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

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Table of Contents

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. These services help people who need assistance with activities of daily living (ADLs) – such as bathing, dressing, using the toilet, transferring from a bed to a chair, caring for incontinence and feeding themselves – or who require supervision and support due to a cognitive impairment. In 2018, approximately 14 million US adults had LTSS needs. Of the adult population reaching age 65, 50% will have significant LTSS needs and for those who need to pay for care, their projected average cost totals over $250,000.[1] Many Americans are surprised to learn that neither private health insurance nor Medicare pay for LTSS. Most of the LTSS costs that people are projected to pay will be out of their own pockets (53%); this is especially true when it comes to home and community-based care (68%).[2] Yet Americans are woefully unprepared to pay for their own care, should they need it.[3]

At the same time, the capacity of family caregivers – who provide the bulk of care for individuals needing LTSS – is diminishing due to smaller family size, the increasing employment of both spouses, the mobility of adult children, and a growing trend of having to care for both children and adult parents (i.e., "sandwich generation" caregivers).[4-5] Moreover, the ratio of potential family caregivers to those in need of care is declining; between 2015 and 2050, the ratio of the population age 80 and older to those in the caregiving age range (45-64) will go from 3-to-1 to 7-to-1.6 That trend will create an increasingly unsustainable burden for family caregivers who are already taking on more than they can handle.

Private long-term care (LTC) insurance, which very few Americans currently have, does pay for these types of care needs. But only about 7% of adults 50 or older have policies and sales have been declining for roughly two decades.[7-8] Attempts to broaden the private LTC insurance market, including a variety of efforts sponsored by both the federal and state governments[9] have not been sufficient to overcome market obstacles. These obstacles have led to declining sales, tightening of underwriting guidelines and high premiums, all of which limit product access. [10-11] Even those who might be able to afford LTC insurance premiums prioritize more immediate expenses (e.g., student loan debt, mortgage, child care, or college expenses) over protecting against an uncertain and very distant potential liability.[12] Many fail to see the value proposition, even in states that have provided modest tax incentives to encourage the purchase of LTC insurance. The bottom line is that private LTC insurance is now out of the financial reach of most middle-income Americans and for that reason, it is not likely to play a meaningful role in financing LTSS costs in the coming decades.[13–15]

This leaves the Medicaid program to serve as a safety net. Medicaid is the largest public payer of LTSS, and is financed jointly by the federal government and individual states. Medicaid provides coverage of LTSS only after individuals have depleted their own resources in paying for care. Currently, Medicaid pays roughly 57% of LTSS costs, elders and their families pay an additional 23%, other public sources contribute 16%, while private insurance pays less than 5% of the nation's bill.[16] Medicaid ensures access to care once someone spends down their own savings, but it does not provide insurance against LTSS costs. The program does cover nursing home and home and community-based care (HCBS), although there is tremendous heterogeneity both in the HCBS waiting list population and in waiting list policies.[17] Over the past five years there has been significant growth in Medicaid managed LTSS programs

whereby states contract with managed care plans to assume overall responsibility for the LTSS and health needs of their Medicaid population.[18] Again, such an approach may assure that people get services, but only after they have exhausted personal financial resources and fallen below certain income and asset eligibility thresholds.

Many people who need LTSS will never access Medicaid and instead rely on a combination of private savings and (to a lesser extent, private insurance) to pay for care; but this can be a risky strategy because half of working-age households are not able to save enough to maintain their pre-retirement standard of living, much less finance their health and LTSS expenses in retirement. Median retirement savings for Americans between age 55 and 64 is roughly $107,000, which is far less than the average expected LTSS costs for those who have to purchase care.[19]

LTSS already comprises a sizeable and growing share (30-45%) of state Medicaid budgets, which are under severe stress. This will only worsen in light of the increasing health demands brought on by COVID-19 – which disproportionately affects seniors with LTSS needs – 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, and apparent for all to see.[20]

Finding a way to better finance LTSS has been high on the list of national challenges. The fundamental LTSS financing problem on which there is widespread consensus is the absence of an effective comprehensive insurance mechanism to protect people against LTSS costs. LTSS presents exactly the kind of unpredictable, potentially catastrophic risk that insurance (i.e., risk-pooling) is best designed to address. However, agreement on a policy solution has long been hindered by a fundamental philosophical conflict between those who would limit public policy to the promotion of private insurance solutions and those who regard public insurance – whether at the federal or state level – as essential to the assurance of adequate and affordable protection.[21] Additionally, some policymakers advocate a model of a public social insurance program combined with private insurance to fill gaps or complement coverage, similar to the Medicare marketplace.

All of the data suggests that our current approach – based on Medicaid, savings, and private insurance – is not meeting the needs of families, providers, nor public payers. Currently, there are two primary strategies designed to move the system toward greater insurance coverage: (1) a federal public insurance approach which is 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, as well as the nature and evolution of their activities in doing so. Specifically, we describe the policy change that was proposed or adopted in each of these states, and identify the common themes that emerged from key stakeholder interviews across these states and draw out implications and lessons learned that may be helpful to inform policy development at both the state and federal levels.

Before we describe in more detail the method and findings of these case studies, it is helpful to review prior and current federal initiatives in this area to provide a context for understanding why more states

are motivated to develop state-based solutions. Put simply, 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.

Taking a Look at Efforts for Federal LTSS Financing Reform

For more than 30 years, federal policymakers have put forward a variety of public insurance plans for LTSS. Most of these proposals – the 1988 Long-Term 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.[22–25] More recently, the Community Living Assistance Services and Supports (CLASS) program was passed as part of the Affordable Care Act, but was subsequently repealed in 2013.[26] The CLASS program would have created a voluntary public LTC insurance option for employees who would have earned eligibility into the program after paying premiums for five years and who would have worked for at least three of those years. After this vesting period, benefit-eligible participants could begin receiving a small daily cash benefit based on their level of need. The payment would have continued for as long as they continued to meet the disability criteria. The program was repealed in part because participation was voluntary, not subject to medical underwriting, and the benefits were unlimited – a combination that would have led to financial instability and collapse of the program.

More recently, in 2018 Congress passed the Bipartisan Budget Act, which included the Chronic Care Act (CCA). This Act 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 (e.g., in-home meals, home safety devices, medical transportation) and also the scope of primarily health-related services to cover certain LTSS benefits.[27] In 2020, just over 600 plans provided at least one health or non-health related supplemental benefit to chronically ill and Medicare-benefit-eligible individuals, many of whom also had LTSS needs.[28] While providing only limited and short-term supportive services for a selective population, the Act does provide an opening for further expansions or integrations of LTSS with Medicare.

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.[29] The Trump administration has focused on reducing Medicaid expenditures and has not developed any proposals directly addressing LTSS financing.[30]

Finally, there are a number of Federal bills put forward by individual members of Congress, all of which attempt to provide mandatory public insurance coverage for LTSS. Some are focused on coverage for home and community-based care and others for all LTSS services. Most of the proposals are based on expanding the Medicare program to cover LTSS. Some of the more prominent bills include: the Medicare for America Act (H.R. 2452), sponsored by Representative Rosa DeLauro (D-CT) and co-sponsored to date by 23 other representatives; the Medicare for All Act (H.R. 1384), introduced in the

House by Rep. Pramila Jayapal (D-WA) and co-sponsored by 118 others, and also introduced in the Senate by Sen. Bernie Sanders (I-VT) with 14 other senators as co-sponsors.[31-32] 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 Efforts at LTSS Financing Reform

LTSS financing has long been a challenge for state governments. In 2002, a statement from the National Governors Association called for LTSS financing reform at the federal level, citing the unsustainable burden of escalating Medicaid spending on state budgets.[33] Most importantly, there was a consensus among state policymakers that the existing model was not sustainable and that unless broad changes in financing the system were made, it would be impossible to meet the needs of the growing population of older adults, people with disabilities, and others in need of LTSS. Fast forward two decades and the "projected" has become the "*reality*" for a growing number of states. At the state level, consumer advocates, providers and other stakeholder groups have started to focus on possible solutions. In the absence of federal solutions that appear timely and viable, and as the reach of private solutions grows smaller, policymakers at the state level are exploring new financing options to ease the burden on Medicaid budgets and to help residents pay for LTSS.

In recent years, a number of states have adopted or are considering innovative state-based LTSS financing reforms. We describe recent LTSS financing reforms in six states, identify motivating factors that are driving policy change, describe how policy design decisions are being made, and document the key players involved in these reform initiatives. While Washington State and Hawaii have gone the furthest with their reforms – having an operational or pre-operational program in place – others are at various stages of the policy development process. The fact that a growing number of states are seeing a broad and disparate array of LTSS stakeholders come together to work in concert on this issue represents a real change in the policy landscape; in essence, it highlights an expansion in the potential policy solution-set for this issue.

The learnings gleaned from the progress of these states will be useful to other states considering state-based action on LTSS financing reform. Moreover, documenting the tactics and strategies, as well as lessons learned thus far across these states can also inform potential future Federal initiatives. There are numerous precedents for state initiatives becoming catalysts for significant federal health care reforms. The Children's Health Insurance Program (CHIP), Medicare Part D, and the health care coverage provisions of the Affordable Care Act are all modeled on earlier successful state-based programs.

Study Method

We conducted comparative qualitative case studies across six states in various stages of developing or executing on reform initiatives including Washington State, which recently passed and is currently implementing a new social insurance program for LTSS; Hawaii, which has programs designed to assist family caregivers; and Maine, which put a specific LTSS financing initiative on the ballot in 2018 that failed to pass. The other three study states – Minnesota, California and Michigan – are at various stages of building stakeholder coalitions to work with policymakers to develop new programs, undertaking studies of the issue to inform policy development, or are ready to move to a full-blown legislative agenda. The states included in this study range geographically and culturally and also have different service delivery and financing capacities. It is not surprising that they have taken different approaches to moving the issue forward and that their results to date also differ.

