current workers, as funds can grow through investment. This is true, however, only insofar as the monies collected are segregated or earmarked for the exclusive purposes of the program. A prefunded system also has more time to adjust to demographic shifts like the aging of the population.

In a **PAYGO system**, the program pays current benefits out of current contributions, and the future benefits of current workers will be paid for out of future contributions. While a PAYGO system can pay out benefits soon after it starts collecting contributions, the contribution rate would likely need to be higher than in a prefunded approach, where benefit payouts are deferred. This is because in a PAYGO system the fund would not earn investment income (which could help fund benefits) and because benefit payouts would occur sooner.

A state could take a mixed approach, using PAYGO and prefunding for different populations. For example, a prefunded program in which workers vest over time could be used for future benefits, while a PAYGO program could be used for those currently needing LTSS. In this approach, social insurance contributions could finance the prefunded benefits, while general revenues or a dedicated tax could fund benefits of the transition cohorts. Those already retired but not yet needing LTSS could participate in the program by paying premiums.

A mixed system could be complex to financially administer because the size of the prefunded and PAYGO components would change over time (with the prefunded component growing and the PAYGO component shrinking as people age). On the other hand, a mixed system would be able to pay benefits to currently eligible individuals while at the same time prefunding future
benefits. A mixed approach also has the potential to garner broad public support because it gives those currently needing LTSS some level of benefits while phasing in potentially more generous benefits for those who will need them in years to come.

As noted previously, another approach would be to rely on Medicaid LTSS to provide benefits (funded by general revenue) for the transition cohorts. This approach would have to take into account Medicaid’s limitations—it requires individuals to deplete their assets and provides limited access to home-and community-based care.

**LTSS Funding in Practice**

In choosing a revenue source for a new LTSS program, it is helpful to consider how some major existing and proposed LTSS programs are—or would be—paid for, both in the U.S. and abroad, as shown in Table 2. The table also identifies the scope of coverage corresponding to each revenue source, as well as whether the system is financed on a prefunded or PAYGO basis.

*A mixed approach also has the potential to garner broad public support because it gives those currently needing LTSS some level of benefits while phasing in potentially more generous benefits for those who will need them in years to come.*
### TABLE 2: Some U.S. and International Programs and Proposals for Financing LTSS

<table>
<thead>
<tr>
<th>Program</th>
<th>Revenue Source</th>
<th>Scope of Coverage</th>
<th>PAYGO or Prefunded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicaid program</td>
<td>General revenues</td>
<td>Means-tested</td>
<td>PAYGO</td>
</tr>
<tr>
<td>Washington State*</td>
<td>Payroll tax on all earned income</td>
<td>Universal</td>
<td>PAYGO with limited prefunding</td>
</tr>
<tr>
<td>Cohen-Feder proposal**</td>
<td>From age 40 onward: Payroll tax on all earned income (split between employers and employees)</td>
<td>Universal (after income-related waiting period)</td>
<td>Prefunded</td>
</tr>
<tr>
<td>Germany</td>
<td>Payroll tax on earned income (split between employers and employees) up to a cap of €4,425 ($5,100)/month; Pensioners pay full contribution; Childless workers pay supplementary contribution; Unemployment Insurance pays contributions for unemployed</td>
<td>Universal</td>
<td>PAYGO with limited prefunding</td>
</tr>
<tr>
<td>Japan</td>
<td>50% contributory (payroll tax [split between employers and employees] for those age 40-64 and modest income-related premiums for those age 65+)</td>
<td>Universal for 65+ and for age 40-64 with aging-related disability (e.g., dementia)</td>
<td>PAYGO</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Contributory for institutional care and 24-hour home care (employee payroll tax on earned income up to cap of €3,280 ($4,009)/month) with general revenue funding for other home care and LTSS</td>
<td>Universal</td>
<td>PAYGO</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>General revenues</td>
<td>65+ only, means-tested</td>
<td>PAYGO</td>
</tr>
<tr>
<td>France</td>
<td>General revenues with smaller social insurance component</td>
<td>Universal 60+, strict disability criteria (3 ADLs), benefit levels inversely related to income</td>
<td>PAYGO</td>
</tr>
<tr>
<td>Taiwan</td>
<td>Increases in estate, gift, and tobacco taxes; general revenues</td>
<td>Near-universal***</td>
<td>PAYGO</td>
</tr>
</tbody>
</table>

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*For a description of the Washington State program, see p. 156 of this chapter.

**A proposal by Marc Cohen of the University of Massachusetts at Boston and Judith Feder of the Urban Institute and Georgetown University would combine back-end (catastrophic) LTSS benefits with gap-filling private LTC insurance to ensure comprehensive protection, focused on middle-income people. For a fuller description, see Appendix III, as well as Marc Cohen, Judith Feder, and Melissa Favreault, “A New Public-Private Partnership: Catastrophic Public and Front-End Private LTC Insurance,” Urban Institute, February 1, 2018, https://www.urban.org/research/publication/new-public-private-partnership-catastrophic-public-and-front-end-private-ltc-insurance.

***Taiwan’s program covers people with disabilities age 49 and under, people with mild or severe dementia age 50 and older, and frail seniors 65 and older.


