

Washington Long-Term Care Trust Fund:

A CAMPAIGN EXPLAINED

MAY 2021



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ACKNOWLEDGMENTS

The passage of the Long-Term Care Trust Act led by Washingtonians for a Responsible Future gives hope to families struggling to afford to care for their loved ones. We were truly inspired by this impressive win and how it provides the nation a vision of what is possible. Our hope is that this report portrays the collective experience of those who played a part in making the Long-Term Care Trust Act a reality, and that it celebrates their hard-won victory. And, we hope that sharing the Washington story will help other coalitions and states advance systems of care that are dignified and sustainable for the workforce, and are more supportive and accessible for all families.

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SEIU 775

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Bea Rector, *Washington State Department of Social and Health Services*

Kate White Tudor, *Washington Association of Area Agencies on Aging*

Judy Warnick, *WA State Senator, 13th District*

*Organizational affiliations are as of the time of the interview and are provided for identification purposes only.



EXECUTIVE SUMMARY

Establishing the nation's first social insurance program for long-term care

In 2019, Washington State passed the Long-Term Care Trust Act establishing the nation's first state-run, publicly-funded long-term care program. Funded through a payroll tax, the program covers a broad range of long-term care services and supports for people aging at home, in a skilled nursing facility, or in a community-based residential setting. It marked a significant victory for the coalition Washingtonians for a Responsible Future who spent a decade developing the legislation and organizing the support for its passage. The Trust Act would not have been possible without the dedicated and strategic leaders at the helm of the campaign coalition who were determined to pass something meaningful to strengthen the state's social safety net. The coalition not only had to make the case for the legislation, it also had to address a strong anti-tax sentiment in the state that constrains public financing options, as well as navigate different stakeholder interests represented within the coalition itself.

Taking early steps to shift towards home- and community-based care

This campaign is a milestone on a much longer path of reshaping how care is delivered, valued, and funded. Since the 1990s, Washington State has been shifting its long-term care infrastructure to make it easier for people to stay in their homes and in their communities. To support a shift from institutional settings to home- and community-based care, the system has become more localized than centralized with the state. What has been established is a network of system providers across the state, partnerships among government agencies, and the information technology systems that support coordination and the delivery of benefits. Having this infrastructure already in place has facilitated the implementation of the new set of supports and services of the Long-Term Care Trust.

Building a coalition of key stakeholders

Washingtonians for a Responsible Future is a coalition of organizations representing stakeholders who have an interest in ensuring that there is a viable and affordable long-term care system in place: caregivers and the recipient families, long-term care services and supports providers, and advocacy organizations. Each organizational partner came to the table with the issues, concerns, and experiences of its particular constituency - for example, SEIU 775 representing caregivers, AARP of Washington State representing seniors, and Caring Across Generations representing a national movement to redefine care. The coalition itself was a space in which an iterative policy development and negotiation process played out. As a result, they could approach lawmakers with a unified vision and solution around which they could mobilize broad support. Together, they developed the policy, organized champions, and worked through differences over multiple legislative sessions until it finally passed with bipartisan support and was signed by the Governor.

Working through differences

While a strength of the coalition lies within its diversity of stakeholders, such differences can also lead to disagreements. In what some referred to as the “Lost Summer of 2018,” the campaign almost came to a halt due to divergences in the proposed program about including family caregivers as beneficiaries. There were strong positions within the coalition and also publicly about its viability. Leaders were able to get a budget allocation to cover mediation planning requiring at least ten meetings that summer, which were facilitated by respected leaders in the field. While it was painstaking and time consuming, everyone agreed that the resulting policy was better because of the debate and process. And what we learn from this case is that it pays off to work through differences as now they are a stronger coalition with a win under their belts and expertise that now carries over in their participation in the oversight commission.

Addressing fiscal conservatism

Coalition leaders kept their determination over the course of ten years during which they deployed what skills, expertise, and resources they had to pass something meaningful for the residents of Washington. In determining how to fund services and supports, the coalition faced strong anti-tax sentiment and fiscal conservatism among both the state’s electorate and its legislators. Conducting a financial feasibility study was critical to overcoming fiscal concerns among legislators. The State and the coalition jointly contracted with an actuarial firm to assess different public and private funding options to help Washingtonians cover long-term care. The detailed analysis of the trends, policy factors, and impacts found that there was potential to generate savings to the Medicaid program thus bolstering the case for a public long-term care insurance benefit.

Linking personal concerns to policy solutions

Messaging to different audiences is part and parcel for any campaign – and this campaign was no different in that respect. Perhaps more importantly than messaging for a policy win was messaging for a fundamental shift in culture that recognizes and values care and caregiving. The campaign led with a narrative recognizing care for our aging residents as a moral obligation that all Washingtonians may face. Yet, given the battle over austerity, the campaign also addressed fiscal responsibility – and the importance of a trust to keep the Medicaid system from collapsing while saving the state (and employers) money. Moreover, the campaign connected people’s personal struggles of caring for an aging loved one to the policy solution – making it a common experience that was more personal than political.

Strengthening what was won

A motto that comes to mind in understanding the campaign is “do not let perfection get in the way of the good.” Even before the signature was dry, the work continues to address issues such as allowing tribal employers to participate in the Trust and providing benefits to qualified workers with developmental disabilities. Parts of the legislation that were left behind in the negotiations to keep an eye on are: an opt-out option that allows private long-term care insurance policy holders to forego the benefit and a process for self-employed individuals to opt-in. In the long-term, educating the public on the importance of government and a strong social safety net – and the role of revenues in providing those essential services and supports – is needed to secure Washington’s future generations.