Through in-depth stakeholder and key informant interviews conducted between August 2019 and January 2020, as well as state-specific document review, we identify similarities and differences among the strategies and program approaches undertaken in each state, and in the program components that have been fleshed out. We probe the history and evolution of these initiatives and identify common themes and lessons learned. More specifically, we identify key elements of each state's approach to the policy development process in terms of the rationale for taking action at this time; the primary problem(s) the state was trying to solve; the key actors and stakeholders moving the initiative forward; the method by which the coalition was built and sustained; critical obstacles and challenges encountered; and the strategies and tactics that were deployed to successfully (or unsuccessfully) overcome them; the rationale for the approach chosen or considered over others; and key learnings, both for states that are still in the reform process and for those that have succeeded in implementing new programs.

We developed six tailored interview guides, based on the progress of policy development in each case-study state. We followed an interview protocol that included primarily open-ended questions, some tailored specifically to each state. Additionally, the protocol had two sets of closed-category questions focused on the relative importance of a list of specific factors motivating the LTSS reform initiative within that state, as well as one on the obstacles that may have been encountered in moving the initiative along. The results from these structured questions are also presented.

In total, we completed interviews with 42 stakeholders and state officials across these states, many of whom were referred by state leaders. Key informants included state officials, leaders working in aging services, consumer advocates working on a broad range of health, disability, and LTSS issues, union leaders, and an assortment of individuals from LTSS provider organizations. On average, between four and ten individuals in each state participated in the structured interviews, which took roughly one hour to complete. Each call was recorded and transcribed and then analyzed separately by two researchers who, along with the third researcher, discussed them to extract common themes and develop a unified view of the process and current result. The qualitative software program NVivo was used to extract key themes related to important lessons learned. These analyses were supplemented with relevant documents that were obtained either directly from each state or through press reports on the initiative. A list of the stakeholders interviewed is found in Appendix 1.

SIX STATE OVERVIEW

Several features of the six states in this case study suggest that they are relatively advanced in terms of their existing LTSS infrastructure. As shown in Table 1, all of them rank within the top half of states in terms of the AARP LTSS scorecard, a rigorous tool used to measure state LTSS system performance from the perspective of service users and their families. Moreover, four of the states are within the top 10 highest rated states in terms of their LTSS system performance. This suggests that these states have already made significant investments in their LTSS infrastructures. When compared to the national average, five of the six states have more assisted living and residential care units per 1,000 people over age 75, and four have higher home-based care capacity (that is, high numbers of home health and personal care aides) per 100 disabled individuals with functional impairments.

TABLE 1: SELECTED STATE CHARACTERISTICS

Characteristic	USA	California	Hawaii	Maine	Michigan	Minnesota	Washington
Total Population*	327,167,439	39,557,045	1,420,491	1,338,404	9,995,915	5,611,179	7,535,591
Aged 18-64, %	61.6%	63.0%	60.2%	60.8%	61.1%	61.0%	62.5%
Aged 65+, %	16.0%	14.3%	18.4%	20.6%	17.2%	15.8%	15.4%
Aged 85+, %	1.9%	1.8%	2.8%	2.6%	2.0%	2.1%	1.7%
Age Dependency Ratio # **[see note 1]**	26.03	22.8	30.6	33.9	28.2	26.0	24.7
AARP LTSS Scorecard Overall State rank[i]**	25	9	7	18	22	2	1
Home health and personal care aides per 100 adults age 18+ with ADL disabilities, 2013-2015	19	28	13	23	17	33	25
Assisted living and residential care units per 1,000 population age 75+, 2014	52	59	52	63	56	88	103
LTC Insurance Policy Ownership, 2018*, ***	6,800,000	622,602	76,434	41,022	176,556	211,648	179,545
Policies per people age 50+, %	5.9%	4.8%	14.5%	7.5%	4.7%	10.6%	7.0%
LTSS Median Monthly Costs, 2019******							
Home Health Care Aide Cost	$4,385	$5,339	$5,220	$5,117	$4,481	$5,815	$5,815
Adult Day Care	$1,625	$1,668	$1,582	$2,513	$1,685	$1,820	$1,441
Assisted Living	$4,051	$4,500	$4,375	$5,169	$4,000	$3,800	$5,500
Nursing Home Care, Semi-private room	$7,513	$8,760	$11,650	$10,038	$8,373	$10,076	$9,112
Median Household Purchasing Power, 2018**********	$63,000	$46,500	$41,500	$49,900	$68,800	$70,700	$69,700

[i] The overall rank is based on a compilation of state data and analysis that measures LTSS system performance using 25 indicators across 5 dimensions and these indicators are then weighted and put together as a composite indicator based on a ranking methodology. For more information see: http://www.longtermscorecard.org/methodology. The most recent edition of the AARP Long Term Care Scorecard was published in 2017. All of the data presented here from the Scorecard are from the 2017 edition.

TABLE 1 CONTINUED

Characteristic	USA	California	Hawaii	Maine	Michigan	Minnesota	Washington
Publicly Financed LTSS, 2016*****							
LTSS as a % of total Medicaid budget	30.3%	17.7%	23.7%	40.3%	18.9%	43.5%	26.6%
Medicaid LTSS, 2016*****							
Medicaid LTSS % Home and Community Care	57%	74%	42%	54%	40%	76%	68%
Growth in LTSS Financing (2013-2016)******							
Total LTSS spending	14%	-2%	9%	17%	9%	24%	27%
Institutional care	2%	-29%	6%	16%	1%	14%	13%
Home and Community-based Care	26%	13%	15%	17%	22%	27%	35%
State Funded HCBS Expenditures for Older People and Adults with Physical Disabilities, 2014***	-------	No	Yes	Yes	Yes	No	Yes
Total Tax Burden by State****** [see note 2]**							
Ranking	------	11	2	3	25	5	32
Total combined tax rate	8.6%	9.5%	11.7%	10.8%	8.4%	10.8%	8.2%
Party Control of State Government, 2012 - 2020							
Governor	D 2012-2016 R 2016-2020	D	D	R 2012 - 2018 D 2019 -2020	R 2012 - 2018 D 2019 -2020	D	D
Legislature: House	R 2012-2018 D 2018-2020	D	D	R 2012 D 2013 - 2020	R	R 2012 D 2013 - 2014 R 2015 - 2018 D 2019 - 2020	D 2012 R 2013 - 2017 D 2018 - 2020
Legislature: Senate	R 2012-2020	D	D	R 2012 D 2013-2014 R 2015 - 2018 D 2019-2020	R	R 2012 D 2013 - 2016 R 2017 Mixed 2018 R 2019 - 2020	D

*Source: U.S. Census Bureau. American Community Survey 2018 1-year estimate, Table ID S0101.
**Source: AARP State Scorecards, 2017. http://www.longtermscorecard.org/
***Source: NAIC LTC Insurance Experience Report, 2018 https://www.naic.org/prod_serv/LTC-LR-19.pdf
****Source: Genworth Cost of Care Survey, 2019. https://genworth.com/aging-and-you/finances/cost-of-care.html
*****U.S. Census Bureau Current Population Survey & The Council for Community and Economic Research. As cited in "Median Household Purchasing Power for the 50 States and DC. Advisor Perspectives. December 19, 2019. Calculated by taking median household income and adjusting it by the C2ER Cost of living index, which yields the purchasing power of dollars.
******Source: Medicaid Expenditures for Long-Term Services and Supports in FY 2016, IBM Watson, May 2018, Table A, B and Appendix C, State Tables. Medicaid.gov/sites/default/files/2019-12/ltssexpenditures2016.pdf
Note 1: #The ratio is calculated as the proportion of adults aged 65+ per 100 adults aged 18-64.
Note 2: Total Tax Burden is a measure of all the total income that residents of a state pay in both state and local taxes. It is derived by combing the rates charged for income tax, property tax, excise and sales taxes in the state. Once the combined tax rate is derived, the states are then ranked from highest to lowest percentage as compared to all other states. The highest tax burden states in the US overall are over 12%.
******* Source: http://worldpopulationreview.com/states/tax-burden-by-state/

In terms of population demographics, four of the states – Hawaii, Maine, Michigan and Minnesota – have a higher percentage of individuals over age 85 compared to the national average. This age group presents the greatest LTSS need and cost to the public system, which could be a factor driving financing reform initiatives in these states. In addition, three of the states – Washington, Maine and Minnesota – show a much larger rate of growth in total LTSS spending between 2013 and 2016 as compared either to the other case-study states or to the U.S. average. In all the study states, the median monthly costs of home care and nursing home care exceed the national average, and in all but two, the median monthly costs for care in an assisted living facility are also in excess of the national average. This indicates a growing payment burden faced largely by families paying out-of-pocket or, on behalf of those who are poor or become poor paying for care, on the state's Medicaid program.

In terms of recent growth in LTSS Medicaid expenditures, and the amount allocated to home and community-based care versus institutional care, no clear patterns emerge across these states. However, four of the states have put in place state-funded home and community-based care programs for older people and adults with physical disabilities who do not meet the threshold of Medicaid eligibility. This suggests an explicit state investment in supporting LTSS needs for populations whose income or asset levels prevent them from qualifying for Medicaid. That four of the six showed somewhat slower growth in expenditures on home and community-based care compared to the national average may reflect the fact that these other states have only more recently made progress in rebalancing their LTSS systems away from institutional care, and thus have the need for more "catch-up" spending on home and community-based care.