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SECTION V: SOCIAL INSURANCE FINANCING OPTIONS 187
As Table 2 shows, there is a variety of financing approaches in public LTSS programs (existing and proposed). One evident pattern is that existing programs tend to be pay-as-you-go because of the political challenges of introducing a system that fails to cover those currently in need, such as today’s seniors or individuals under age 65 with disabilities.

**Existing programs tend to be pay-as-you-go because of the political challenges of introducing a system that fails to cover those currently in need, such as today’s seniors or individuals under age 65 with disabilities.**
Section VI.

COMPARING THE COST OF DIFFERENT STRUCTURAL OPTIONS BY FINANCING SOURCE
While our discussion so far has focused on choices in program design, what likely looms largest for policymakers is the question of cost. That is, how much will it cost to finance a program, and what will this cost mean for those required to contribute to it? To answer these questions, we engaged the Actuarial Research Corporation to estimate what it might cost to pay for some illustrative programs of different types and ensure their fiscal solvency for a 75-year period, based on current knowledge of service utilization, the tax base, and expected demographic trends. To facilitate comparisons across major program types (e.g., front-end coverage, back-end coverage, etc.), we held constant many other program parameters (such as the structure and amount of the daily benefit and the benefit eligibility criteria). The estimates are expected to cover all benefit payments and expenses over the 75-year period under PAYGO financing. The programs are modeled as if they will be implemented nationally; however, a state program might cost more or less than the national estimate because of demographic and economic factors specific to the state.

In Table 3 we show the tax rate on workers required for three program structures, each of which reimburses the costs of covered services up to a daily benefit of $100 and has the same benefit eligibility criteria (the same required level of functional or cognitive impairment). The Washington Front-End Plan pays benefits up to a total amount of $36,500 (whether claimed all during one year or over a beneficiary’s lifetime). What we call the “Home Health Program” pays benefits to participants who meet eligibility thresholds but continue to live in the community (not a facility such as a nursing home). For this plan we model benefits payable over three different time periods: 365 days of services ($36,500 maximum), 730 days of services ($73,000 maximum), and an unlimited duration or dollar amount of benefits. The Cohen-Feder Catastrophic or Back-end Plan pays benefits only after an individual has satisfied the benefit eligibility criteria for two years. Due to their vesting requirements, the Washington and Cohen-Feder models collect income for a period of time before any benefits are paid out and so have a degree of prefunding.

The tax rate that would be charged for each program is estimated for four different tax bases: (1) on the Social Security tax base (earnings up to an annual cap); (2) on the federal income tax base (income with no cap); (3) on the combined Medicare payroll (earnings without a cap) and Additional Medicare Tax on high earners (on income over $200,000 single/$250,000 married) tax bases; and (4) on the combined Medicare payroll, Additional Medicare Tax on high earners, and Medicare Net Investment Income Tax (paid on certain investment income by high earners) tax bases.

What likely looms largest for policymakers is the question of cost. That is, how much will it cost to finance a program, and what will this cost mean for those required to contribute to it?

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TABLE 3: Tax Rates Required to Fund Some LTSS Programs, for Different Tax Bases
75-Year Rates Based on a $100 Daily Benefit*

<table>
<thead>
<tr>
<th>LTSS Program</th>
<th>Social Security Payroll Tax Rate</th>
<th>Income Tax Rate</th>
<th>Medicare Tax (if payroll tax only)</th>
<th>Medicare Tax (if payroll &amp; investment income tax)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Payroll tax rate</td>
<td>Additional rate on earnings above $200k/$250k</td>
</tr>
<tr>
<td>Washington Front-End</td>
<td>0.75%</td>
<td>0.58%</td>
<td>0.59%</td>
<td>0.18%</td>
</tr>
<tr>
<td>Home Health, $36,500 Benefit Max</td>
<td>1.08%</td>
<td>0.83%</td>
<td>0.85%</td>
<td>0.26%</td>
</tr>
<tr>
<td>Home Health, $73,000 Benefit Max</td>
<td>1.73%</td>
<td>1.33%</td>
<td>1.37%</td>
<td>0.42%</td>
</tr>
<tr>
<td>Home Health, Unlimited Benefit Max</td>
<td>4.03%</td>
<td>3.11%</td>
<td>3.19%</td>
<td>0.99%</td>
</tr>
<tr>
<td>Cohen-Feder Catastrophic</td>
<td>0.74%</td>
<td>0.57%</td>
<td>0.58%</td>
<td>0.18%</td>
</tr>
</tbody>
</table>


* The tax rate needed to assure fiscal solvency for a 75-year duration, that is, a projection period from 2018 to 2092, is calculated so that the present value of income (taxes) is sufficient to cover the expected benefits and expenses.

The Washington State and Cohen-Feder plans have very similar costs, and the required tax rates are nearly the same across the different tax bases. However, although they both pay a $100 daily benefit (reimbursement for covered service expenses up to $100 per day), the average total benefit received under the front-end Washington plan is less than under the back-end Cohen-Feder plan, but the Washington plan pays benefits to more individuals. The Home Health Program is more expensive, because it is PAYGO covering those who are currently disabled, and the difference in cost is of course greater for versions that pay benefits for a longer period.

In thinking through program choices, policymakers may have in mind a certain level
of taxation that they believe is acceptable and politically feasible. It may be helpful to compare these three programs by assuming the same tax rate across all programs and estimating the daily benefit amount that this rate could sustain. Figures 9 through 11 show the estimates of daily benefit amounts that could be supported by each program under a 0.50%, 0.75%, and 1.00% tax rate across each of the tax base options.

