



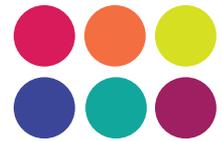
Learning from New State Initiatives in Financing Long-Term Services and Supports

Executive Summary

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The LeadingAge LTSS Center @UMass Boston conducts research to help our nation address the challenges and seize the opportunities associated with our nation's growing older adult demographic group. The LTSS Center combines the resources of a major research university with the expertise and experience of applied researchers working with providers of long-term services and supports (LTSS). This joint venture of **LeadingAge** – a national organization representing 6,000 non-profit aging services providers – and the University of Massachusetts, Boston translates research into policy and practice to improve quality of care and quality of life for the most vulnerable older Americans. As an independent entity, the LTSS Center conducts applied research for the benefit of government agencies and other policymakers, providers and the general public. It builds on UMass Boston's partnership with Community Catalyst, a national consumer health advocacy organization. For more information visit www.ltsscenter.org.

The Center for Consumer Engagement in Health Innovation (CCEHI) at Community Catalyst is a hub devoted to teaching, learning and sharing knowledge to bring the consumer experience to the forefront of health innovation in order to deliver better care, better value and better health for every community, particularly vulnerable and historically underserved populations. The Center engages in investments in state and local advocacy, leadership development, research and evaluation, and consultative services to delivery systems and health plans. For more information, visit healthinnovation.org. Follow us on Twitter @CCEHI.

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Introduction

For more than four decades, individuals, families, and state and federal policymakers have been grappling with one of the largest challenges facing people as they age: how to pay for long-term services and supports (LTSS), if and when these needs arise. Of the adult population reaching age 65, 50% will have significant LTSS needs; and for those who need to pay for care, average costs can exceed \$250,000.¹ Yet Americans are woefully unprepared to pay for their own care, should they need it.² The capacity of family caregivers – who provide the bulk of care for individuals needing LTSS – is diminishing;^{3,4} private long-term care insurance is out of the financial reach of most middle-income Americans;⁵ and the largest public payer of care, the Medicaid program, which comprises a sizeable and growing share of state Medicaid budgets, is under severe stress.⁶ The resulting lack of preparation will only worsen in light of the increasing health demands brought on by COVID-19, as well as the economic upheaval resulting from the pandemic. The need for solutions to address an inadequately financed and underfunded LTSS service system is critical.

The current approach – based on Medicaid, personal savings, and private insurance – is not meeting the needs of families, providers, nor public payers. Currently, the two primary strategies designed to move the system toward greater insurance coverage are: (1) a federal public insurance approach designed to add social insurance coverage for LTSS to existing health insurance programs offered at the federal level, and; (2) state-based social insurance programs which represent the most recent efforts at reform and for which there is growing interest across multiple states. These state-based efforts are the primary subject of this report.

The purpose of this analysis is to characterize the status of emerging state-based LTSS financing initiatives, using a case-study approach to describe the nature of the reform(s) that six states are pursuing. Based on findings from structured interviews with 42 key stakeholders in these study states, we describe the policy change that was proposed or adopted in each of these states. We also identify the common themes that emerged from key stakeholder interviews and draw out implications and lessons learned that may be helpful to inform policy development at both the state and federal level. We begin by describing prior and current federal initiatives as context for understanding why states are motivated to develop state-based solutions. The lack of a federal response to addressing the LTSS financing challenge was cited by many stakeholders as one of the important reasons for state action.