We compared the amount of taxes paid per capita by the study states to explore two opposing concepts. The first is that a high tax rate per capita could reflect a state's willingness to invest in social infrastructure, inferring a greater probability that they would be willing to continue to do so for LTSS finance reform. These "high tax rate" states may have a strong desire for policy change and a track record of addressing such needs. There is some evidence to support this hypothesis in the other metrics previously mentioned, such as the high ranking on the AARP scorecard with regard to how well these states are meeting LTSS needs. On the other hand, states with higher than average taxes per capita may be reluctant to put in place new programs requiring additional tax increases, feeling that citizens are already paying enough in taxes. While there is a great deal of variation in the ranking of taxes paid per capita among the case study states, five of the six states are within the top half of the country in terms of overall "tax burden," and four of them are in the top 11.

Finally, while there has been quite a bit of change over the past eight years in terms of party control of governorships and state legislatures, over the last two years all six of the studied states moving a reform initiative forward had a Democratic governor and Democrats held majorities in five of the six state Houses and four of the six state Senates. Only Michigan and Maine currently have divided party control of government. The Maine ballot initiative that was put forward in 2018 occurred when the governorship and state Senate were both controlled by Republicans. There was bipartisan disapproval of the measure and none of the candidates for governor at the time of the election supported the measure.

Profile of State 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 reforms in the states that are furthest along in their reform efforts build on multi-year tactics. In Appendix 2, we include state timelines showing key milestones in the move to adopt these financing initiatives. They clearly illustrate that 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 (that is, in 2017) begun the stakeholder engagement and policy development process.

The profiles begin with a brief description of the type of initiative, its current status and the nature of the coalition working on it. Also summarized are the primary motivators driving the LTSS reform efforts identified by respondents. These motivators include easing the burden on family caregivers, concern about the growth in Medicaid budgets, financial help for the middle class, improving financial access to LTSS services, improving support for the LTSS workforce, and compensating for the failure of the private market. Other descriptive details and background information unique to each state follow.

In Appendix 3 we identify the key stakeholders in each state's coalition.

CALIFORNIA

A broad coalition of stakeholders, under the umbrella of the California Aging and Disability Alliance (CADA), is currently working toward putting forward a social insurance proposal for LTSS reform. The driving force in California is the need to address what stakeholders cited as "a rapidly rising and unsustainable" Medicaid budget. Additionally, there is concern with providing financial protection for the state's broad middle class. As one stakeholder stated the problem, "I would say it's primarily related to the fact that people who are above the Medi-Cal eligibility level…I would say, the whole middle-income…of our state, can't afford the cost of long-term care. They're having to impoverish themselves…And Medi-Cal is not an ideal system…it has its own challenges." Working with an outside actuarial firm, the coalition is presently exploring a wide variety of program design options and the pricing implications of each.

California also has an early history of exploring innovations and new options for LTSS reform within the state. In 2013, stakeholders from California were involved in discussions led by LeadingAge – the national trade association representing the non-profit aging services and senior housing sector – to explore the potential for states to forge a path toward finance reform. California's participation in these discussions was followed by a 2014 report entitled *LeadingAge Pathways: A Framework for Addressing Americans' Financial Risk for Long-Term Services and Supports.* Equally important, in 2014 the California State Senate Select Committee on Aging and Long-Term Care issued the "Shattered Systems Report,"

which helped make the case for taking action on the issues. At the same time, a number of labor, disability and provider groups launched the Care Agenda, a campaign to elevate the stories of caregivers in the state and advocate for funding to further study their challenges and needs. The convergence of different groups initially working separately but with similar interests and subsequently coming together is common to other states engaged in the reform process.

In 2017, what became known as the California Aging and Disability Alliance (CADA) was formed with anchoring organizations including AARP, LeadingAge, SEIU, UDW/AFSCME, CalPACE, the California Foundation for Independent Living Centers (CFILC) and others. The 21 member organizations developed a formal structure with working groups and subcommittees. In 2018, CADA successfully lobbied the state to allocate $3 million in the state budget to support inclusion of LTSS questions on the California Health Interview Survey. This effort laid the groundwork for future LTSS initiatives by developing champions for the issue and educating the legislature on the need for a statewide LTSS financing program. Subsequently, in 2019, CADA successfully secured $1 million for a feasibility study exploring a state-based LTSS financing program, which would then position CADA to further develop legislative champions and work toward a legislative or ballot initiative approach to addressing the issue. In late 2019, the modelling and actuarial analysis work began; findings will be finalized in the second quarter of 2020 and are due to the legislature on June 30, 2020.

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In the meantime, Governor Gavin Newsom signed an Executive Order authorizing a Master Plan for Aging – an idea first put forward by The SCAN Foundation – to be completed by October 2020. Among the various working groups and committees, there is a Long-Term Care Subcommittee, studying issues that likely overlap with the analyses CADA is doing. Additionally, the Master Plan Stakeholder Advisory Committee includes some individuals who are also members of CADA. The Master Plan process is likely to strengthen and reinforce the goals and directions for LTSS finance reform that CADA is currently pursuing. The LTSS Subcommittee will 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, and has been delayed due to the COVID-19 outbreak.

HAWAII

Hawaii does not currently have an LTSS social insurance program. However, of all the case study states, they have the longest history of attempting to pass a social insurance program for LTSS, as we describe below. Instead, the state has passed a program in support of family caregivers and a program expanding home and community-based services for non-poor elders in need. These are summarized below. The programs were put in place to address one of the primary problems driving their interest in LTSS finance reform – the needs of family caregivers. Hawaii's focus has consistently been on "allowing people who chose to age in place to have the financial resources to assist them." The reform work on these programs has been supported over the years by a collaboration between the Executive Office on Aging, the state legislature, outside experts, grassroots organizations and other stakeholders.

Unlike other states reviewed here, current activity in Hawaii is more narrowly focused on improving the caregiver support program rather than on trying to develop a new social insurance program for LTSS. 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 may come together on an ad-hoc basis to support program improvements.

Hawaii's focus has consistently been on "allowing people who chose to age in place to have the financial resources to assist them."

Public officials within the Executive Office on Aging, gerontologists at the University of Manoa, actuaries and other experts have been studying and modeling a social insurance approach as far back as 1985. In 2012, the legislatively appointed State LTC Commission recommended establishing a "limited, mandatory public LTSS insurance program." It was to be funded by a 0.5% general excise tax on businesses and would provide 365 days of front-end insurance coverage paying up to $70 per day in benefits. The measure failed to pass the legislature, reportedly because of an additional and competing public policy proposal to tack on a 0.5% general excise tax to support educational funding. Viewed together, the price tag of a 1% tax was seen by legislators as too high, which led them to abandon both proposals. Another attempt was made when a universal LTSS bill was introduced in 2016, but it did not gain traction. Social insurance for LTSS has not been taken up since that time.

Even so, Hawaii maintained its interest in addressing resident LTSS needs but no longer through a social insurance mechanism. The state put in place two programs, one of which – the Kapuna Care Program – was enacted in 2008 and was designed to provide targeted home and community based care benefits to individuals age 60 years and over who needed LTSS at home but were not poor enough to qualify for Medicaid.

The other program enacted in 2017 – the Kapuna Caregivers Program – was designed to support family caregivers employed outside the home. The intent of the program is to help working caregivers stay in the labor force by helping them pay for home care services for their loved ones. To be eligible to receive program benefits, a qualified caregiver has to work at least 30 hours per week and also provide direct care to a qualified care recipient. A qualified care recipient must be age 60 or older, not currently receiving benefits under other government or private program services (except Kapuna Care Services) and live outside of a care facility. They must also need assistance in two or more activities of daily living or instrumental activities of daily living or help with at least one of either of these categories of activity. Additionally, individuals with a cognitive impairment requiring substantial supervision are also considered a qualified care recipient.

Subject to the availability of funds, up to $70 per day in benefits is 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). In 2019, the benefit allowance was changed from $70 per day to a weekly reimbursement of $210. While overall this represents a lower total amount available to individual families, its intent was to maximize the number of caregivers served by the program within the context of an overall fixed program budget. 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. The budget for this program, based on general revenue allocations, is modest – roughly $1.2 million in 2018. Because it is not a social insurance program, the availability of program benefits is dependent upon the allocation of general revenue funds and the number of individuals eligible for the program. In an appendix of a report completed in December of 2019, the program's first full year of operation and plans for expansion are summarized.

MAINE

Maine's attempt at LTSS financing reform was based on a ballot initiative – rather than the legislative approach in the other five states studied – to establish a social insurance program focusing exclusively on comprehensive in-home care. The ballot measure failed when put to a vote in November 2018. The ballot initiative was led by the large state-based non-profit community action organization, the Maine Peoples' Alliance, supported by union and other advocacy organizations. Stakeholders we interviewed in Maine most often identified "easing the burden on family caregivers" as the most important priority for their state-based reform initiative. One stakeholder described the broad objective of the reform: "I think the core of it is that long-term care is not considered to be a basic public good that everybody should be able to access effectively. So our goal was to change that." The Universal Home Care Trust Fund would have provided in-home assistance to all residents of Maine aged 65 years or older and to people with disabilities. The program was to be funded by a 1.9% tax on individuals' earned income over $128,400. Employers would also have contributed 1.9% on earned income above $127,500. Additional funding would have come from a 3.8% tax on investment income above the Social Security tax cap, reduced by the payroll taxes paid.