As shown in these figures, across all tax rate levels modeled, the Washington front-end and the Cohen-Feder catastrophic back-end programs support higher daily benefits over the 75-year projection period for a given tax rate, although they will also provide fewer person-days of benefits compared to the other programs. Moreover, the analysis shows that, on average, the income and Medicare payroll tax bases yield greater revenues for the same tax percentage than do the other potential tax bases.
SECTION VI. COMPARING THE COST OF DIFFERENT STRUCTURAL OPTIONS BY FINANCING SOURCE

**Figure 9: Daily Benefit for a 0.50% Tax Rate by Financing Source and Program Type**


Note: Medicare Payroll and Payroll + NIIT tax rates are set at 0.5% for the base payroll tax. High earnings and NIIT are set relative to the base payroll tax.

**Figure 10: Daily Benefit for a 0.75% Tax Rate by Financing Source and Program Type**


Note: Medicare Payroll and Payroll + NIIT tax rates are set at 0.5% for the base payroll tax. High earnings and NIIT are set relative to the base payroll tax.

**Figure 11: Daily Benefit for a 1.00% Tax Rate by Financing Source and Program Type**


Note: Medicare Payroll and Payroll + NIIT tax rates are set at 0.5% for the base payroll tax. High earnings and NIIT are set relative to the base payroll tax.
Section VII.

INTEGRATION WITH CURRENT LTSS PAYMENT AND DELIVERY SYSTEMS
States that establish a new LTSS program will need to make decisions about the integration of the program with other payers and benefits, as discussed in this section.

**Coordination of Benefits with Other Payers**

One key issue is who will be the primary and who will be the secondary payer. (The secondary payer pays benefits only for services not covered by the primary payer.) By law, Medicaid is the payer of last resort for its beneficiaries, so Medicaid would be the secondary payer for any LTSS services also covered by a new state program. Regarding private long-term care insurance policies, they, too, include a coordination of benefits provision designed to prevent duplication of coverage and overpayment (that is, a beneficiary receiving benefits from two payers for the same service). States will need to determine whether there should be a coordination of benefits provision in the new LTSS program, and if so, how it should be structured.

**Federal Medicaid Funding Issues**

A new program should be structured so that the state will not lose federal Medicaid matching dollars. In one approach, the new program could be designed to cover LTSS services or populations not (or not fully) covered by the state’s Medicaid program. For instance, many state Medicaid programs do not fully cover home-and-community-based services (either throughout the state or in some areas), and a new program could emphasize filling this gap, thereby complementing Medicaid. The unsuccessful Maine Universal Home Care ballot initiative, for example, authorized the Board creating the program to “design the program to reduce the amount of unmet need and to supplement and not supplant existing programs.”

Alternatively, states could seek a federal waiver allowing the new program to operate as the secondary payer to Medicaid. However, it is unclear whether such a waiver would conform with Medicaid’s Third-Party Liability regulations. Moreover, such a provision

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64 Code of Federal Regulations, Title 42 Public Health, https://www.ecfr.gov/cgi-bin/text-idx?SID=25d5f81f5390085e084f2454df1ef87d&mc=true&node=sp42.4.433.d&rgn=div6#se42.4.433_1140.

65 Private insurers can make coverage changes to existing LTCI policies to accommodate a new state LTSS program and avoid duplication of benefits if the changes favor the policyholder, but not if they do not. Companies are likely to make such changes. In the future, private policies that seek to coordinate with an LTSS social insurance program or to fill gaps in it will have to define which payer is primary and which is secondary.


67 It is unclear whether such a waiver could or would be approved. Medicaid’s Third-Party Liability regulations state that they are implementing Sections “1902(a)(25), 1902(a)(45), 1903(d)(2), 1903(o), 1903(p), and 1912” of the Social Security Act. The Section 1115 waiver authority is only valid for items in Section 1902. In theory, anything flowing from Sections 1903 and 1912 cannot be waived, but 1902(a)(25) and (45) could be waived for a demonstration that promotes the objectives of Medicaid and is budget-neutral for the federal government. A state seeking such a waiver could argue that the substantive requirement is really in Section 1902 (not in 1903 and 1912), which can be waived. (Government Publishing Office, Electronic Code of Federal Regulations, December 20, 2018, https://www.ecfr.gov/cgi-bin/text-idx?SID=25d5f81f5390085e084f2454df1ef87d&mc=true&node=sp42.4.433.d&rgn=div6.)
would need to be structured in a way that required benefit coordination with Medicaid only for beneficiaries already on Medicaid, rather than requiring all new program beneficiaries to prove that they are not eligible for Medicaid, which would place a heavy bureaucratic burden on the new program.

Finally, states could seek a waiver to retain projected federal matching dollars as some state spending on LTSS shifts from Medicaid to the new program, on the grounds that the new program promotes the objectives of Medicaid and would be budget-neutral for the federal government. With such a rationale, Massachusetts was able to secure a waiver in the late 1990s and has renewed that waiver twice since then. Washington State’s recently enacted Long-Term Care Trust Act instructs its Department of Social and Health Services state to request any necessary waivers in this regard.

