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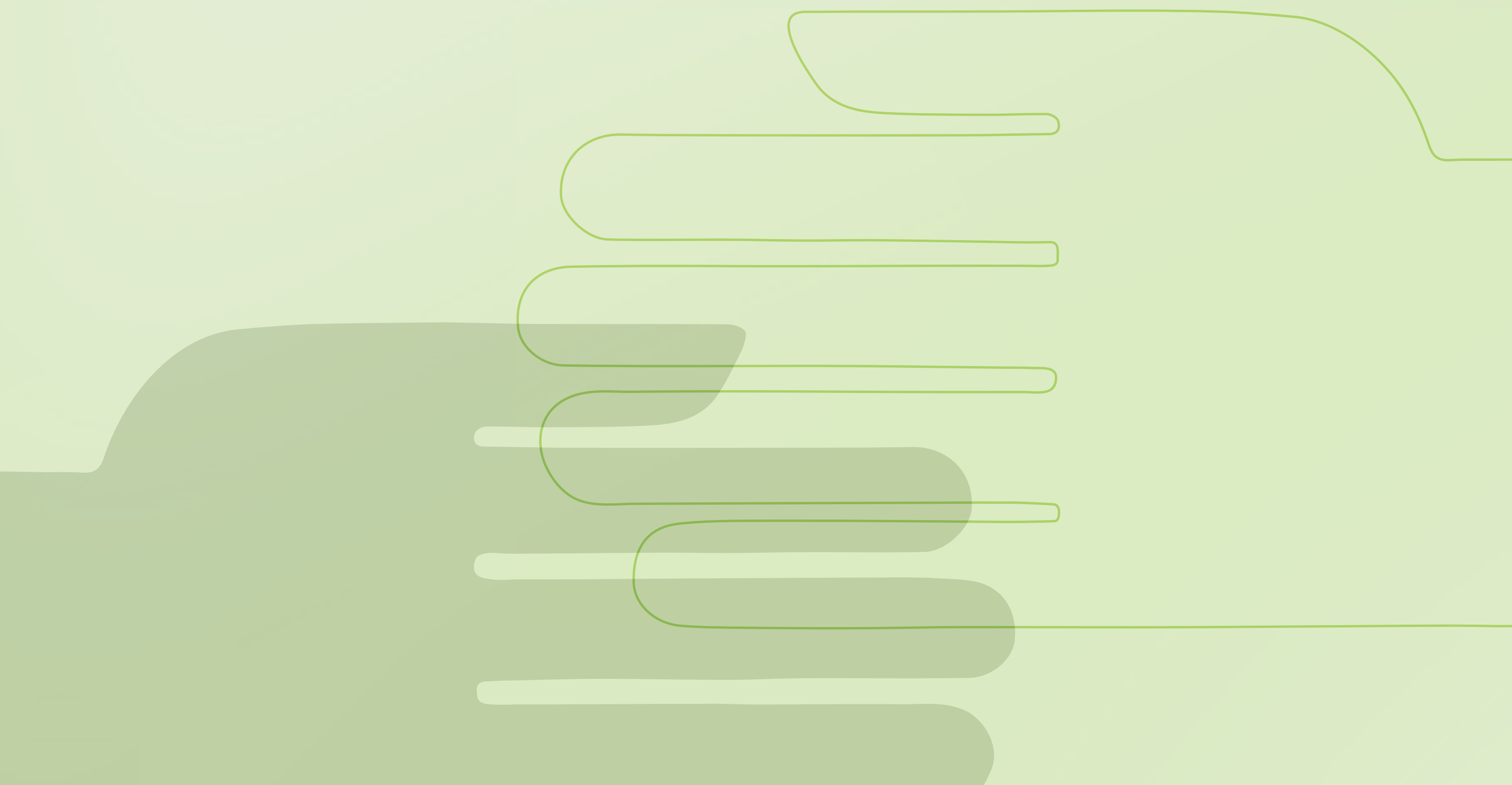
CENTERING EQUITY IN LONG-TERM SERVICES AND SUPPORTS

Navigating Tradeoffs in Building an Equitable LTSS Social Insurance Program

By **Allison Cook, Fatemeh Hosseini,** and **Grant Williams**

MIT CoLab
COMMUNITY INNOVATORS LAB



EXECUTIVE SUMMARY

The American long-term services and supports (LTSS) system exacerbates existing inequities and does not meet the needs of many groups, including direct care workers, older adults, people with disabilities, and family caregivers.