There were robust media campaigns for and against the ballot initiative, with supporters spending $2 million and the opposition about $1 million. Despite the intent of the proposal to expand reimbursement for in-home care, it was opposed by the Home Care and Hospice Alliance of Maine. Both Republican and Democratic gubernatorial candidates opposed the measure. Opposition also came from the Maine Hospital Association and the Maine State Chamber of Commerce. Those opposed to the program cited concerns about the progressive nature of the tax increase, the lack of residency or income requirements in order to impose control on who might access the benefit, and the creation of a parallel oversight structure outside of the purview of the legislature which would be making spending decisions.

In November 2018, Ballot Question 1 was put to the voters of Maine:

"Do you want to create the Universal Home Care program to provide home-based assistance to people with disabilities and senior citizens, regardless of income, funded by a new 3.8% tax on individuals and families with Maine wage and adjusted gross income above the amount subject to Social Security taxes, which is $128,400 in 2018?"

"I think the core of it is that long-term care is not considered to be a basic public good that everybody should be able to access effectively. So our goal was to change that."

Despite a Suffolk University poll four months prior that predicted passage of the proposal, with 51% in support of the bill, the Ballot Question was rejected by Maine voters a few months later by a vote of 63% to 37%. Currently the focus of activity in Maine has been on reforms related to service delivery rather than on overall financing reform.

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, although providing financial protection for the broad middle class was cited as the most important motivating factor by two of the stakeholders we interviewed. Other motivating factors cited by interviewees were addressing Medicaid budget pressures and alleviating family caregiver burdens. Specifically, one stakeholder identified that "the goal of this ultimately is to get to some sort of sustainable funding stream," while also mentioning the service access disparities in different parts of the state. The lack of provider capacity was also cited. "We are in a direct care worker shortage crisis and we are not going to be able to meet the needs of care by 2020 if we don't have at least 30,000

more direct care workers." The Michigan stakeholders are working in coalition, and have hired an outside actuarial firm to model the pricing impacts of a variety of program options.

> "We are in a direct care worker shortage crisis and we are not going to be able to meet the needs of care by 2020 if we don't have at least 30,000 more direct care workers."

With the support of a state representative, Michigan created the Bipartisan Care Caucus in 2017 to advocate for LTSS care and finance reforms. Since 2017, a broad coalition has been forming that includes the Michigan Caring Majority (a statewide movement and coalition of family caregivers and advocacy organizations focusing on caregivers' and care workers' needs) and 20 other organizations representing home care providers, disability rights organizations, family caregivers, senior advocacy groups and other providers. Legislation was introduced in the 99th Legislature (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 appropriation of $100,000 from the legislature was contingent upon additional matching funds being raised by coalition stakeholders. They were able to raise an additional $300,000 and the study is currently underway. Stakeholder listening sessions, the actuarial analysis, and a workforce analysis are in process. 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 including feedback from stakeholder listening sessions and a thorough review of workforce needs in the state. The study is due to be completed before December 1, 2020 and delivered to the legislature within 60 days of the study completion date.

MINNESOTA

A stakeholder in Minnesota stated the problem broadly yet simply. "Well, the problem is that we have lots and lots of people who are going to live a long time and they have not prepared in terms of their planning and also the financing of that long life." That is why their reform approach is unique in focusing on options to enhance affordable private market solutions for middle-income families. Interviewed stakeholders cited concern about a strained and growing Medicaid budget as the most important factor driving state efforts, along with concerns about financial protection for the broad middle class. For many years, Minnesota has focused on raising consumer awareness of the need to plan for LTSS needs and building better private LTSS financing vehicles to meet the needs of the middle-income market. The state convened an Advisory Panel of stakeholders including business, consumer groups, providers, and others to explore several

new concepts under a broad initiative called "Own Your Future." The effort began in 2012 with a large-scale community-education campaign using social media, direct mail and the internet. The Advisory Panel guided strategy and content for the Own Your Future campaign and the Lieutenant Governor chaired the Panel.

In 2014, the state hired an outside expert to help identify and develop new public and private product options for the middle-income market. Of fifteen potential product concepts prioritized by the Advisory Panel, two were chosen for development, using the committee's criteria for viability. The first product is called LifeStage, a term life insurance policy that converts into long-term care insurance coverage when someone reaches the "policy conversion age." At that time – roughly age 65 – the life insurance benefit would convert to LTSS coverage with no change to the premium level.

> "Well, the problem is that we have lots and lots of people who are going to live a long time and they have not prepared in terms of their planning and also the financing of that long life."

That State's role has been to provide funding for the actuarial analysis and other feasibility studies, including market research and an analysis of the impact on Medicaid if LifeStage were to be broadly implemented in Minnesota. The State is also currently conducting research to identify remaining regulatory and implementation issues to be addressed. This product would be sold by private companies likely in employer settings as a voluntary employee-pay-all offering. Minnesota state employees may be one of the first groups considered for product roll out.

The second product seeks to add expanded coverage for a package of home and community services to Medicare supplemental health policies sold in Minnesota. Unlike the federal Chronic Care Act that focuses only on Medicare Advantage Plans, Minnesota's efforts intend to **require** all Medicare supplemental plans to add a package of personal care services similar to what is provided in the state's Medicaid program to chronically ill individuals receiving Medicare benefits who need nonmedical supports in order to stay safely in their home. A study is currently underway to identify possible service packages, pricing, and other implementation issues. Both initiatives, along with a discussion of broader reform options, were presented at a LTSS finance reform forum convened in January 2020.

Additionally, in late 2019, the Governor appointed a Blue Ribbon Commission to study LTSS finance reforms for Minnesota that go beyond these private sector product options. The commission's work is about to commence and a number of stakeholders are interested in exploring social insurance options including a program to provide catastrophic coverage for individuals with long-duration LTSS needs.

WASHINGTON

With the passage of the Washington State LTC Trust Act in 2019, Washington became the first state in the country to establish a social insurance program for LTSS. The program was intended, as one stakeholder described, as "…a bridge program that would delay entry into the Medicaid program and bend the spending on Medicaid because resources are scarce and targeting high-acuity, high-need people with those scarce Medicaid dollars, we felt that would be highly beneficial." This program emerged from work begun in 2013 by the Joint Legislative Executive Committee and a grassroots organization called Washingtonians for a Responsible Future. This coalition represented a broad-based grouping of aging and disability advocates, businesses, long-term care providers, labor, consumer rights organizations, and families working to address the LTSS financing issue. The state is currently putting in place the mechanisms to implement the program with plans to leverage the administrative infrastructure that is being used for the recently enacted Paid Family Medical Leave program. Premium collection for the LTSS program is scheduled to begin in 2022, with full program implementation in January 2025.

The LTSS program will be available to all employed state residents (including those who are self-employed); 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. Specifically, individuals are eligible for benefits when they have qualifying deficits in three of any of the following functional and/or cognitive domains: Ambulation/mobility; Bathing; Body care; Cognitive impairment; Dressing; Eating; Medication management; Personal hygiene; Toileting and; Transfer assistance. 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 more family care, personal savings, or private long-term care insurance. 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

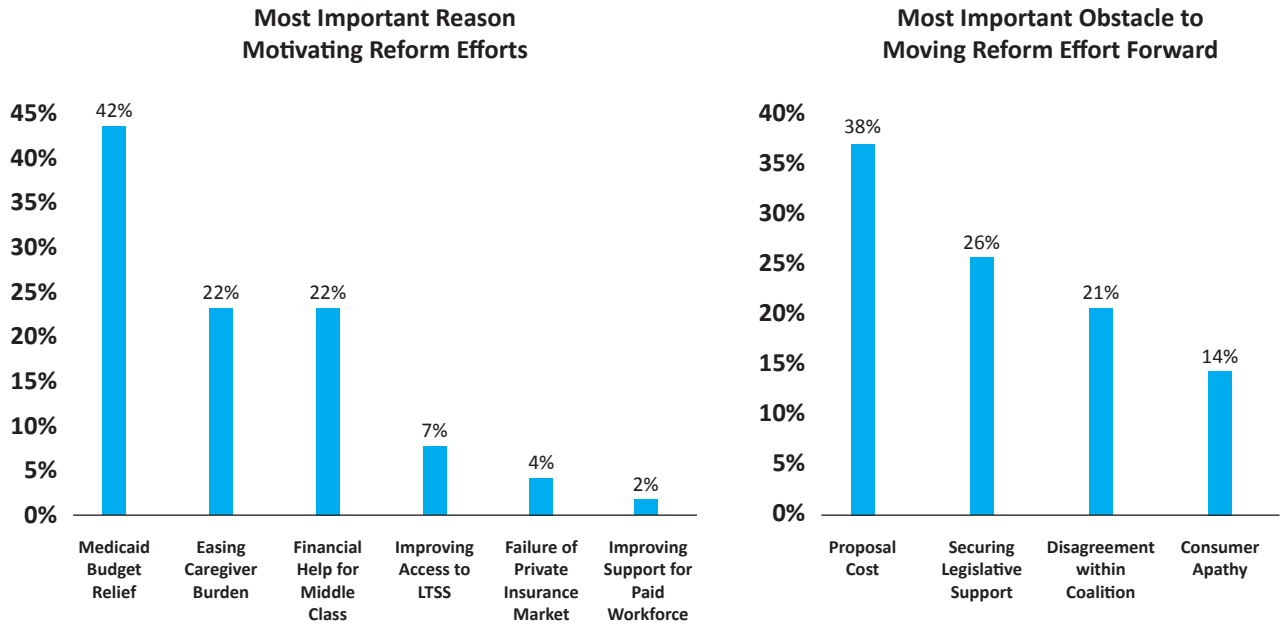
"…a bridge program that would delay entry into the Medicaid program and bend the spending on Medicaid because resources are scarce and targeting high-acuity, high-need people with those scarce Medicaid dollars, we felt that would be highly beneficial."

challenges for individuals who currently have or choose to purchase policies, as it could result in discontinuities in receipt of benefits.