Another issue: States contract with private-sector health plans to provide managed LTSS to their Medicaid populations. If some beneficiaries of the new LTSS program are on Medicaid and enrolled in one of these private plans, will the LTSS program pay their benefits directly to the plan? If so, there is a risk of losing federal Medicaid matching dollars. Here, too, a waiver may be necessary.

Are Program Benefits Income?

Another question: Would benefits paid by a new LTSS program be considered income for the purpose of Medicaid eligibility? Some sources of income are exempt for eligibility purposes, and a state could seek a waiver to exempt the new program’s benefits. States will also want to seek clarification from tax experts on whether benefits paid by the new LTSS program would, like most private LTCI benefits.

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68 Ibid.


70 Another issue to be resolved will be whether benefits paid by the program are considered income for the purpose of SSI eligibility.
benefits, be considered tax-qualified, and so not treated as taxable income.\textsuperscript{71}

Policymakers are looking for ways to contain health care spending growth, and there is a growing body of evidence that access to LTSS and integration and coordination of LTSS with medical care can both improve the quality of care and significantly reduce care costs, especially for high-need, high-cost individuals (with multiple chronic health conditions and functional limitations). For instance, in coordinated systems of integrated care, such as the Minnesota Senior Health Option (MSHO) for individuals dually eligible for Medicare and Medicaid (“dual eligibles”), those living in both nursing homes and the community had fewer hospital stays and fewer preventable hospitalizations and emergency room visits.\textsuperscript{72} Similarly, dual eligibles in Massachusetts’ Senior Care Options program experienced fewer hospital days and fewer nursing home placements than comparable dual eligibles in a fee-for-service environment.\textsuperscript{73} Enrollees in the Program of All-Inclusive Care for the Elderly (PACE)—which provides comprehensive preventive, primary, acute, and long-term care and social services to adults 55 or older with insurance through Medicare and/or Medicaid who have chronic conditions and functional and/or cognitive impairments—experienced fewer hospitalizations but more nursing home admissions.\textsuperscript{74} Other efforts at acute and long-term care integration are underway across the country.\textsuperscript{75} States implementing a new LTSS social insurance program should consider how the new LTSS benefit could be integrated into their existing LTSS—and acute care—delivery systems, as a way to both hold down costs and improve the care and quality of life of state residents.

\textbf{There is a growing body of evidence that access to LTSS and integration and coordination of LTSS with medical care can both improve the quality of care and significantly reduce care costs, especially for high-need, high-cost individuals.}

\textsuperscript{71} The basic question would be whether benefits of the new LTSS program pay for “qualified long-term care services” as defined by the IRS, and whether other requirements for tax-qualified status are met by the program. A ruling from the IRS may be needed, although current language allows for a “state-maintained plan” to receive tax-qualified status. While this was intended for state-provided long-term care coverage paid from individual premium contributions (e.g., the CalPERS Long Term Care Program), it is useful to note that this reference to a state-maintained plan currently exists within the IRS ruling for tax qualified long-term care.


As states introduce a new LTSS social insurance program, they should be mindful of how such a program relates to existing public and private LTSS and health insurance and delivery systems. The landscape of health and long-term care integration is undergoing rapid change, and an LTSS social insurance program should be designed in a manner that can easily evolve with that transformation. As a state proceeds to adopt a new program, it should seek advice from LTSS experts, experts in Medicaid law, managed LTSS plans, and state and federal administrators on best practices for integrating new LTSS benefits with the existing health and long-term care infrastructure.

As a state proceeds to adopt a new program, it should seek advice from LTSS experts, experts in Medicaid law, managed LTSS plans, and state and federal administrators on best practices for integrating new LTSS benefits with the existing health and long-term care infrastructure.
Section VIII.

IMPLEMENTATION CONSIDERATIONS
Pre-Implementation Analyses

There are a number of analyses states will want to consider before program implementation, to prepare for an appropriate and successful program launch. Two of the most important are the following:

■ **Build or buy?** One of the first decisions a state must make is whether it will build the capabilities it needs to run the entire program itself or contract out (through competitive bidding) some program components to one or more third-party entities with expertise. States already face a similar choice for state employee health insurance, managed LTSS, and other programs. A state can begin by assessing the capabilities of existing state systems and programs to accommodate required program functions (discussed below). A state needs to determine whether these capabilities currently exist in a single entity or in several entities with a well-established record of working together. The more closely aligned current programs and department functions are with the new program’s requirements, the better able a state will be to implement the program on its own. If the state has a logical and strategically identified implementation leader, but lacks an obvious supporting infrastructure, an outsource approach could be a viable alternative.

■ **Provider adequacy.** While providing funding to consumers to help them pay for LTSS is very important, if sufficient numbers and types of LTSS providers are not available and accessible, consumers will still find it difficult to obtain the care they need. States may need to address problems in their service infrastructure so that when program monies are infused into the system, the providers will be in place and prepared to meet program objectives. For example, if an expanded program of LTSS coverage cannot be handled by the current care workforce, perhaps the new initiative could include a component supporting incentives, training, and certification to expand the workforce. A state might also forgive student loans for those engaged in care or training. And recent studies have shown that even small increases in the minimum wage can attract more workers into the LTSS workforce. In seeking to identify systems capacity and access issues, specific concerns regarding the needs of family caregivers, workforce challenges, and more, state policymakers could start by reviewing AARP’s Long-Term Services and Supports State Scorecard, which provides detailed ratings and rankings for each state across a wide variety of domains affecting the service delivery system.