With growing and unsustainable Medicaid budgets and the inaccessibility of private LTSS insurance for all but high earners, some states are exploring establishing LTSS social insurance programs as a more sustainable way to provide coverage to a broader swath of the population.

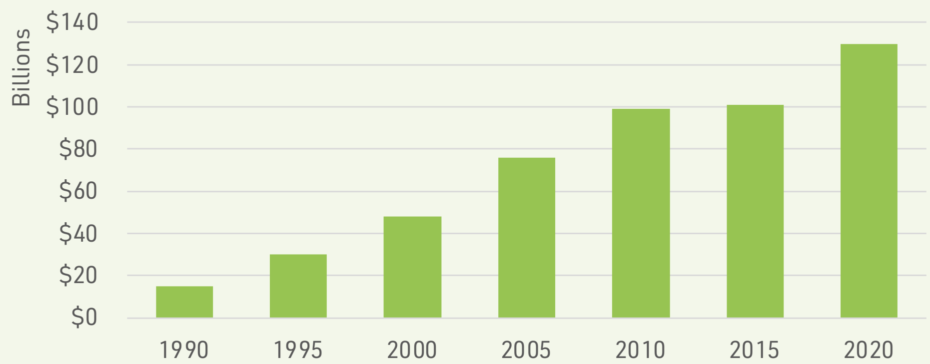
Creating a new LTSS social insurance program is a viable approach for many states, but stakeholders must confront many important tradeoffs as they design this new program. To help with those decisions, they should first identify a guiding framework to navigate decision points, including: the program goal, key political considerations, coordination with the care ecosystem, and workforce objectives. They can then refer to this guiding framework to navigate decision points. This report identifies key tradeoffs associated with an LTSS social insurance program and provides helpful tips and examples around navigating each tradeoff.

NEED FOR LTSS REFORM

The American long-term services and supports (LTSS) system is both inefficient and insufficient, exacerbating current inequities in broader society.

Affluent individuals are able to pay for LTSS out of pocket, while those without means are covered by Medicaid (the largest payer for LTSS[1]). Those who fall in between, though, are often forced to spend their life savings to qualify for Medicaid or rely upon unpaid family caregivers. This can limit the accumulation of generational wealth—an issue that particularly impacts working families and families of color[2]—as well as negatively impact family caregivers' ability to save for their own retirement or advance in the workforce.[3] Plus, the burdens upon family caregivers are unsustainable, often causing them to choose between their own health and financial well-being and supporting the needs of their loved ones. These burdens disproportionately fall upon women and further burden lower-income individuals.[4] And the lack of investment in the workforce means that essential direct care workers, who are primarily women and people of color, struggle to earn a living.[5] Understandably, they are leaving the field in droves, just as the demand is expected to shoot upward due to the aging of the Baby Boomer generation and medical advances that allow younger individuals with disabilities to live longer.[6] Ultimately, the LTSS system exacerbates existing inequities faced by women, people of color, and low- and moderate-income families.

Inflation Adjusted Medicaid LTSS Expenditures 1990-2020



Source: He & Gokhale. 2022. "Projecting Medicaid's Long Term Care Expenditures." Budget Model. Penn Wharton, University of Pennsylvania. https://budgetmodel.wharton.upenn.edu/issues/2022/3/9/projecting-medicaids-long-term-care-expenditures.

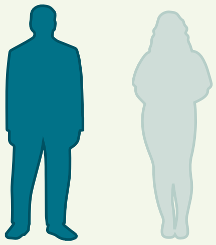
While Medicaid is a vital safety net, it was never designed to be the primary payer for LTSS.