SUMMARY – STATE OVERVIEW

Stakeholders across these states share common concerns that are motivating them to take action and also point to common obstacles associated with moving reform efforts forward. Figure 1 below summarizes the frequencies with which such motivations and obstacles are cited by stakeholders.

FIGURE 1: MOST IMPORTANT MOTIVATIONS AND OBSTACLES ASSOCIATED WITH REFORM INITIATIVES (N=32)



The primary motivations underlying reform efforts cited by stakeholder most frequently include the concern about how the current LTSS financing system is putting untenable budgetary pressure on states' Medicaid budgets, how caregiving burdens are growing, and that the broad middle class needs financial help to deal with this problem. The most commonly cited obstacles to moving initiatives forward include concern about proposal cost, followed by challenges associated with securing legislative support, and disagreements within the coalition. Only a small number of stakeholders pointed to consumer apathy as a problem.

How each state is responding to these issues, who the key stakeholders are that are driving reform, and the process by which it is evolving do differ. Yet there are common patterns of progress and themes that emerged from our stakeholder interviews. While for at least half of these states it is still too early to conclude that they will succeed in moving their reform initiative to their end goal of implementing a new program, the process and approach undertaken by these six states provide important insights into the components of what drives a successful strategy and what can derail success.

Common Themes and Lessons Learned

Despite the number and diversity of individuals interviewed and the differences in 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. More specifically, this includes views on the parties that need to be involved in the reform process, the strategies and tactics that move efforts forward, the obstacles and challenges most likely to be encountered, and how they might best be overcome. This section highlights the key factors identified with advancing state-based reform across these states and the critical lessons learned thus far from the 42 stakeholder interviews. Many of these lessons relate to strategies for building and maintaining an effective coalition, which is viewed by stakeholders as essential to creating and sustaining a viable reform initiative and moving it forward. The uniform view was that "success" – defined by an ability to form and sustain a coalition, articulate a common goal, and (for states further along in the policy development process) identify and/or implement a specific approach or program – depends on effectively developing, mobilizing and channeling ground-level demand for policy change.

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.[34-35] 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 stages of the reform process.

The state coalitions that were furthest along or had successfully implemented a program coalesced around a shared goal or goals that were broad enough to have popular acceptance with other stakeholders. As mentioned, two goals that emerged frequently across states were the pressing needs to relieve pressure on the Medicaid budget and to provide financial protection for the middle class. Coalition members typically also had "background" goals unique to their organizational perspective, but agreed that having the "flagship" goal as the coalition's main talking point was important to raising awareness and building support among the broadest set of policymakers and the public at large.

Even a second-order goal which may not be put forward publicly cannot be ignored if it is particularly important to a critical stakeholder. As an example, in Washington State, one of the stakeholder groups felt that its concerns regarding the training of family caregivers had not been adequately addressed, even as the legislature was preparing to vote on the plan. The result was that the legislation was pulled, the coalition parties reconvened to address that issue, and the legislation was reintroduced and passed a year later. The level of trust-building that had occurred over the two- to three-year period of working together as a coalition enabled the group to address the issue and obtain legislative support for the proposal.

In general, the coalitions furthest along in their process have worked hard early on to assure consensus around the definition of the problem to be solved and to stay focused on what they were trying to solve for. Simply put, there was an understanding that the group could not solve all problems through a single initiative. 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."* In addition, across all of these initiatives everyone understood that new financing sources would have to be harnessed to address the problem and this made agreement on high-level goals easier. 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."*

"...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."

Broad and equitable stakeholder involvement is associated with moving initiatives forward. As one individual expressed it, *"include all the noses that are at the trough."* Across a number of states this meant including both the aging and disability communities, citing in particular that the disability community *"...has more activist energy."* Another stakeholder advised including organizations that are associated with the issue and have strong reach and expertise in messaging on LTSS issues – both to consumers and policymakers: *"Be as broad as you can. Everyone that has a mutual stake and interest in these issues needs to be included."*

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.

"...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."

A counterfactual to what is occurring in California and happened in Washington State is the Maine initiative. While there were a number of reasons why the reform

initiative 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. That said, other stakeholders felt that the ability to form a broad coalition in Maine was never possible from the outset because not all interested parties shared the same perspective on a critical underlying issue around LTSS reform – the need for a revenue-raising measure.

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, rules, and allocated resources – that is, staff time for managing the process. For example, members in the California Aging and Disability Alliance shared a "duty of loyalty statement" and all CADA documents and discussions are being treated as confidential within the group. There is broad agreement not to introduce opposing legislation on the issues that are under discussion. In addition, any disagreements that emerge must be brought to consensus in the group. Finally, 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. As one stakeholder observed, *"…have a coalition manager to make sure the team is getting the information they need and everyone is getting heard, recognize stakeholders' self-interests, align them with the group goals, and address issues within the context of a coalition working agreement, guidelines and structure."*

"…recognize stakeholders' self-interests, align them with the group goals, and address issues within the context of a coalition working agreement, guidelines and structure."

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 – a stakeholder had an important remaining concern. 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.

As seen in the development of state timelines and milestones regarding the policy development process (see Appendix 2), the pathway to LTSS finance reform can span years and, in one case (i.e., Hawaii), even decades. Despite more than two decades of strong and persistent effort, coalition stakeholders in Hawaii still have not implemented comprehensive LTSS financing reform. What accounts for this long timeline? 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.

Other essential activities that take time are the 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. As one stakeholder indicated, *"…spend more time up-front in defining the problem than you'll spend campaigning for the solution."* 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.

"…spend more time up-front in defining the problem than you'll spend campaigning for the solution."

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 time consuming or 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 on the discussions around specific policy designs. It also concentrated 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. A Hawaii stakeholder suggested that for its caregiver support program, *"…having a target price provided 'grace and goodwill' with the legislature because they were starting with modest budgetary demands"*; this approach then allowed them to build on their initial success and eased the way to incorporating the Kapuna Caregiver Program into the budget.

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 latter 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.

"…we went too fast with the policy"

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."*

"…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."

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. Once they increased the general excise tax for the rail funding, it's like, yeah, you're not getting another bite at that apple the next year, or even within two years"*

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 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."*

In some cases, the political climate had changed and was viewed as more favorable. In California, after years of struggle, the state budget was in balance and the sense of fiscal crisis had passed. As one coalition member said, *"…the good economy opened up an opportunity for looking at some policies that nobody would ever look at when things are going south on the economy."*

"…the good economy opened up an opportunity for looking at some policies that nobody would ever look at when things are going south on the economy."

This was also the case in Washington State and it opened up a runway to discuss new programs. In Maine, given the strategy of trying to pass a program through a ballot initiative, there was a strong belief that high voter turnout in the 2018 mid-term elections would be a major advantage and the coalition driving the issue could leverage past successes (i.e., Medicaid expansion and raising the minimum wage). In California, the election of a new governor brought renewed interest in the issue, and with basic health care issues resolved by the Affordable Care Act, the "policy bandwidth" expanded and could more easily accommodate policy development.

In Michigan and Minnesota, there was a feeling that demographic pressures were creating a sense of urgency to "do something" and that a growing number of sandwich generation caregivers were now holding a significant number of statehouse seats; this meant that the issue was becoming more salient for them in a personal way. Finally, the private sector was uniformly viewed by stakeholders as having underperformed across all of these states, even those with relatively high (10%) penetration rates for private insurance. This provided an opening to policymakers and advocates to begin to examine greater public sector involvement in LTSS financing beyond social safety-net approaches.

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. A number of states began their 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. As one coalition member put it: *"Start with something non-threatening...the study is useful. It's not just window dressing. Get that through the legislature and show that you can do something legislative...Show that you have some clout as a coalition, you can get something done."* 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) examine social insurance solutions and private market approaches in terms of effectiveness in "moving the needle" on reform objectives; (3) provide a framework for discussions to make them more productive and provide a common factual basis; and, (4) support trust-building and experience working together. One stakeholder observed that such studies can assure that *"…every legislator knows the level of need of elders in the community and in their constituency."* It also helps communication and messaging efforts.

"...the study is useful. It's not just window dressing. Get that through the legislature and show that you can do something legislative...Show that you have some clout as a coalition, you can get something done."

Given the complexity of this issue, as well as the understanding that a solution will require additional funding, many stakeholders thought it was important to move incrementally and "…rack up early victories" with minimal cost implications. Examples include seeking modest funding for a statewide survey, a demographic study, or a finance department report to obtain the important information needed to frame the problem and provide education about it. The coalition in California found that working together to persuade the state to include LTSS questions on a state health interview survey helped disparate organizations build a level of trust early in the process; this has enabled constructive resolution of challenging conversations at later stages in the course of policy development.

Minnesota adopted an incremental approach by beginning its efforts focused on creating new and more middle-market accessible long-term care insurance products. The state is unique in comparison to the other five in that the policy agenda was driven by state officials and arrived at by consensus by the state's broad coalition of experts. Some within the coalition *"…were definitely pushing a social insurance model….[but]…it didn't make the cut."* A number of stakeholders in Minnesota suggested that successful implementation of one or both of these first two initiatives might well be the "starter win" leading to efforts designed to cover a greater share of the population.