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Framework for Implementation

Regardless of the program structure adopted, there is a series of implementation activities that will be necessary to ensure program success. The primary implementation activities include:

- Program startup
- Program administration
- Program monitoring, evaluation and modification

Program Startup

To help guide program startup activities, a state may consider the creation of a temporary or permanent entity (e.g., Implementation Oversight Council) that coordinates program implementation over a multi-year period. That entity might consist of all the state agencies involved in implementation and actuarial and insurance experts, as well as stakeholders, such as representatives from provider and consumer groups. Some of the primary startup activities are the following:

- Raising awareness about the program among consumers, employers, LTSS providers, and other stakeholders. Stakeholders will need to be educated about what the program means for them—both what they have to “give” and what they are likely to “receive.” It is important to build public understanding of how the program works, who will benefit, under what circumstances benefits will be paid, what is and is not covered, how benefits will be provided, how the program is funded, and any other issues that stakeholders or the public might have concerns about.

Indeed, stakeholder input and support are critical as early as the program design phase. To obtain broad political support, the program must address the needs and wants of stakeholders while at the same time maintaining affordability and program feasibility.

- Enrollment. For the types of programs discussed in this report, the presumption is that enrollment is automatic for those
who meet eligibility criteria. Thus, there needs to be a well-defined process for verifying that these criteria have been met. Also, there must be clear ways to communicate to individuals about their program status, and to make information accessible and accurate when an individual needs benefits. Importantly, the state needs to decide which existing agencies will handle which of these functions, or whether a separate state entity needs to be created to administer them, or whether some functions should be contracted out.

It is important to build public understanding of how the program works, who will benefit, and many other matters.

**Provider credentialing.** If the program reimburses LTSS providers for services rendered to participants, providers must meet certain requirements (e.g., licensure, capacity, staffing, and others) to be reimbursed. These requirements must be clearly stipulated. A program may credential providers in advance—that is, in order to be admitted as participants in the program providers must show that they meet these standards—or the program may verify that providers meet the standards only at the time they submit a claim. Credentialing in advance places a greater burden on program administrators and providers. It may also limit the providers from which consumers can choose. On the other hand, if credentialing only occurs at the time of claim, the burden falls more on consumers; they must understand the requirements providers must meet, because if they use a provider that is not eligible, the program will not pay reimbursement. In contrast, if the program simply pays participants a cash benefit, credentialing may not be required. However, even in this case there may be a desire to provide guidance to consumers about which providers may be preferred or most appropriate to meet various care needs.

**Program documents and contracts** must be developed to ensure transparency and program controls. Approaches can vary, but the program may have a coverage agreement or program explanation document; this identifies the terms of coverage to be provided to beneficiaries and specifies what constitutes a covered service, the duration of coverage, and the conditions under which benefit eligibility will be re-assessed or coverage will end. This coverage document would also set forth the terms and conditions under which an individual would no longer be eligible to participate in the program (e.g., leaving the state for a certain number of years) and how they could re-enter the program if eligibility is lost. If participating providers are under contract to the program, provider contracts would need to be developed, along with a process for reviewing, renewing, modifying, or discontinuing them. If outside vendors will be used for program functions, requests for proposals (RFPs) need to be developed, issued, and evaluated. Once selections are made, vendor contracts need to be developed.
Program Administration

The critical components associated with administering a social insurance program for LTSS likely do not differ from those currently performed by private long-term care insurance companies. A brief description of key administration functions includes:

- **Provider/service verification.** A program that reimburses LTSS providers for services would require state vetting of providers to safeguard program integrity. A program that pays a cash benefit to participants would require little or no provider credentialing, but given the complexities of the LTSS service system, a state may want to consider making care coordination and counseling services available. If benefits are paid to family caregivers, a state may want to require some minimal level of training and a program provider ID in order to ensure a minimum level of quality. Overall, a program will need to balance affordable care and provider choice with consumer safety and quality assurance.

- **Enrollment processing** includes new enrollments, disenrollments, and re-enrollments (in accordance with the rules of the program regarding maintaining coverage, portability when leaving the state, and conditions that cause enrollment eligibility to end or be reinstated). Processing new enrollments means ensuring that consumers satisfy requirements for participation in the program, both at the outset and over time.

- **Tax/premium collection and management** encompasses collecting revenues and, for a prefunded program, establishing and managing the dedicated LTSS fund. Actuarial expertise is needed (and may be obtained from a vendor) to oversee claim and investment activity, monitor the adequacy of the fund, and
identify actions needed to maintain the health of the fund. A predetermined schedule of financial performance should be established so that any adjustments to contributions or benefit levels required to ensure program sustainability can be made in a timely manner.