The Medicaid program is struggling with growing LTSS costs, putting pressure on state and federal budgets. And private LTSS insurance has failed to succeed in the U.S., with only about 7% of Americans aged 40+ have private LTSS insurance plans.[7]

High premiums have prevented lower- and middle-class Americans (who would benefit most from this coverage) from accessing it, creating a benefit that primarily helps affluent individuals.[8] The U.S. desperately needs a new system that works better for all individuals and lessens inequities faced by underserved communities.

LTSS social insurance programs can be a financially responsible approach to driving more equitable LTSS access and outcomes. Social insurance programs require most people to pay into the program in order to receive a defined benefit at a later point in time, regardless of their income or assets. By spreading the risk across a larger population, social insurance programs make unpredictable LTSS costs more manageable. This is a model that has been highly successful in other sectors in the U.S., as demonstrated by Social Security, Medicare, and some state paid family and medical leave programs. Importantly, an LTSS social insurance program would not replace Medicaid. But it could lessen the financial pressures upon it, creating opportunities for Medicaid to better meet the needs of underserved populations, such as people (of all ages) with disabilities.

Due to a lack of movement at the federal level, more states are beginning to explore their own LTSS social insurance programs. However, stakeholders—including elected officials, state administrators, advocates, LTSS providers, and unions—can find it challenging to navigate the many tradeoffs associated with structuring a new social insurance program. This report will provide tips on how to navigate decisions around key tradeoffs in order to build a more equitable LTSS financing system.



1 in 2

Americans aged 40+ (incorrectly) expect to rely on Medicare for LTSS coverage

Source: The AP-NORC Center for Public Affairs Research. 2021. "Long-Term Care in America: Americans Want to Age at Home." https://apnorc.org/projects/long-term-care-in-america-americans-want-to-age-at-home.

PART I: KEY CONSIDERATIONS FOR PROGRAM DESIGN

Before diving into decisions around specific tradeoffs, it is helpful for stakeholders to outline factors like the goal of the program, key political considerations, and coordination with the care ecosystem. Coming to agreements concerning these aspects can make challenging determinations around tradeoffs much easier.

Program goal

Determining a driving goal can help provide focus when considering tradeoffs. The goal can shape the population included and the structure of benefits, among other aspects.

SELECT QUESTIONS: Is the primary goal of the program to increase LTSS access for all consumers? To prevent or delay low- and moderate-income individuals from having to rely on Medicaid? To support but not replace family caregivers? To maximize family caregiver workforce participation? To protect generational wealth? To support a robust care infrastructure and fair worker compensation?

EXAMPLE: Japan decided not to offer cash benefits in its LTSS financing program due to concerns about reinforcing gendered patterns of work and care.[9]

Key political considerations

The political environment in each state is unique and can narrow down what is needed for a program to become law. Truly understanding what is politically possible can save stakeholders a lot of time and effort when designing their LTSS social insurance program.

SELECT QUESTIONS: Which populations (e.g., current retirees or individuals with disabilities) must support the program for it to become law? Are there certain taxation strategies or amounts that are politically feasible? Does the program need to be structured in a certain way to get federal waivers that allow the state to keep a portion of Medicaid and/or Medicare savings?

EXAMPLE: The WA Cares Fund was structured around a 0.58% payroll tax because stakeholders and focus groups suggested this was the highest amount they considered politically viable.[10]

Coordination with the care ecosystem

A new LTSS financing program will not operate in a silo. Other programs can make all the difference in ensuring a more equitable LTSS system.

SELECT QUESTIONS: Is there a separate program that will better meet the LTSS needs of certain sub-populations? What programs, like paid leave, are needed to support family caregivers? Is there a role for private long-term care insurance?