Federal LTSS Financing Reform Efforts

Over more than 30 years, federal policymakers have put forward a variety of public insurance plans for LTSS. Most proposals – the 1988 LongTerm Care (LTC) Assistance Act, the 1988 Life-Care LTC Protection Acts, the 1990 Pepper recommendations, and the 1993 Clinton Health Security Act – never made it out of Congress.^{7,8,9,10} One exception, the Community Living Assistance Services and Supports (CLASS) program was passed as part of the Affordable Care Act, but was repealed in 2013, in part because the program, as designed it was deemed financially unsustainable.^{11,12}

More recently, in 2018 Congress passed the Bipartisan Budget Act, which included the Chronic Care Act (CCA) that expanded supplemental benefits to meet the needs of chronically ill Medicare Advantage (MA) beneficiaries and allows plans to provide benefits that are not necessarily health-related and can cover certain LTSS benefits.¹³ The presumptive 2020 Democratic presidential nominee, Joseph Biden, has put forward plans that build on the current approach to financing LTSS by strengthening and making more flexible the Medicaid program, providing tax incentives for the purchase of private insurance, and giving a tax credit for family caregivers.¹⁴ The Trump administration has focused on reducing Medicaid expenditures and has not developed any proposals directly addressing LTSS financing.¹⁵ Finally, a number of Federal bills have been put forward, all of which attempt to provide mandatory public insurance coverage for LTSS and most of which are based on expanding the Medicare program to cover LTSS (e.g., the Medicare for America Act (H.R. 2452) and the Medicare for All Act (H.R. 1384)).^{16,17} In light of the fiscal strain brought on by the COVID-19 pandemic, as well as uncertainty regarding the upcoming federal election results, it is highly unlikely that these bills will move forward in the immediate future.

State LTSS Financing Reform Initiatives

We summarize below the LTSS finance reform approaches undertaken by each state. While the financing reform activities in these states have recently garnered significant attention, for the most part, the states that are furthest along in their reform efforts build on multi-year tactics. The journey of reform is best described as a “long and winding road” filled with both off-ramps and on-ramps. Hawaii has the longest history at attempting reform, reaching back to the 1980’s. Current reform initiatives in California, Washington and Minnesota date back to 2012-2013 (and earlier when considering efforts in the 1980s and 1990s focused on rebalancing state and Medicaid funds toward home and community-based services). In contrast, Michigan and Maine have only more recently begun the process. A common feature of most of these states is that they have already made significant investments in their LTSS infrastructures.¹⁸



CALIFORNIA

A coalition of stakeholders, under the umbrella of the [California Aging and Disability Alliance \(CADA\)](#), is currently working on a social insurance proposal for LTSS reform. Stakeholders in California cited “a rapidly rising and unsustainable” Medicaid budget as the driving force for reform, along with concern over financial protection for the state’s middle class. In 2017, CADA was formed with anchoring organizations including AARP, LeadingAge, SEIU, UDW/AFSCME, CalPACE, the California Foundation for Independent Living Centers (CFILC) and others. In 2019, CADA successfully secured \$1 million for a [feasibility study](#) exploring a state-based LTSS financing program. Working with an outside actuarial firm, the coalition is presently exploring the pricing implications of a wide variety of program design options.

Also, California Governor Gavin Newsom has authorized a [Master Plan for Aging](#). Among the working groups and committees, the Long-Term Care Subcommittee is studying issues that likely overlap with the analyses CADA is doing. The Master Plan process is thus likely to strengthen and reinforce the goals and directions for LTSS finance reform that CADA is currently pursuing. The LTSS Subcommittee is expected to issue a report and include recommendations to create a public universal LTSS financing benefit. The report was originally planned to be issued in spring 2020, but has been delayed due to the pandemic.



HAWAII

Hawaii does not currently have an LTSS social insurance program, despite repeated advocacy and legislative efforts over three decades that were motivated largely by the desire to address issues related to the challenges of working family caregivers. The reform work in Hawaii has been supported over the years by a loosely aligned coalition comprised of grassroots and cultural organizations, local and community entities, the Office on Aging and both Hawaii-based and mainland academics and policy advocates. Enacted in 2017, the [Kapuna Caregivers](#) Program supports working caregivers by subsidizing paid care for their loved ones. A qualified caregiver for the program must work at least 30 hours per week and also provide direct care to a qualified care recipient – someone age 60 or older, not currently receiving other government program benefits, and not living in a facility – who needs LTSS. As of 2019, the program offered a weekly benefit allowance of up to \$210 paid directly to providers under contract with the program to supply a variety of home and community-based services (e.g., adult day care, meals, transportation, and homemaker and personal care services). The program is administered by the Executive Office on Aging, through the county Area Aging Agencies, which determine benefit eligibility and the services that are provided. Because it is not a social insurance program, the availability of program benefits and the number of individuals receiving benefits are dependent upon the allocation of general revenue funds.