- **Benefit eligibility determination.** Participants applying for benefits must be assessed to determine whether they meet the program's benefit eligibility requirements, and there must be a workforce that is trained to equitably and objectively make this determination. States will be able to rely on the HIPAA criteria for functional and cognitive loss, a proven set of assessment tools and technologies, and trained personnel familiar with the use of these tools. A set of issue papers published by the SCAN Foundation in 2011 to assist the U.S. Department of Health and Human Services in implementing the Community Living Assistance Services and Supports (CLASS) Act provide helpful guidance for states in this regard. In addition to initial assessment, there must be protocols for timely reassessment of beneficiaries who are likely to improve. A reassessment timeframe is typically established at the time of the initial claim, based on the nature of the underlying condition and the likelihood of recovery or change. Finally, a transparent and easily understood appeals process needs to be defined. The National Association of Insurance Commissioners (NAIC) has developed a set of consumer protection standards related to appeals and grievances which offers a strong framework (along with procedures and specific language) for states to consider.79

- **Benefit payment.** If the program reimburses providers for services, systems will be needed to confirm that the provider and the service are eligible for reimbursement under the program, and to verify the amount of expense incurred. For programs with cash benefits, procedures will be needed for making payments to participants or (if assignment of benefits is allowed) directly to providers. For either type of program, there must be a way to confirm that the claimant is benefit-eligible. Explanation of benefits statements help ensure that both program administrators and beneficiaries can keep track of how benefits have been used and the value of remaining benefits.

- **Care coordination** can be helpful to beneficiaries and their families as they navigate a complex LTSS service delivery system. Care coordinators can help beneficiaries determine their care needs, find appropriate providers, identify less costly alternatives to paid care (e.g., home modifications, voluntary community-based services, and others), and train and support family caregivers. A state LTSS program may or may not include care coordination; it may be offered to participants as an option, or it may be mandatory. Mandatory care

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coordination or counseling may be appropriate for cash benefit programs. (This is the approach of the federal “Cash and Counseling” program that is being implemented in 15 states.\(^\text{80}\)) A state may build care coordination capability itself or find a third-party vendor.

- **Program integrity** refers to efforts to monitor and address fraud, waste, and abuse. In a program that reimburses for services, it must be verified that providers are credentialed and that they are actually providing the services for which they bill at the frequency with which they bill. In both reimbursement and cash benefit programs, it must be verified that beneficiaries are in fact eligible for benefits, both initially and over time. This involves determining that a disability exists and that any recovery is reported in a timely manner. The state may also want to ensure that individuals are receiving the care they need (e.g., not having their benefit misappropriated by family or caregivers), and that they are receiving safe and appropriate care.

### Ongoing Monitoring of Sustainability and Program Evaluation

One of the lessons that can be gleaned from the experience of private long-term care insurance companies is that it is extremely challenging to estimate the costs of a specific set of benefits and requirements and the premiums that will be needed to fund it. When a state LTSS program is prefunded and expected to pay benefits well into the future, fiscal sustainability of the program is subject to a variety of trends that are difficult to project. And while this may be less of an issue with a PAYGO approach, there is still enough variability in service use and need to necessitate close monitoring of program revenues (premiums and/or taxes) and expenses (benefit payouts and administration).

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One of the lessons that can be gleaned from the experience of private long-term care insurance companies is that it is extremely challenging to estimate the costs of a specific set of benefits and the premiums that will be needed to fund it.

Consequently, periodic reviews of the program’s financial status should be built into the implementation plan to ensure that, as experience unfolds, policymakers can be apprised of any emerging threats to the program’s long-term financial sustainability. This will also help to build confidence in the program, which is particularly important for ensuring political support over time.

In addition, while it is not essential, it is useful to conduct periodic program evaluations to assess the effectiveness of the program’s design in meeting its stated objectives. For this, the parameters against which the program would be evaluated and the timeframe for evaluation would ideally be established in advance. Prior to program implementation, the systems for collecting the data needed for evaluation and the method of evaluation (e.g., outside contract or other approach) would also need to be identified. Metrics for evaluation might include the number of participants receiving benefits, access to care in the least restrictive setting, timely payment of claims, accuracy of claim payments, satisfaction ratings of consumers and caregivers, measures of quality of home-and community-based care based on measures (developed by the National Quality Forum and others), consumer and provider satisfaction, complaint rates, and others. Areas of program improvement could be identified, with clear plans laid out for implementing program changes based on evaluation results.

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Section IX.

CONCLUSION
With the need for LTSS projected to rise in the coming years and the availability of family caregivers projected to decline, there will be a growing need for formal, paid LTSS. LTSS is expensive, however, and most Americans cannot afford to pay for it out of pocket. This is true not only for people with lifelong LTSS needs, but also for most of those whose needs begin in old age. The majority of people approaching retirement today lack sufficient savings to maintain their standard of living after they quit working, even without accounting for health and LTSS costs.

Even for Americans who can afford to save for LTSS, it would not be efficient to do so. While the risk of needing LTSS is universal, it is also unpredictable, difficult to plan for, expensive, and a threat to retirement security—all characteristics that could be addressed through risk pooling, that is, insurance. Moreover, the primary public payer for LTSS—the Medicaid program—is unlikely to be able to adequately address this growing need. It is a targeted program available only to those who have low income and assets or who spend almost all their assets on care. And for those who meet its strict financial and functional eligibility criteria, Medicaid guarantees access only to nursing home care, not home care. Taken together, these individual and public challenges argue for a new approach to financing and, more specifically, one based on principles of insurance. A universal social insurance program option is a potentially efficient way to mitigate the financial risk associated with LTSS and meet a host of other systemic objectives important to families.