EXAMPLE: Germany's LTSS financing system relies on family caregivers taking a significant role in caring for their loved ones, so it offers a cash benefit as well as expanded paid family and medical leave supports for those caregivers.[11]

Investment in the direct care workforce

Any new financing program should incorporate workforce supports into its design and administration. Supporting the workforce has economic benefits for broader society.[12] It is also vital to accomplishing the goal of any new LTSS program, whether to build a more equitable society (most workers are women of color and many are immigrants[13]), support access to LTSS, or assist family caregivers (which will both require addressing the workforce shortage).

SELECT QUESTIONS: Should the program require workers to be paid a living wage? How will the program support training and the development of career ladders? Are there ways to compensate and support family caregivers? Should a separate workforce investment pool be established?

EXAMPLE: New York's Medicaid program provides dedicated funding for Workforce Investment Organizations to offer a variety of types of training to home care workers employed by agencies across the state.[14]

Other Actions That Can Help Stakeholders Determine Acceptable Tradeoffs

PUBLIC EDUCATION
Educate the public about the financing options and seek feedback.

STAKEHOLDER ENGAGEMENT
Create a formal stakeholder engagement strategy that includes the input of consumers, family caregivers, workers, advocates, union leaders, providers, and others.

POLLING
Conduct polls around specific aspects of the program to answer political feasibility questions. Note that this polling may have to correspond with public education.

PART II: LTSS SOCIAL INSURANCE TRADEOFFS

Stakeholders will confront a number of key decision points as they structure a new LTSS social insurance program. While these determinations are often challenging, keeping the goal, political considerations, and other supportive care programs in mind can help ease the burden of this decision-making process and ensure a sustainable program.

FUNDING

ELIGIBILITY

BENEFIT AMOUNT

BENEFIT DESIGN AND DELIVERY

FUNDING

The source and amount of funding for an LTSS social insurance program can determine many other aspects of the program, including the benefits, populations that can be covered, and more. Importantly, decisions on how funding (such as taxes) are collected can also have equity implications.

Creating a sustainable funding structure can be helpful in building and maintaining support for a program. A program is considered sustainable if it is solvent for a 75-year window based on current financial projections.[15]

PREMIUM VS. OTHER FUNDING SOURCES

The most common way to fund a social insurance program is via a payroll premium—a premium based on a percentage of your earnings that's automatically deducted from your wages. This payroll premium can be paid only by employees and/or employers. However, other types of taxes can be utilized, such as an income tax, sales tax, property or estate tax, or another earmarked tax. It should be noted that "sin taxes" (on items such as lottery tickets or alcohol products) disproportionately burden lower-income individuals[16] and can create a less stable funding base as tastes change over time.

But payroll premiums and taxes aren't the only potential sources of funding—premiums on non-working or retired individuals can also be collected, and dedicated program funding can be supplemented by state or local general budget funds.

While having more than one funding source makes the funding more sustainable, it also makes the program more complicated to administer. Stakeholders should consider what types of funding options make the most sense in their state. For example, some states do not collect any income or sales tax, making that route less feasible.[17] Stakeholders could also consider different sources of funding for different populations. For example, benefits for the majority of enrollees can be funded through a payroll premium, but current and near-retirees can receive a lower level of benefits through a premium supplemented by state general funds.

Funding and Equity

Nearly all elements of a new LTSS social insurance program would impact equity, but funding decisions have an especially clear tie. Stakeholders should consider how funding decisions impact lower-income individuals and historically marginalized communities.

A few examples of policies that can create a more equitable LTSS system include:

- Supplementing contributions for lower-income individuals
- Ensuring there are culturally-competent educational materials about contributions and other aspects of LTSS coverage
- Ensuring there are wrap-around supports for lower-income individuals, including paid leave for family caregivers, social security contributions for family caregivers who are unable to work, and more.