MAINE

Maine's attempt at LTSS financing reform, which ultimately did not succeed, was based on a 2018 ballot initiative to establish a [social insurance program](#) focused exclusively on in-home care. This initiative, led by the [Maine Peoples' Alliance](#), was meant to ease the burden on family caregivers and support the paid caregiving workforce. The program would have provided in-home assistance to all residents aged 65 years or older and to people with disabilities. It would have been funded through a payroll tax on employees and employers, with additional funding from a progressive tax on investment income above the Social Security tax cap. The ballot question was rejected by Maine voters by a vote of 63% to 37%.



MICHIGAN

Michigan, like California, is in the earlier stages of building a coalition and exploring approaches for a social insurance LTSS finance reform solution. Stakeholder opinions in Michigan have not yet coalesced around a single problem definition. Within the last three years, the Legislature has created the Bipartisan Care Caucus to advocate for LTSS care and finance reforms. Since 2017, a broad coalition has been formed including the [Michigan Caring Majority](#) and 20 other organizations representing home care providers, disability rights groups, family caregivers, senior advocacy groups and other providers. [Legislation](#) was introduced in 2017-2018 to require a feasibility study on a variety of LTSS finance and workforce reform proposals, including an actuarial study of a social insurance model. The actuarial modeling mirrors that which was completed for Washington State, namely, analyzing the costs associated with various social insurance program designs while also taking into account the unique characteristics in Michigan and seeking feedback from stakeholder listening sessions and a thorough review of workforce needs in the state.



MINNESOTA

Minnesota's reform efforts are unique in focusing on options to enhance affordable private market solutions for middle-income families. Concern over a burdened Medicaid budget is the key driver of LTSS financing reform efforts in Minnesota, along with concern about providing financial protection for the broad middle class. The state-led "[Own Your Future](#) Advisory Group" has identified two new product designs – a low-cost term life insurance product that converts to long-term care coverage at age 65, and a product that [embeds home and community services](#) and supports in all Medicare supplemental health plans. The State's role with regard to these new product concepts has been to provide funding for actuarial analyses and other feasibility studies, including market research, regulatory analysis and a study of the impact on Medicaid. The state is currently working on research to identify opportunities for, and barriers to, implementation. At the same time, the Governor has appointed a Blue Ribbon Commission to study LTSS finance reforms for Minnesota that go beyond these private options and include exploration of social insurance approaches like state-based back-end catastrophic protection to supplement the more up-front private coverage approaches being considered.



WASHINGTON

Driven by rising Medicaid LTSS costs, the [Washington State LTC Trust Act of 2019](#) made Washington the first state to establish a social insurance program for LTSS. This program emerged from work begun in 2013 by the Joint Legislative Executive Committee and a grassroots organization called [Washingtonians for a Responsible Future](#). It will be available to all employed state residents; it is funded through a mandatory employee payroll tax of 0.58%.

The program reimburses expenses up to \$100 per day (with annual adjustments for inflation) for care provided at home, in the community and in care facilities, up to a lifetime dollar maximum of \$36,500. All workers who contribute to the program become eligible for benefits after an initial vesting period and once they meet eligibility requirements based on functional or cognitive impairments. Eligibility for receiving program benefits mirror those used in the State's Medicaid program. Because the program would cover up to \$36,500 in LTSS costs, residents with more significant LTSS needs will either need to supplement this amount with family care, personal savings, or private long-term care insurance.^a Premium collection is scheduled to begin in 2022; full program implementation in January 2025.