This report has taken a deep dive into what it might mean for a state to introduce a new universal, state-based LTSS social insurance program and the programmatic design features and tradeoffs that must be considered. In 2019, Washington State
enacted one version of such a program: a front-end benefit available shortly after onset of need, providing a fixed amount of support over a beneficiary’s lifetime, funded by a modest employee contribution. To make LTSS more affordable and accessible for their residents, policymakers in other states could follow suit and avail themselves of one of the range of viable structural design and financing options described in this report. Such options could enable those in need of care to remain at home longer and retain their autonomy. They also would give people the peace of mind of knowing that they will have access to the care they need as they age, without burdening their spouse or children. Proactive policies could lessen the financial pressure on state Medicaid budgets, reduce care burdens on families, and also support significant job creation in one of the fastest-growing sectors of the economy—personal care and home health care.

Given the lack of federal action in this area, and the enormous social good that could result from addressing this problem, it is not surprising that a growing number of states are considering such an approach.

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Appendices
**Appendix I**

**ADDITIONAL CONSIDERATIONS IN STRUCTURING AN LTSS PROGRAM**

**Benefit Amount**

How much a program pays in benefits affects both its cost and state residents’ perceptions of its value. LTSS social insurance programs are designed to cover a portion of LTSS costs; there is currently no program in the world that covers all costs for all levels of need. A program pays a daily or weekly benefit; as mentioned, the beneficiary could be paid a flat dollar amount, or their incurred expenses could be reimbursed up to the benefit amount. Either way, the benefit amount can be set to cover roughly a certain portion of either nursing home care or home care. For instance, a program might set a dollar amount that is roughly equal to 50 percent of the average nursing home daily charge in the state. Or the benefit might be based on 75 percent of the average cost of home and community-based services. A benefit intended to cover most of the cost of nursing home care will be higher than one designed to cover most home care costs, since facility costs are usually higher. (Nursing homes provide room and board and round-the-clock care, while many people receive home care for only a few hours a day.)

Of course, beneficiaries’ care costs will vary widely, depending on the type and frequency of the services they receive. One person might need continuous supervision or 24-hour personal care, while another might only require help for an hour or two once or twice a day. Costs will also vary by location within a state. If the program has a relatively low benefit based on home care, it will provide all beneficiaries with some help, but it may cover only a small portion of the expenses of those with the greatest needs (generally those in a facility). However, some argue that the benefit should reflect only LTSS costs, not the room and board costs of facilities. A state could have two benefits, a higher one for those in a facility and a lower one for those being cared for at home. This adds some complexity but enables a program to better meet individual needs.

It must also be considered whether and how benefit amounts will be increased over time to account for the rising costs of care. Benefit amounts could be automatically adjusted by a fixed rate each year. (The annual inflation rate in long-term care costs has historically been around 3 percent.) Alternatively, they could be periodically adjusted to reflect actual increases in LTSS costs, or increases could be

There is currently no program in the world that covers all costs for all levels of need.
linked to the consumer price index, a home care worker wage index, or other indices that are published consistently.

**Benefit Eligibility Triggers**

An LTSS program must identify objective, reliable, and easily measured criteria for when someone qualifies for benefits. There is a prevailing standard of significant LTSS need that meets this test, is required for federally tax-qualified LTCI policies, has been used in the private LTCI market for more than 25 years, and is consistent with HIPAA definitions. Under this standard, individuals qualify for benefits when they need substantial assistance from another person to perform two or more activities of daily living (ADLs) and this is expected to last at least 90 days, or when they have a severe cognitive impairment. However, some state Medicaid programs cover certain home and community-based services for those with a lower level of impairment (such as the inability to perform only one ADL), while others restrict certain LTSS benefits to those meeting a higher standard (such as loss of three or more ADLs or a severe cognitive impairment.)

A program could pay a higher benefit to those with a greater need for care (such as those unable to perform more ADLs). Indeed, most existing LTSS social insurance programs around the world differentiate benefits in some way based on the level of need. Such an approach would provide benefits more in proportion to each beneficiary’s actual need. However, it would necessitate significant investment to achieve the administrative sophistication required to precisely assess each beneficiary’s level of need.

**Comparing Cash Benefits and Service Reimbursement**

In this report we have discussed two models of benefit payment: cash benefits paid to participants who qualify as disabled and reimbursement of incurred expenses for qualified services, up to a preset limit. As shown in the figure below, there is actually a continuum of choices, with many options between the “all cash” and “all service reimbursement” approaches. Private LTCI insurers have paid benefits under all the options shown below, and policymakers can draw on their experience to better understand the implications of these approaches for pricing, program integrity, administrative burden, and consumer flexibility and choice. The cash payment model normally requires only the documentation of a qualifying disability, without regard to services used or expenses incurred. However, variations of the cash model may require beneficiaries to receive counseling on the most appropriate services and providers for their needs, or to receive care in accordance with a plan developed by a care manager. Cash benefits maximize the ability of beneficiaries to choose the services and providers they prefer, including ones without any certification or licensure. However, there are concerns about the safety or appropriateness of care, particularly for beneficiaries who are vulnerable because

There is actually a continuum of choices, with many options between the “all cash” and “all service reimbursement” approaches.
of a cognitive impairment or when there is potential for elder financial abuse. All else being equal, a cash benefit approach also costs more, because benefits are paid for each day of disability, even if services are not needed every day. A cash approach avoids some administrative expenses related to provider credentialing and verification of services delivered, but it incurs other administrative costs associated with frequent and personalized benefit eligibility determinations.