FUNDING

STRUCTURE OF FUNDING

A program can be "pre-funded" (an individual's contributions go towards the cost of their future LTSS benefits) or "pay-as-you-go" (an individual's contributions today pay for the program benefits of those currently receiving LTSS). A pre-funded structure allows for a lower contribution rate because funds have time to grow through investment. But the program takes a longer time to get running and typically excludes current retirees. A pay-as-you-go structure, meanwhile, requires a higher contribution rate because there is no time for contributions to grow through investment, but a program can begin immediately.[18]

There is also a set of structural aspects to consider if taxes are being used, such as:

- **The size of the tax base:** The larger the base, the more funding. For example, should a payroll tax only be on employees or should employers also pay a tax?
- **Whether an income or payroll tax is uniform or progressive:** A uniform tax places a higher burden on lower-income individuals, but a progressive tax (that charges a higher percentage to higher-income individuals) is more complicated to administer and, in some states, could be more politically challenging to pass.
- **Whether to subsidize contributions for low-income individuals:** This is another key equity consideration and can be achieved through a progressive tax, tax refund, or exemption from contributions.
- **Whether to cap contributions:** Excluding high earnings from a payroll or income tax would significantly limit the financial health of a social insurance program, due to growing income inequality in the U.S.[19]

EXAMPLES:

Medicare Part A (primarily hospital coverage) is funded through a payroll tax. Medicare Part B (primarily doctor coverage) is funded through premiums paid by enrollees and general federal budget funds.[20]

Japan funds its LTSS social insurance program through a combination of premiums and general funds. The premiums are deducted from an individual's payroll only after age 40, and individuals must still pay the premiums even after they retire.[21]

The **WA Cares Fund** is a mixture of prefunded and pay-as-you go. To earn the full benefit, individuals must pay in for either at least 10 years (without an interruption of more than five years) at any point in their careers, or at least three of the past six years (see eligibility examples for information about partial benefits). This means that full benefits will not be paid out until years after the payroll tax starts to be collected.[22]

ELIGIBILITY

Decisions around who is eligible for an LTSS social insurance program can inform the amount of benefits that can be provided, the pool of people who pay into the program, and the way benefits are delivered. While the most equitable program would be as expansive as possible, that is not always financially feasible.

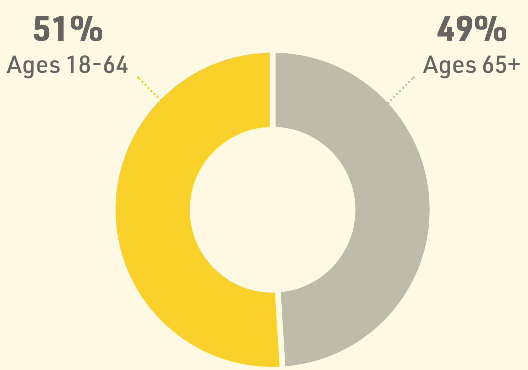
ALL POPULATIONS VS. SUB-POPULATIONS

Stakeholders must decide if they want to include all populations or target the program toward certain sub-populations. One of the most persistent debates is over how a program should provide services for older adults versus younger individuals with disabilities.[23] Older adults tend to require LTSS for a shorter period of time and, on average, the cost of LTSS is less than for younger individuals with disabilities. Further, younger individuals with disabilities may have different needs (such as job supports) than older adults. Other populations with unique needs that should be considered are undocumented immigrants (who often do not qualify for federal programs) and spouses (who may not have their own qualifying contributions).

Going back to the three foundational considerations—the goal of the program, political factors, and coordination with the care ecosystem—can help make this determination. In turn, decisions about included populations can also inform how stakeholders decide time-limited versus comprehensive benefits (see "Benefit Amounts"). It can also be helpful to remember that a program can be expanded to additional populations in the future, as has been done with Medicaid over time.

14.7 million

American adults have independent living difficulties



Source: US Census Bureau. "2021 ACS 1-Year Estimates Subject Tables: S1810 - Disability Characteristics." Accessed November 30, 2022. https://data.census.gov/table?q=disability&tid=ACSST1Y2021.S1810.