While Maine attempted to pursue LTSS reform through a ballot initiative, thus far, the view among other states is that a legislative approach should be the first option, if possible. A referendum or ballot initiative is viewed as expensive, difficult, and less likely to succeed, unless its purpose is to provide political support for legislators who are reluctant to raise additional taxes, even for worthy program efforts. Given that most have or are pursuing legislative strategies, identifying legislative champions on both sides of the political divide – if possible – is always viewed as critically important. Given the nature of this issue, and the fact that so many people have had a personal LTSS experience either as a caregiver or recipient, the issue can often appeal to unlikely allies. As a key stakeholder from Hawaii noted, *"…it all comes down to political will and champions who have the decision-making capacity."*

"…it all comes down to political will and champions who have the decision-making capacity."

To address the issue of legislative turnover, Washington State leveraged a Joint Legislative Executive Committee on Aging and Disability (JLEC) to foster and maintain LTSS expertise in the legislative arena. By institutionalizing such a committee, it assured that even in the presence of legislative turnover, there would remain an internal constituency educated on the topic: *"JLEC provided an opportunity for advocates and executive branch agencies that are represented, as well as legislators to move – keep momentum on a particular topic. It included Republicans and Democrats and is made up of the Senate, House and Governor's Office. When they meet two or three times a year, you can really do deeper dives into topics like this one that would really be difficult to do in just a single legislative session."*

SUMMARY

Across these six states, stakeholders identified a number of key factors associated with moving reform initiatives forward; these 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."*

Study Limitations

The stakeholders interviewed for this study provided a great deal of wisdom regarding the efforts in their state. Nevertheless, the conclusions drawn from this study must be viewed within the context of the limitations inherent in a case study approach conducted with stakeholders across six states. Moreover, most of these states are still in the policy development stage with only Washington State having implemented a social insurance policy reform. A qualitative study such as this limits the extent to which findings can be generalized to a broader population of states. The states studied here are at different stages of policy development, have dissimilar economic and political environments, diverse coalition members, and have adapted various approaches to moving the issue forward. Even so, they offer a range of insights about the manner in which reform processes take shape and early lessons that are relevant for other states considering transforming their financing systems.

Our ability to draw firm conclusions about the factors contributing to or preventing policy change is somewhat limited. While we selected individuals to interview who could provide us with the most up-to-date and comprehensive information about the state's journey and activities, we are certain that had we interviewed more individuals, we would have learned more. Our intention was to obtain a diversity of perspectives, but we did not always achieve the same balance across all the study states, nor were we able to include additional states which may be at slightly earlier stages of coalition or policy development.

It remains to be seen whether additional states will consider moving in this direction, given the challenges imposed by the current strain on budgets due to the coronavirus pandemic-induced economic downturn and increasing demands on the social safety net. Other states have been considering LTSS finance reform and starting similar coalition-building and analyses that were not included in this study (e.g., Illinois). Additional research might focus on expanding the qualitative data set by conducting additional case studies in newly emerging states to help validate, refine or expand on the findings generated here. Of particular interest would be to follow-up on identifying state-specific factors that influence the process and program approach. For the study states included here that are still in the beginning stages of policy development, a follow-up analysis of coalition status and activities, especially in light of the challenges these states now face, would be especially informative. Have they changed course, suspended action, dismantled, or continued with greater urgency given the greater need in light of COVID-19? For those states who have already implemented reforms, it is also important to evaluate whether and how their programs are performing relative to the goals and benchmarks that were established during the policy development process.

Conclusion

The current financing model for LTSS leaves many Americans without sufficient coverage to meet their needs. Efforts are ongoing to address LTSS financing reform at the federal level, but have not been successful to date. The initiatives described in this report provide examples of potential actions that could be taken at the state level. Through qualitative interviews, we identified some of the factors that policymakers and stakeholders may wish to consider in developing and advancing state-based LTSS

finance reforms. The current experience in these states suggests 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. Finally, 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 move forward at the right time.

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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Appendix 1: Stakeholder Interview Participants

CALIFORNIA			
Name	**Category**	**Title**	**Organization**
Anastasia Dodson	Administration	Associate Director	California Department of Health Care Service
Kristina Bas Hamilton	Labor	Legislative Director	UDW/AFSCME Local 3930
Jedd Hampton, MPA	Provider	Director of Public Policy	LeadingAge California
Peter Hansel	Provider	CEO	CalPACE
Amanda Ream	Labor	Research Director	United Domestic Workers/ AFSCME, Sacramento, CA
Sarah S. Steenhausen, MS	Consultant	Senior Policy Advisor	The SCAN Foundation
Nina Weiler-Harwell, Ph.D.	Advocacy	Associate State Director – Community	AARP California

HAWAII			
Name	**Category**	**Title**	**Organization**
Pedro Haro	Advocacy	Hawaii Advocacy Director	Caring Across Generations (formerly)
Lawrence H. Nitz	Academic	Professor, Department of Political Science	The University of Hawaii at Manoa
Marilyn R. Seely, MPH,	Administration	Former Director	State Executive Office on Aging
Jim Shon, PhD	Advocacy	Former State Legislator	Kokua Council for Senior Citizens
Kevin Simowitz	Advocacy	Consultant	

Appendix 1: Stakeholder Interview Participants (continued)

MAINE			
Name	**Category**	**Title**	**Organization**
Newell Augur	Provider	Attorney	Pierce Atwood, LLP, Representing the Home Care and Hospice Alliance of Maine
Ben Chin	Advocacy	Deputy Director	Maine Peoples' Alliance
Richard A. Erb	Provider	President & Chief Executive Officer	Maine Health Care Association
Jess Maurer, Esq.	Community organization	Executive Director	Maine Council on Aging
Paul Saucier	Administration	Director	Office of Aging and Disability Services, Maine DHHS
Kevin Simowitz	Advocacy	Consultant	
David Winslow	Provider	Vice-President	Maine Hospital Association

MICHIGAN			
Name	**Category**	**Title**	**Organization**
Laura DePalma	Advocacy	Campaign Director of the Michigan Caring Majority	Michigan United
Susannah Dyen	Advocacy	Director of Organizing and Field	Caring Across Generations
Jon Hoadley	Legislature	State Representative, 60th House District, Minority Vice Chair of the Appropriations Committee	Michigan State Legislature
Sarah Slocum	Consultant	Co-Director	Altarum Program to Improve Eldercare

Appendix 1: Stakeholder Interview Participants (continued)

MINNESOTA			
Name	**Category**	**Title**	**Organization**
Fred Andersen, FSA, MAAA	Administration	Chief Life Actuary	Minnesota Department of Commerce
Liz Conway	Private health plans	Director of Product Management	UCare
John Cutler, JD	Consultant	Consultant	Minnesota DHS and Society of Actuaries on LTSS reforms
Mary Jo George	Advocacy	Associate State Director, Advocacy	Minnesota AARP
Walter C. Gray, CRPC®	Private insurance	franchise financial advisor	Representing Ameriprise Financial Services LLC
Pahoua Hoffman	Policy and Advocacy	Executive Director	Citizens League
LaRhae Knatterud	Administration	Director, Aging Transformation	Minnesota Department of Human Services
Gayle M Kvenvold	Provider	President and CEO	LeadingAge Minnesota
Maureen O'Connell	Lobbyist	Public Policy Consultant	O'Connell Consulting, LLC
John O'Leary, MBA	Consultant	Consultant	O'Leary Marketing

WASHINGTON			
Name	**Category**	**Title**	**Organization**
Mary Clogston	Legislature	Senior Policy Analyst	House Democratic Caucus, Washington State House of Representatives
Madeleine Foutch	Labor	Legislative and Campaigns Director	Public Affairs department, SEIU 775
Cathy MacCaul	Advocacy	Advocacy Director	AARP Washington State
Dan Murphy	Provider	Executive Director	Northwest Regional Council
Alyssa Odegaard	Provider	VP, Public Policy	LeadingAge Washington
Lauri St. Ours	Provider	Executive VP of Government Affairs	Washington Health Care Association
Bea Rector	Administration	Director, Home and Community Services Division	Aging and Long Term Support Administration, Washington State Department of Social and Health Services
Ann Vining	Advocacy	Staff Attorney	Northwest Health Law Advocates
Kate White Tudor, JD	Lobbyist	Legislative Liaison	Washington Association of Area Agencies on Aging

Appendix 2: Individual State Timelines

CALIFORNIA		
Year	**Key Actor(s)**	**Description**
2013	LeadingAge, TSF, AARP (jointly funded)	Begins Pathways Task Force to build capacity in states to engage in LTSS reform discussion. California is one of the participating states (along with MN and WA).
2015	LeadingAge	LeadingAge reaches back out to CA (and other selective state partners) from earlier "Pathways" work. Convenes nationally-funded conversations in these states with experts to facilitate broad stakeholder conversations. Meeting includes many entities that comprise present day CADA.
2017	UDW/AFSCME	UDW/AFSCME brought together California Domestic Workers Coalition and Caring Across Generations to form the Care Agenda. Grassroots organizing and elevating the real-life stories of caregivers and families. Holds events around 2018 election, targeting candidates for Governor to educate and build support for universal LTSS.
2017	CADA	California Aging and Disability Alliance (CADA) founded with organizations from Care Agenda and "Pathways" efforts. Partners include UDW, Leading Age, AARP, and CFILC, SEIU, California Foundation for Independent Living, Alzheimers, CalPACE, etc. Formalized working group structure and meeting process across 21-member organizations. Expands work around 2018 election and educating and building support for universal LTSS.
2018	CADA	CADA leads campaign to secure funds in state Budget to include questions about LTSS on the CA health interview survey. $3 million awarded. First round of surveys in 2019 and 2020
2019	CADA	CADA leads campaign to secure funds in state Budget for actuarial report. Budget appropriation approved for contract to Milliman to model LTSS finance options; findings due to legislature June 30, 2020
2019	Governor Newsom	Executive Order N-14-19 for Master Plan on Aging due Oct 2020. Includes a LTSS Subcommittee. Appoints Stakeholder Advisory Committee
2019	CADA and Senator Pan	SB 512 introduced to create an LTSS Board appointed by the Governor to oversee and invest revenue in the CA LTSS Benefit Trust Fund program; Bill to create the governing structure that would be needed to implement LTSS financing program (if and when). Hoping for passage in 2020 or 2021