Insights and Common Themes

Despite the different approaches, LTSS environments, and political cultures across the study states, there is a remarkable degree of consensus regarding the factors needed to move forward with a reform initiative. This consensus includes views on the parties that need to be involved in the reform process, the strategies that move efforts forward, the obstacles most likely to be encountered, and how they might best be overcome. This section highlights key insights learned thus far from the 42 stakeholder interviews.

Reform movements advocating for changes in social policy all generally go through a life cycle which is marked by the following progressive stages: emergence, coalescence, bureaucratization, and decline.^{19,20} Across the studied states, most reform activity is situated in the “emergence” and “coalescence” stages. The emergence phase is typically characterized by the recognition among growing numbers of people that there is a specific problem that needs to be addressed due to mounting discontent; in this case, it is with current LTSS financing approaches. During the coalescence stage, multiple stakeholders come together and organize around the issue. They become strategic in their outlook by developing goals and objectives, recruiting members to a broad-coalition, developing plans for legislation and obtaining resources to move their policy agenda forward. The processes and insights of stakeholders that we summarize below adhere closely to one or both of these initial reform stages.

The state coalitions that were furthest along coalesced around shared goals broad enough to have popular acceptance across stakeholders (e.g., relieve pressure on the Medicaid budget and provide

^a The eligibility criteria for receipt of program benefits are not aligned with the criteria typically used by private long-term care insurance companies as outlined in the 1996 Health Insurance Portability and Accountability Act ([HIPAA](#)). This could create certain challenges for individuals who currently have or choose to purchase policies, as it could result in discontinuities in receipt of benefits.

financial protection for the middle class). They also worked hard early on to assure consensus and to stay focused on the definition of the problem to be solved. Simply put, there was a shared understanding that no initiative could solve all facets of the problem. As one member expressed it, *“...consensus flows naturally from a shared sense of urgency. Because the level of desperation is so high on this issue, [members] are willing to come together.”* Also, stakeholders felt that having a new funding source to support the initiative facilitated agreement on high-level goals. As a Washington State coalition member said, *“...new money makes consensus easier because it is not a situation where one stakeholder has to give something up for someone else to get something.”*

Broad and equitable stakeholder involvement is associated with moving initiatives forward. Stakeholders advised including organizations that have strong reach and expertise in messaging on LTSS issues – both to consumers and policymakers: *“Everyone that has a mutual stake and interest in these issues needs to be included.”* Additionally, a diverse set of constituents also creates a more powerful coalition. California’s alliance noted that *“...because we have so many interest groups under a single umbrella organization (California Aging and Disability Alliance, CADA), when ‘we’ speak, our voice is more powerful than any single coalition member and our clout makes it more likely that we are heard.”* Moreover, it makes it much easier for supporters in the legislature to work and coordinate with a single organization, rather than many disparate organizations, all of whom may have different, albeit related agendas.

The Maine initiative illustrates a contrast. While there were likely a number of reasons why it did not succeed, some stakeholders cited the lack of a broad coalition as a contributing factor. They indicated that outcomes may have been different if the alliance had been designed differently and included the full spectrum of aging services and providers. Additionally, there was a sense that had the alliance come forward with a transparent engagement process for developing a proposal rather than putting forward a solution for others to sign on to, there would have been a greater likelihood of success.

Many stakeholders from across the states observed that for a coalition to be effective in moving a reform initiative forward, there needs to be a formal organizational structure, clearly delineated rules, regular meetings, subcommittees, a clear understanding of expectations, and allocated resources – that is, staff time for managing the process. For example, members of CADA shared a “duty of loyalty statement,” such that all documents and discussions are being treated as confidential and when members speak in public on a topic that has been agreed to within the structure of CADA, they understand that they represent CADA, not their respective agencies or organizations.