ELIGIBILITY

SHORTER VS. LONGER QUALIFICATION PERIOD

Stakeholders must decide how long someone must pay into a program before they qualify for benefits (this is known as the "vesting period"). Current and near-retirees would be most likely to need LTSS in the near-future and are least likely to have time to pay into a social insurance program in order to be eligible for benefits. The goal of the program and political considerations can be especially useful in navigating this determination. Financial modeling can also be useful in narrowing down the feasible vesting periods.

EXAMPLES:

To rein in costs, **Japan** only covers LTSS for certain age-related conditions for those aged 40-64, and a more comprehensive set of LTSS for those over 65. This reduces the individual contributions to the program.[24]

WA decided on a 10-year vesting period* to support the financial sustainability of the program and keep the tax rate low. But a revision to the law permits partial benefits for near-retirees, allowing those born before 1968 to earn 10% of benefits for each year worked.[25]

Germany covers all people over the age of 18, has a short vesting period of two years, and allows individuals to qualify based on the contributions of their spouses or parents—provisions that significantly expand who is eligible for its LTSS program. This makes the program more expensive, but broadens its base of political support.[26]

* To qualify for full lifetime benefits, individuals must contribute for ten years with no break of more than five years. To qualify for full early-access benefits, individuals must contribute for at least three of the past six years. To qualify for partial benefits (at 10% per year of contribution), individuals must have been born before 1968 and work at least 500 hours per year.

BENEFIT AMOUNT

The most fundamental challenge that stakeholders must grapple with when structuring a social insurance program is benefits versus costs. Of course, the most equitable program would have an unlimited amount of benefits and cover everyone, but the cost to do so would be prohibitively high, so choices about the benefit amount must be made.

TIME-LIMITED VS. COMPREHENSIVE

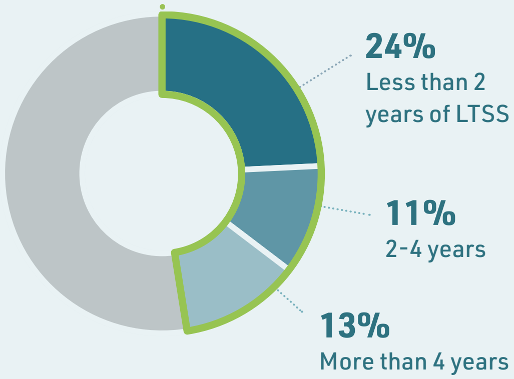
A time-limited benefit, such as one that only provides coverage for one or two years, would make it far easier to build a sustainable program and to project costs. However, a time-limited benefit typically meets the needs of older adults better than younger people with disabilities (who have needs throughout their lives). A comprehensive benefit does not have a time limit. This is more expensive but better meets the needs of individuals, no matter the duration of their LTSS needs.

If stakeholders decide to go with a time-limited benefit, they must consider whether that benefit should be front-end (offered as soon as someone meets the qualification threshold) or back-end (offered after someone has already had LTSS needs for a certain amount of time). Front-end programs provide benefits to a broader swath of the population in exchange for lower individual benefits. Back-end programs meet the needs of a smaller population (those who have longer-term LTSS needs) in exchange for a larger benefit for individuals who are more likely to be facing extremely high LTSS costs.

Duration of LTSS Needs for Older Adults

Note: There is a lack of comparable data for individuals under 65 with LTSS needs.*

48%
Percent of those 65+ who require any LTSS*



* Johnson. 2019. "What is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports?" Urban Institute. https://aspe.hhs.gov/reports/what-lifetime-risk-needing-receiving-long-term-services-supports.

Source: Atkins, Claypool, Hite, & Tobias. 2018. "Data Resources to Determine the LTSS Needs of Working Age Adults with Disabilities." LTQA. http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images/LTQA-Disability-Data-White-Paper---7-30-18.pdf.

BENEFIT AMOUNT

When examining these tradeoffs, it can be useful to look back at the goal of the program and coordination with other care programs. If a time-limited design is selected, it can be helpful to outline what other programs—whether existing or new—could provide for longer-term needs and to conduct financial analysis of the length of coverage that is most feasible while still offering a meaningful benefit.