HAWAII		
Year	**Key Actor(s)**	**Description**
1985-1994	Administration, outside experts, University of Manoa	Administration saw importance of LTSS financing initiative. Over the years, gathered academic minds to research and model feasibility of new approaches based on design principles of being inclusive and affordable.
		Created Hawaii-specific actuarial model as working tool. Brought on actuarial firm with social security background as good fit for program vision (Actuarial Research Corporation)
1992		First social insurance program proposed
2000		Second social insurance program proposed. Failed to get governor signature based on tax implications. Republican administration.
2008	Legislature	SB 3255 Establish State LTC Commission to identify needed reforms to meet state policy objectives and to explore an array of funding options to help support the provision of LTSS in the future.
2011		First Report of the State LTC Commission to the Hawaii State Legislature
2012		LTC Reform in Hawaii: Report of the Hawaii LTC Commission recommends establishing "a limited, mandatory public LTC insurance program…"
2014		LTC Commission helps forge new social insurance program, but broader with broader tax basis (GET) than previously. On its way to passage at cost of 0.5%. Edged out of consideration when Teachers' union asked for 1% increase on GET for education budget. Political appetite for any increase in the GET eroded.
2015		Legislature suggests as alternative "starting small" with $12 M spread out over biennium for a service package in lieu of social insurance program – Kapuna Caregiver Program
2015	Advocacy coalition	Caring Across Generations working with Faith Action for Community Engagement (FACE)
2016		Caring Across Generations hires local advocacy director in Hawaii to renew 21year long struggle to bring LTSS finance reform on board and sustain coalition building.
2017	Legislators and advocacy coalition	Sen Baker and Rep Mizuno worked on design and funding for what became Kapuna Care. Begins with $600,000
2018		Budget doubled and benefit changed to weekly rather than daily amount

MAINE		
Year	**Key Actor(s)**	**Description**
2017	Maine Peoples' Alliance	Anchor organization, working with Caring Across Generations, Maine State Employees' Association (The Maine SEIU affiliate) and the Fairness Project. Efforts begin to focus on Universal Home Care initiative. Petition work and draft language to put forward to the legislature.
November 2017	Maine Peoples' Alliance	Introduced legislation Maine Question 4 to increase from 10 to 20 years the time required for the state to pay off unfunded liabilities crated by experience losses to the Maine Public Employees Retirement System. The purpose of this was to enable a more stable state budget environment into which to introduce a new state LTSS finance reform initiative. The question passed 63% to 37%
March 13, 2018	Legislature	Legislative Document 1864 – 128th Legislature. Legislative hearing on initiative language for the Universal Home Care Trust Fund (and Universal Home Care Trust Fund Board.) Legislature reports it out to the voters in the form of a ballot initiative.
August 2018	Opponents	Suffolk University poll of Maine residents finds 51% support the initiative, 34% oppose it and 14% undecided.
		Supporters raised almost $2 million and opponents raised $1 million.
		Opposed by both Republican and Democratic gubernatorial candidates[v]. Other opposition: Home Care & Hospice Alliance of Maine, the Maine Hospital Association and the Maine State Chamber of Commerce. Reasons include the tax increase on some Maine residents and concerns about patient privacy although some claim these concerns were spurious.
Nov 2018	Election Day	Ballot Question 1, Do you want to create the Universal Home Care Program to provide home-based assistance to people with disabilities and senior citizens, regardless of income, funded by a new 3.8% tax on individuals and families with Maine wage and adjusted gross income above the amount subject to Social Security taxes, which is $128,400 in 2018?
		Maine voters rejected the proposal 63% to 37%
Post-election	Supporters	Supporters express disappointment and plans to keep trying. "The program is badly needed in Maine because half its residents either have served as caretakers or have received home care themselves," said Mike Tipping, communications director for Mainers for Home Care, which is backed by a broad coalition including the Maine State Nurses Association, labor unions and patient advocacy groups. His group now plans to seek legislation to expand access to home care services.
	Opponents	Opponents said the proposal was flawed because it didn't have residency or income requirements, violated patient privacy, and it would have established a board outside of state government to manage the program. They also felt that voters were tired of the referendum approach and question its use for a tax issue.
March 2020	Provider	Home Care for All, one of Maine's largest home care providers and a strong supporter of the ballot initiative, announced its intent to close its doors due to low reimbursement rates provided by the state.

[v] With ranked choice voting in Maine, there were multiple gubernatorial candidates in the primaries

MICHIGAN		
Year	**Key Actor(s)**	**Description**
2017	Michigan United and Caring Across Generations Michigan Caring Majority	Building bipartisan support on LTSS issues through personal care stories. Moved that along to a bill to provide funding for an actuarial study for LTSS finance reform. In 2017, MI Caring Majority started forming a coalition–over 20 organizations–family caregiving, homecare providers, disability rights, senior advocates, et al
	Rep Hoadley, CAG, and Michigan Caring Majority	Introduce HB 4674 requiring feasibility study for LTSS program; public-private risk sharing model, potential Medicaid savings and impact on LTSS workforce. Report to be completed within 9 months, with report to Legislature 60 days thereafter.
2018	Michigan Caring Majority	Michigan Caring Majority built a Steering Committee of 15+ organizations that signed a support letter around HB 4674 and helped to lobby for the bill to be passed in the state budget as boilerplate.
	Legislature	Legislature passed the Long-Term Care Study (formerly HB 4674) as boilerplate in the state budget with a $100,000 appropriation. Study was contingent on stakeholders raising additional matching funds.
	Stakeholders	Michigan Caring Majority raised $200,000 from Michigan Health Endowment Fund, and Sarah Slocum at Altarum raised $100,00 from the Ralph C. Wilson Foundation to support and match legislative funding for the LTSS study. Hired Milliman for the study. Study includes actuarial analysis and study of workforce issues (subcontract to Altarum and PHI.)
2019	Milliman and subcontracting partners	Oct. 1, 2019, the LTSS Feasibility Study officially started.
	Rep Hoadley and Laura DePalma	Co-created the bipartisan Caring Majority Legislative Caucus to advocate for care reforms in LTSS.
	Laura DePalma - MDHHS-led oversight	At least three (3) stakeholder listening sessions included as part of the feasibility study to get broad community input. First Stakeholder Committee meeting September 2019 and second meeting was December 2019.
	MDHHS	Overseeing the actuarial analysis
	Stakeholder Coalition	Providing input to the actuarial study and also provided support for the underlying need to do the research
	Michigan Caring Majority	The Michigan Caring Majority is a campaign and is a different bucket of work than the LTSS Feasibility Study. The campaign is organizing family caregivers and directly impacted people around issues platform, hosting community events, organizing the legislative caucus as well as public-facing events.
	Michigan United	Convening stakeholder committee meetings and listening sessions.
	Altarum and PHI	Conducting research (as specified in the feasibility study) with regard to LTSS workforce issues.
		Other supportive stakeholders: 35+ people/organizations on Stakeholder Committee for the LTSS Feasibility Study. In terms of coalition building within the Michigan Caring Majority campaign, Michigan Protection and Advocacy Service, Inc.; Community Alliance of Southeastern Michigan; Area Agency on Aging Association of Michigan, Alzheimer's Association of Michigan, National Association of Social Workers - MI, Michigan Nurses Association have all been key organizations involved with the campaign from 2017-present.

MICHIGAN (CONTINUED)		
Year	**Key Actor(s)**	**Description**
2020	Michigan Caring Majority	Conducting informant interviews with directly impacted people in the Upper Peninsula. Informant interviewees include older adults and people with disabilities that are receiving long-term services and supports and family caregivers that are providing long-term services and supports to a family member.
	Stakeholders	Two more Stakeholder Committee meetings are scheduled- one in March around care workforce and one in the summer to release the results of the LTSS Feasibility Study.
		Target date for having an initiative ready for passage: 2022-2023

MINNESOTA		
Year	**Key Actor(s)**	**Description**
2012	DHHS	Begins Own Your Future educational effort: website and community outreach to support LTC planning and awareness
	Lt Governor is prominent participant	Forms broad-based Advisory Panel of stakeholders to guide all the OYF activities and content. PR events, state fair, social media and direct mail.
		OYF activities continue
2014		Shift in focus and Advisory Panel brings in technical consultant to help facilitate identification of policy and product options for the state to consider to expand the options middle market Minnesotans have to fulfill their LTC planning needs.
		Extensive analytic process. Two options are chosen for further development: LifeStage (term life that transitions to LTC) and Enhanced Home Care which proposes to add personal care services to state's Medicare supplemental plans on mandatory basis
2017		Bring in additional consultants to work further on these two product options
		Funding obtained to do actuarial study and state-impact study for above products; some limited funding for consumer market testing at high concept level. And study of impact on Medicaid
Dec 2018		Preliminary findings presented at LTC Finance Forum
2019		Additional funding awarded for implementation work to bring products further along
January 2020		Second LTC Finance Forum
		The Governor, House and Senate agree together on legislation that establishes a blue ribbon commission –17 members charged with finding $100 million in the health and human services budgets that could be cut and provide that much savings in the state biennial budget. The commission is looking at all possible options for these savings including long-term care expenditures for older adults and persons with disabilities. The two options that OYD has done most of their work with are being considered – the Medicare nonmedical services and (on the back burner) the LifeStage option.