Stakeholders also felt that the experience of initially focusing on issues that were more conducive to agreement (i.e., defining the major problem to be solved and broad goals and objectives for an initiative) was a critical investment in building a level of trust between members that would pay off when contentious issues regarding the specifics of policy design had to be addressed. The Washington state example above speaks to this point. Even though the Coalition had initially signed off on a program design that met agreed-upon cost criteria – no more than 0.5% added to the payroll tax – one participating stakeholder remained concerned that the proposed tax level would be insufficient. The Coalition was able to obtain additional funding to do further actuarial analysis to find a way to make revisions and agree on a slight increase in the payroll tax to 0.58%. The member’s concern was addressed and the coalition had a stronger understanding of and support for the final legislation. The positive experience of working together over a number of years and the building of trust between the coalition members allowed this to happen.

These states' experiences illustrate that the pathway to LTSS finance reform can span years – even decades. To start with, it takes time to invest in and sustain an effective coalition, and assure that the right people are around the table. It also requires discipline and effort to develop consensus around goals before specific solutions are debated. Data collection and analysis that support needed up-front agreement on the dimensions and magnitude of the problem to be solved, the actuarial work necessary to test the price and policy design tradeoffs of alternative options, and the advocacy and educational component of a public campaign require ongoing patience and commitment.

Many stakeholders discussed the importance of gathering stories from individuals and families about what a reform could mean for them personally, which takes the policy from the abstract realm to the concrete and personal realm. Identifying and building relationships with legislative champions who are committed to seeing the initiative through – even if activities occur over multiple legislative sessions – and to build political support for a program with a highly visible price tag also takes time. Moreover, policy development rarely occurs in a static political environment and political or economic winds can quickly shift, leading to significant delays or requiring flexibility to move quickly when opportunities for progress arise.

Contrary to what one might expect, designing the specific policy solution is not always the most difficult part of the process. In many cases, the analytic work has been done to allow people to quickly evaluate cost and benefit trade-offs, there is already a shared sense among stakeholders of the goals that are most important, and the discussions typically occur within a collective understanding of a cost constraint. For example, in Washington state there was an understanding that whatever reform came about, it had to add no more than roughly 0.5% to the payroll tax. This had a very important impact of concentrating the discussions around desirable solutions within the framework of cost-feasibility. The coalition did not spend a great deal of time on “wish lists”, but rather on the very practical question of what the revenues from a 0.5% tax increase could buy.

In Washington, Maine and Hawaii – where specific programs have been put forward or implemented – stakeholders held that advancing a specific solution represents one of the later steps in the process and embarking on a solution prematurely can lead to failure. As one stakeholder put it, “...start with raw goals and work out a proposal collaboratively rather than going to other stakeholders with a concrete proposal.” A problem cited by stakeholders in Maine was that the solution – a comprehensive home care program financed in a particular way – was identified before a fully inclusive coalition could be formed to agree on a shared objective; in fact, the solution put forward alienated some potentially natural allies who were instead reluctant to join the coalition. A key stakeholder from Maine said that “...we went too fast with the policy” so that certain groups that had concerns with the reform approach (including its cost and how it was designed), did not join in and provide support, even though they acknowledged the need to address many of the problems the reform was trying to solve.

Other stakeholders spoke about the importance of focusing on solutions that are **appropriate** to the politics that are **possible**. More specifically, one stakeholder observed that “...we have been working on these issues forever and [we] realize it's a political problem...While the merits of the technical proposal...are very valid...it's going to take a political solution...to move this through the Legislature.” Most stakeholders had an understanding that the politically feasible solution was preferred to the technically perfect one. In Minnesota, for example, there has been an acknowledgment that “...at the end of the day it was a political decision [guiding the policy proposals that we brought forward]. Because we have a divided government, we felt we had to bring something that could have bipartisan appeal.”

Across these stakeholders it is clear that the precise structure of the reform itself becomes somewhat of a second order issue once the “who” (i.e., who is in the coalition and who are the legislative and administrative champions), the why (i.e., what unites them as the reason for needing the reform), and the “when” (i.e., when is the most politically expedient time to move forward with a reform initiative) are addressed.