LIMITED AMOUNT VS. COMPREHENSIVE BENEFITS

Another key determinant of the cost of a social insurance program is the amount of benefits offered to enrollees. Benefits (and, therefore, costs) can be limited in a variety of ways. For example, a service benefit could be limited by: placing an annual or lifetime limit on benefit value, only covering services in specific settings, and placing annual or lifetime limits on the amount of services covered (i.e., hours of home care you can receive, or days in a nursing home), among other factors. It should also be noted that individuals with longer-term LTSS needs, such as younger individuals with disabilities, would find it more difficult to fill the gap if a limited amount of benefits is provided.

Stakeholders should examine how each of these tradeoffs impact consumers' ability to access services, family caregivers' capacity to support their loved ones, and the job quality of direct care workers. It can be helpful to conduct financial modeling to show how each of these iterations impact the overall cost of a program and help to determine which tradeoffs are acceptable.

EXAMPLES:

The **WA Cares Fund** will have a lifetime dollar limit for benefits (of $36,500, adjusted annually for inflation).[27] This helped to keep the cost of the program within the reach of a politically feasible payroll tax of 0.58%.

Plans under consideration in **California** would cap the amount of benefits an individual can claim per month and limit the total number of months an individual can claim benefits.[28]

Germany offers an LTSS social insurance program without time limits, offering a meaningful benefit for both older adults and people with disabilities. Consequently, as demographics have shifted, it has increased funding to cover the cost of care.[29]

BENEFIT DESIGN AND DELIVERY

The way benefits are designed and delivered can be shaped by the population a program is aiming to serve, as well as by the funding of that program. Benefit design and delivery also has equity implications around aspects like how expensive it is for low-income individuals who don't qualify for Medicaid and how easy it is for disadvantaged populations to access the LTSS they need.

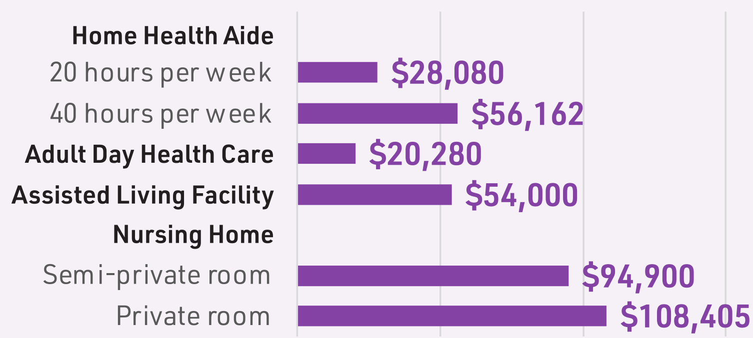
SERVICES VS. CASH

Benefits can be offered in cash (an additional payment made to the individual each month) or in services (reimbursement paid directly to an LTSS provider). A cash benefit provides more flexibility, allowing the individual to use the cash as they see fit. For example, it could be used for home modifications, paying a family caregiver, or contracting for paid LTSS. But a cash benefit could be seen as taxable income that impacts a person's ability to qualify for public support benefits, and it is challenging to ensure these funds go toward the desired purpose. Offering benefits through services provides more standardization of benefits, guaranteeing that funding goes toward providing LTSS. This approach also provides greater control over quality of services. A state could choose to only contract with providers that meet certain quality thresholds. But consumers have less control over how to use their benefit.

Services and cash benefits each have their pros and cons. A cash benefit gives consumers more control but is more expensive because all eligible individuals would receive the full payment they are eligible for every month (as opposed to only receiving the benefit if they utilize the services).[30] On the other hand, a services benefit provides more room for targeted quality investment but is far more complicated to administer, requiring the state or locality to identify and credential providers, set payment rates, and create billing processes. From a workforce equity perspective, the services benefit provides more levers to incentivize investment in the workforce. Stakeholders could choose to offer both cash and services benefits (see Germany example, below). This would allow enrollees to decide which benefit is the best fit for them, though that would add to the complexity of the program.