WASHINGTON		
Year	**Key Actor(s)**	**Description**
2013-2014	Stakeholders	Broad Coalition forms to tackle LTC financing crisis – begin to engage the public and the legislature
	Legislature	Joint Legislative Executive Committee – JLEC Long Term Care Funding Overview Long Term Care Options and Medicaid Avoidance
	Stakeholders	Washingtonians for a Responsible Future (WRF) advocates for feasibility study – actuarial analysis
2015-2016	Stakeholders	WRF coalition continues education, outreach and advocacy Heavy Heart Report https://responsiblefuture.org/heavy-hearts/
	Legislature	Mandates feasibility study and appropriates funding. Study directed to include both social insurance program design and efforts to enable private market solutions.
	Legislature	Milliman and subcontractors are engaged for actuarial analysis
		Stakeholder interviews conducted by Milliman team to offer guidance on plan design and policy objectives to include in the actuarial modeling.
2017	Actuarial Consultants	Milliman completes and presents findings of the actuarial study which includes modelling of large number of program design scenarios, and study of private market option
	Legislature	Introduces Washington LTC Trust Act
2018	Legislature	LTC Trust Act gets bi-partisan support. Passes through two committees
	Stakeholders	Local, Statewide and national media campaign and attention
		Division within stakeholder coalition as AARP pulls support prior to the vote on the bill. Raises concern with criteria for receiving benefits and flexibility of in-home benefits
	Legislature	Appropriates funding for additional actuarial analysis. Requires stakeholder workgroup over the interim to work on areas of concern.
	Stakeholders	Interim stakeholder workgroup discusses concerns, works on amendatory bill language and builds coalition of support. Bill language is approved as a result of collaborative work.
2019	Legislature	SHB 1087 to establish the Washington LTC Trust Act is passed
		Implementation development efforts begin
		Ability to leverage PFML infrastructure for payroll premium collection – facilitates program development
		Premium collection begins 2025

Appendix 3: State Coalitions Working on LTSS Financing Reform

CALIFORNIA

AARP California
Alzheimer's Association
California Alliance of Retired Americans
California Association for Adult Day Services
California Commission on Aging
California Domestic Workers Coalition
California Foundation for Independent Living Centers
California Long-Term Care Ombudsman Association
California PACE Association
Caring Across Generations
Congress of California Seniors
Disability Rights California
Disability Rights Education and Defense Fund
Hand in Hand: The Domestic Employers Network
Justice in Aging
Leading Age California
SEIU Local 2015
State Independent Living Council
The ARC of California
United Domestic Workers (UDW)/AFSCME Local 3930

HAWAII

AARP
Alzheimer's Association - Aloha Chapter
American Association of University Women, Hawaii
American Congress of Obstetricians and Gynecologists
Caring Across Generations
Executive Office On Aging
Faith Action for Community Equity
Hagadone Printing
Hawaii Appleseed Center for Economic Justice
Hawaii Family Caregiver Coalition
Hawaii Medical Association
Hawaii Pacific Health
Hawaii Public Health Association
Hawaii State Commission on the Status of Women
Healthcare Association of Hawaii

ILWU
Manoa Cottage
Maui County Office on Aging
Mental Health America of Hawai'i
Native Hawaiian Health Task Force
Paraprofessional Healthcare Institute
Policy Advisory Board of Elder Affairs
Prime Care Services Hawaii, Inc.
We Are One, Inc

MAINE

Aetna Medicare
Alliance for Addiction & Mental Health Services Alpha One
Alzheimer's Association, Maine Chapter Androscoggin Home Care & Hospice
Aroostook Area Agency on Aging
Aroostook Community Action Program
Avesta Housing Development Corp
Bedard Senior Care
C&C Realty Management
Care & Comfort
Catholic Charities of Maine
The Cedars
Central Maine HealthCare
City of Hallowell
City of Saco/Age Friendly Saco
City of South Portland
Community Concepts
Community Health Options
Consumers for Affordable Health Care
Dirigo Geriatrics Society
Downeast Community Partners
Eastern Area Agency on Aging
Elder Abuse Institute of Maine
Freeport Community Services
Foundation for Art & Healing
Good Shepherd Food Bank
Harvard Pilgrim
Healthcentric Advisors
Healthy Peninsula
Home Care & Hospice Alliance of Maine
Home Instead Senior Care
Housing Initiatives of New England Corp. Jackson Laboratory
KVCAP

LeadingAge ME/NH
Legal Services for the Elderly
Maine Community Action Association
Maine Council of Churches
Maine-Dartmouth Geriatric Medicine
Maine Equal Justice Partners
MaineGeneral Community Care
Maine Health Care Association Maine Highlands Senior Center Maine Immigrants' Rights Coalition
Maine LTC Ombudsman Program Maine Nurse Practitioner Association Maine People's Alliance
Maine Primary Care Association
Maine Senior College Network
Maine State Bar Assn/ Elder Law Section MCD Public Health
Mid Coast Senior Health
Muskie School of Public Service
Nale Law Offices, LLC
National Digital Equity Center
No Place Like Home
North Country Associates
OceanView At Falmouth
Opportunity Alliance
Penquis
People Plus
Perkins Thompson
Pine Tree Home Health Care
SAGE Maine
Saint Joseph's College
SeniorsPlus
Southern Maine Agency on Aging Spectrum Generations
Thrive Penobscot
Town & Country FCU
Town of Cumberland
Tri-County Mental Health Services UMaine Center on Aging
Tri-County Mental Health Services
UNE College of Osteopathic Medicine University of Maine System
Volunteers of America NNE
Waldo Community Action Partners
York County Community Action Corp
Associate Members: MCH, MaineHealth Care at Home, Northern Light Acadia Hospital, Vinalhaven Eldercare Services
Community Members: Judy Rawlings, Cheryl Rust, Ted Rooney, Shirl Weaver, Julie Fralich

MICHIGAN

Altarum
Alzheimer's Association of Michigan
Area Agencies on Aging Association of Michigan Caring Across Generations
Christin Carthage, Individual Advocate
Community Alliance
Community Catalyst
Terry Earnley, Individual Advocate
Emily Dieppa, PHI
Kelly Dillaha, Candidate for Oakland County Commissioner
Rep. Jon Hoadley
Huron Valley PACE
IMPART Alliance
Institute of Gerontology, Wayne State University LA SED
Donald Keyes, Individual Advocate and Home Help Participant
Rep. Padma Kuppa
Jennifer Lugo, Direct Care Worker
Maureen McConnell, Individual Advocate
Laura McCoy, Individual Advocate
Terri McKinnon, Individual Advocate
Michigan Developmental Disabilities Council
Michigan Disability Rights Coalition
Michigan Elder Justice Initiative
Michigan League for Public Policy
Michigan Nurses Association
Michigan United
Deanna Mitchell, Individual Advocate
Patricia Myles, Individual Advocate
National Association of Social Workers
Patricia Paul, Individual Advocate
The NOAH Project
Rep. Laurie Pohutsky
Progressive Residential Services, Inc. and the Life Enrichment Academy
Lois Robbins, Individual Advocate
St. Catherine of Siena Parish, Portage, Michigan
Sarah Slocum, Individual Advocate
Chasidy Stevens, Direct Care Worker
Hollis Turnham, Individual Advocate
Unity Lutheran Church, Southgate, Michigan

MINNESOTA

AARP Minnesota
Minnesota Leadership Council on Aging
Alzheimer's Association
Citizens League
UCare
Long, Reher and Hanson, P.A.
Ameriprise Financial, Inc.
Minnesota Home Care Association
MN Insurance and Financial Services Council
LeadingAge Minnesota
Care Providers of Minnesota (CPM)
Newman Long-Term Care
Horizon Agency
Minnesota Board on Aging
Central MN Council on Aging
Minnesota Business Partnership
Minnesota Chamber of Commerce, Health and Transportation Policy
Minnesota Department of Commerce
Minnesota Department of Health
Minnesota Department of Human Services, Continuing Care for Older Adults (CCOA)
Minnesota Department of Human Services, Health Care Eligibility Policy
Minnesota Management and Budget (MMB)
SEIU Healthcare Minnesota, Home Care Sector
Minnesota State Retirement System
Reverse Mortgages SIDAC
Training to Serve (trains agencies to meet needs of GLBT older adults)
Twin Cities Medical Society
Twin Cities Public Television, Inc. (TPT)
Greater Twin Cities United Way
University of Minnesota, Family Economics and Gerontology

WASHINGTON

AARP
Adult Family Home Council of Washington State
Alzheimer's Association Washington State Chapter
Asian Pacific Islander Coalition Washington
Caring Across Generations
Casa Latina
ElderCare Alliance
Equal Rights Washington
First Choice In-Home Care
Keiro Northwest formerly Nikkei Concerns

Latino Community Fund
LeadingAge Washington
LGBTQ Allyship
One America
Progreso: Latino Progress
Puget Sound Advocates for Retirement Action
SEIU 775
Washington Association of Area Agencies on Aging
Washington Health Care Association
Washington State Senior Citizens' Lobby
Washington State Long-Term Care Ombudsman

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

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