The reimbursement model affords participants less flexibility than the cash model. They cannot spend their benefit money on anything they please—it goes to reimburse allowable expenses. These are defined up front, based on the types of providers and services covered (e.g., nursing home, assisted living facility, home health care agency, home care agency, respite care, hospice care, etc.). However, given that participants typically enroll in an LTSS program years if not decades before they use providers, there is typically some flexibility, allowing reimbursement of care or provider types that emerge after the policy or program begins. For the same reason, participants are not limited to any network of providers—they can usually use any licensed and/or certified provider of a covered type of care. A program may also reimburse care provided by family members or other unpaid caregivers, provided certain conditions are met. There are variations on the reimbursement model, as shown in the figure. A program might reimburse for some services (such as facility care) but pay a cash benefit for others (such as home care or unpaid caregivers).

The reimbursement model has higher administrative costs than the cash model; costs are incurred in confirming that providers and services are eligible, reviewing...
bills, issuing explanations of benefits, and keeping track of accounts. However, access to care notes and service records may limit the expense of determining and recertifying benefit eligibility. On the other hand, benefit costs are lower under the reimbursement model. Paying benefits only on days when expenses are incurred is less costly, and reimbursement also may reduce incentives to utilize the system.
Appendix II

ELIGIBILITY FOR MEDICAID LTSS

As discussed in Section III, to qualify for Medicaid on the basis of disability or age (65 and older), as most of those seeking Medicaid LTSS coverage do, applicants must meet both income and asset (resource) criteria. That is, they cannot have countable assets above a certain very low amount, and they must have low income (or spend most of their income on their care while on Medicaid). These financial eligibility rules vary by state (within federal requirements).

Financial eligibility for Medicaid has traditionally been linked to eligibility for cash assistance (welfare) programs, so that only the very poor can qualify. To qualify for Medicaid based on disability or age, applicants must often meet the standards for receiving Supplemental Security Income (SSI). For 2018, SSI recipients must have monthly countable income at or below $750 for an individual or $1,125 for a couple, about 74 percent of the federal poverty level (FPL). As for assets, applicants typically can have no more than $2,000 in countable resources ($3,000 for a couple). Furthermore, federal law allows states to use even more restrictive financial eligibility criteria, and several states do so.82 On the other hand, some states offer LTSS coverage to those with incomes—and, in some cases, assets—above the SSI thresholds.83 For example, states have the option to expand coverage to individuals who require institutional-level care and have income up to 300 percent of the SSI Federal Benefit Rate (roughly 222 percent of FPL); 44 states have adopted this option.84

Many middle-income people who do not meet these restrictive financial requirements when they first need long-term care nonetheless eventually receive Medicaid LTSS coverage.

It should also be kept in mind that many middle-income people who do not meet these restrictive financial requirements when they first need long-term care

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82 Section 209(b) of the 1972 amendments to the Social Security Act allows states to use their own more restrictive criteria to determine Medicaid eligibility for seniors and people with disabilities, in lieu of granting eligibility for Medicaid coverage to all individuals who qualify for SSI benefits. Eleven states have adopted this waiver option—some using disability criteria, some using financial criteria. (Kaiser Family Foundation, “Total SSI Beneficiaries, 2017,” State Health Facts, 2019, https://www.kff.org/medicaid/state-indicator/total-ssi-beneficiaries/.)


nonetheless eventually receive Medicaid LTSS coverage. They spend their countable assets on care until they have only $2,000 left. (They can keep non-countable assets, which often include their home.) In most states they can qualify even if their income is above the required levels provided that, while on Medicaid, they spend all but a small portion of their income on their care. There are also allowances that preserve income and assets for a Medicaid applicant’s spouse, so that he or she is not left with nothing to live on. As noted previously, some middle-income people may transfer liquid assets to their children well in advance—typically five or more years—of needing LTSS, so that they can qualify for Medicaid when the need arises. However, little is known about the magnitude of this practice and there is little empirical evidence to support the notion that it is widespread.

In addition to satisfying categorical and financial eligibility criteria, those applying for Medicaid LTSS coverage must also meet federal and state functional or clinical eligibility criteria. There is significant variation among state Medicaid programs, particularly with regard to eligibility for home and community-based services (HCBS). Moreover, meeting financial eligibility requirements for Medicaid HCBS coverage is not a guarantee that an individual will be approved to receive coverage. States have a great deal of flexibility in how they structure access to HCBS.

There is significant variation among state Medicaid programs, particularly with regard to eligibility for home and community-based services (HCBS).

Working-age people with disabilities may qualify for Medicaid LTSS coverage through other avenues. For example, if an SSI recipient with a severe impairment re-enters the workforce and their earnings exceed the maximum allowed, federal standards require states to maintain their Medicaid coverage. Adult children with disabilities (over the age of 18) who lose SSI eligibility on becoming eligible for Social Security benefits due to the retirement, death, or disability of their primary caregiver must still be eligible for Medicaid coverage. Federal standards also require states to cover working people with disabilities who are eligible for Medicare Part A (due to receipt of Social Security Disability Insurance benefits) whose earnings are under 200 percent FPL and whose assets are below twice the standard for SSI. In addition to these federally required standards, states have a variety of additional options to expand the reach of Medicaid coverage for people with disabilities.