Average Annual Cost of Long-Term Services and Supports (2021)

Source: Genworth. "Cost of Care Survey." Accessed November 30, 2022 at https://www.genworth.com/aging-and-you/finances/cost-of-care.html.



BENEFIT DESIGN AND DELIVERY

ALL LTSS VS. CERTAIN TYPES OF LTSS

An LTSS program with a service benefit could cover all types of LTSS, only home- and community-based services (since that is the preferred setting for most individuals[31]), or only nursing homes (since that is the most expensive setting[32]). It is most helpful for stakeholders to return to the goal of the program and the preferences of the populations served to choose the types of benefits. Stakeholders can also structure benefits in a way to encourage home- and community-based services over institutional settings (such as providing more coverage for home- and community-based services than for nursing homes).

IN-STATE VS. PORTABLE BENEFITS

When establishing any state-based program, stakeholders must decide if the benefits are only provided to those who live in-state, or if they are also available for those who move to another state (referred to as the benefits being "portable"). Only offering benefits to individuals who remain in-state limits the cost of the program. On the other hand, it may create opposition, as people don't want to pay into a program that they won't benefit from if, for example, they retire out-of-state. The political considerations, along with actuarial projections, can be especially useful in navigating this determination.

EXAMPLES:

Germany provides the option of receiving its LTSS benefit through services or through cash, though the cash benefit is lower than the services benefit. It also does not cover room and board in a nursing home, incentivizing HCBS. However, the utilization of the cash benefit has led to the rise of a subset of temporary migrant home care workers who are paid substandard wages and benefits.[33]

The **WA Cares Fund** will provide a service benefit that covers both nursing homes and HCBS. It also amended the law to offer workers who live out-of-state the option of applying for an exemption because the benefits are only available to state residents.[34]

CONCLUSION

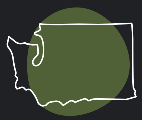
Older adults, people with disabilities, family caregivers, and LTSS workers are all suffering because the U.S. hasn't established a thoughtful, equitable LTSS financing system.

In the absence of federal action, some states are beginning to explore creating their own LTSS financing programs, with social insurance emerging as the primary model they are considering. An LTSS social insurance program requires stakeholders to determine acceptable tradeoffs. While making these decisions is not easy, examining tradeoffs is the first step in building a stronger, more inclusive, and more sustainable LTSS financing solutions.

Bringing together a key group of stakeholders and providing opportunities for public input (through polls, focus groups, and other opportunities for public comment) can provide a space to hash out many of the tradeoffs involved in building a new LTSS program. This group of stakeholders can also create a base of support for a new LTSS social insurance program, making it easier to get a new law passed. In the end, this work will enable states to build more equitable LTSS systems, which can catalyze movement in other states and at a national level.

APPENDIX

Actuarial Studies of LTSS Social Insurance Programs in the U.S.



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THE COMMUNITY INNOVATORS LAB (COLAB) is a center for planning and development within the MIT Department of Urban Studies and Planning (DUSP). CoLab facilitates the interchange of knowledge and resources between MIT and community organizations. We engage students to be practitioners of this approach to community change and sustainability.

THE MEL KING COMMUNITY FELLOWS PROGRAM is carried out by the Just Urban Economies program within CoLab, which seeks to accelerate social innovation in and from marginalized communities in the United States. The program is dedicated to the legacy of Mel King, a still-active champion of cities and the communities they comprise. The fellowship program builds on a 40-year-old tradition of bridging practice-based knowledge and academic research. Mel King Fellows are recognized leaders in communities across the country and have experience in a range of social justice pursuits.

Department Of Urban Studies And Planning
Massachusetts Institute Of Technology
Building/Room 9-238
77 Massachusetts Avenue
Cambridge, MA 02139

Phone: 617-253-3216
Fax: 617-258-6515
colab.mit.edu
colab-info@mit.edu
@MITCoLab

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