The LTSS financing challenges that these and other states are facing are not new. The problems of paying for care, burdens on caregivers, and pressure on state Medicaid budgets have been escalating for decades. The interviews revealed that many of these states have been attempting reform for quite some time. So, we asked stakeholders: why now? What factors in the current environment are enabling these initiatives to finally begin to gain traction? And what changes in the environment moving forward might stall those efforts?

First and foremost, participants felt that their state’s political and financial climate had changed and become more stable and receptive to policy reform. LTSS finance reform loses out when there is a crowded policy agenda. Hawaii’s early attempts at social insurance reform faced this uphill battle several times. For example, after identifying a viable revenue source – the general excise tax – for their modest reform program, a rail project emerged and claimed use of that funding. One stakeholder put it succinctly: *“The policy agenda was already crowded and that tax had already been spoken for.”*

Reform efforts are now rising to the forefront in Minnesota because other issues that had occupied a prominent role on the policy agenda such as health care reform have found some resolution through the Affordable Care Act. Similarly, California stakeholders mentioned having more “bandwidth” to pay attention to LTSS reform now that the state is “out of a constant crisis period” and the change in administration has offered a new opportunity to move the issue forward. Stakeholders in Washington State and in California also felt that having a more favorable financial situation gave policymakers the bandwidth to be open to a new program. As one stakeholder said, *“...I think the tipping point was the improved economy.”*

Another common theme across the states was that those advocating for reform had the burden of proof to both demonstrate the nature and extent of the problem for which a solution is needed and to identify appropriate and feasible reform options. Several states began the reform process by having a legislative bill authorize funding for a study of the issue including the pricing and modeling of public insurance options, an assessment of the feasibility of existing or new private market solutions, or to study state-specific issues such as the caregiver workforce or the needs of family caregivers. Most often conducted by outside third-party experts, the study was typically used to (1) raise awareness among and educate legislators, partner stakeholders and others about the nature and scope of the problem; (2) build support for social insurance reforms by illustrating the flaws of other solutions; (3) provide a framework for more productive discussions on a common factual basis; and, (4) support trust-building and experience working together. One stakeholder observed that such studies can also help build legislative support since *“...every legislator knows the level of need of elders in the community and in their constituency.”*

Conclusion

The conversation on whether and how states can create LTSS finance reforms is likely to continue since the current financing model for LTSS leaves many Americans without sufficient coverage to meet their needs and efforts at the federal level have not been successful to date. The initiatives described here provide examples of the paths states have taken regarding the design (and in some cases) implementation of reform. Through qualitative interviews, we identified a somewhat “natural progression” of steps for state reform. States that are further along in LTSS system development and have a history of investing in social infrastructure are also among the first to move on financing reform. Within these states, there is a broad-based health care advocacy and grassroots infrastructure that has been activated to come together and demand policy change that is heard loudly and clearly by policymakers. Yet moving reforms forward is often opportunistic – it comes down to identifying a “window of political opportunity” and having the program initiative and supporters ready to jump through it with an appropriate solution at the right time.

In short, factors associated with moving reform initiatives forward include: (1) the development of an effective coalition that successfully activates and organizes key stakeholders; (2) deploying multi-faceted strategies and tactics so as to avoid common strategic and tactical pitfalls over what is likely to be a long policy-development process, and; (3) understanding that reforms move forward when there is an understanding that “...the **good** that is possible is better than the **great** that is impossible.”

We recognize that the COVID-19 pandemic is likely to impact current and future LTSS reform efforts. The pandemic is straining state finances and capacity, but it has also led to additional burdens on families and caregivers, potentially adding further impetus to the need for financing reform, whether at the state or federal level. In this context, we hope that this analysis of state efforts will be illuminating and potentially applicable for other states considering LTSS financing initiatives, as well as for federal policymakers.

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