Overseeing its implementation

Beyond the immediate legislative amendments, there is much work to ensure the Act's implementation. State agency rules should be clearly defined, assigned, and then codified in the legislation. The Long-Term Services and Supports Trust Commission begins its work making “recommendations and decisions guided by the joint goals of maintaining benefit adequacy and maintaining fund solvency and sustainability.” With Washington State as an early adopter, many will have their eyes on the financing mechanism and the Trust’s financial viability. Allowing the state to invest the Trust funds – as the state does so for public pension or retirement funds and for the industrial insurance trust fund – is not yet allowed as voters did not pass the initiative in the 2020 ballot. But efforts to put it before voters again are underway.

Looking at the Road Ahead

This campaign will benefit aging adults, those with long-term disabilities, their families, and their caregivers. It happened on the heels of the Paid Family and Medical Leave Act which benefits primarily working families and younger families. In Washington, there are ongoing efforts to move towards a system of universal pre-K. Progress on these three efforts are pushing Washington towards a vision of universal family care. And what happens in Washington does not stay in Washington. SeaTac passed the first \$15 minimum wage that energized efforts across the country. It is the same spark that we hope the Long-Term Care Trust Act will ignite in the years to come.



INTRODUCTION

In 2019, Washington State passed the Long-Term Care (LTC) Trust Act establishing the nation's first publicly funded long-term care insurance program. The LTC Trust Act was the result of a ten-year effort led by Washingtonians for a Responsible Future (WRF), a broad coalition of organizations representing stakeholders who have an interest in ensuring that there is a viable, affordable long-term care system in place for caregivers and the recipient families, long-term care services and supports providers, and advocacy organizations.

Other states have their eyes on this pioneering approach as the aging wave is a demographic reality nationwide. An increasing number of families throughout the country struggle with the costs of care for oneself and for loved ones.¹ Medicaid covers only medical needs, not living supports like home health aides or nursing homes. Elders with low enough incomes—depending on the state, anywhere from \$6,825 to \$47,139 a year—qualify for Medicaid, which does cover nursing-home costs. Those with greater resources must first spend down their savings and assets in order to qualify. They also must demonstrate they have a need for nursing-home care. Some state Medicaid programs do not cover in-home care or cap the number of people who can access it.

While action is needed at the federal level, state-level solutions like Washington's LTC Trust program are important because they not only improve the lives of their population, but they also serve as models for other states and inform federal action. There are several states that are likely to be interested in the lessons from Washington. In Hawaii, efforts to establish a social insurance program for long-term care date as far back as 1985 yet have yet to come to fruition. In California, the governor released a Master Plan for Aging in January 2021 marking its commitment and strategies for preparing for its growth in aging adults.² Illinois and Michigan are thinking about long-term care financing mechanisms.³

This report is an attempt to share insights and lessons from Washington with those interested in long-term, sustainable, and publicly funded and operated solutions in their own state. In 2020, USC Equity Research Institute interviewed people who were deeply involved in the effort behind the LTC Trust Act about their experiences, knowledge, insights, and learnings. While there are aspects of the legislation - and the road to win it - that are uniquely Washingtonian, there are aspects that are relevant and applicable regardless of the particular conditions and capacities in one place. Our hope is that by sharing lessons from the campaign, it may shorten the number of years it takes to win similar, or improved, legislation in other states - and that the cumulative impact is to inform a federal solution.

This report is organized as follows: It starts with the basics of the legislation and the broad-based coalition behind it. Because the campaign to develop and pass the legislation is part of a long trajectory of organizing, advocacy, and coalition building, we then detail the valuable lessons learned through the process. To conclude, we offer some recommendations to those considering how to find solutions to the growing long-term care crisis.



WASHINGTON LONG-TERM CARE TRUST ACT

The Long-Term Care (LTC) Trust Act establishes the first-of-its-kind, state-administered social insurance program for long-term services and supports. Starting in 2025, the program covers up to \$36,500 for workers older than 18 years needing long-term care whether they are living at home, in a skilled nursing facility, or in a community-based residential setting.

The LTC Trust Act covers a broad range of supports and services that are not covered by Medicaid: a home health aide to provide periodic support and care; the installation of an accessible shower or ramp in the person's home; transportation to and from medical appointments; and food delivery for someone who is homebound. A younger person who suffers an unexpected injury or illness could similarly hire someone to help them in their home. Those with disabilities, and the family members who support them, can help cover some of their more episodic needs, particularly for individuals whose needs aren't severe enough to require living in a facility.

Starting in 2022, the state will begin to fund the trust through a payroll tax of 0.58 percent on employees. The payroll premium will collect about \$1 billion each year for the dedicated trust fund. "This structure supports the work that we've done in Washington to professionalize caregivers," noted Sterling Harders, president of SEIU 775, which represents home health workers. While her members had already secured a \$15 minimum wage, affordable health insurance, and a retirement benefit in Washington, across the country their peers mostly earn less than that and have little access to benefits. The LTC Trust Act will "help ensure that the people providing this care are skilled, trained, certified, and that they are paid fairly for their work," said Harders.

To be eligible, residents have to show they need help with at least three routine activities, such as dressing, bathing and other personal hygiene needs, eating and cognitive issues. One has to have paid the payroll tax for

“...it was kind of a convergence of a variety of things...the infrastructure that we had in the state, the support of the legislature to look at a creative option, and then also the fact that the private market was not working in the state and we saw kind of a cataclysmic event happening with long-term care as the Age Wave continued.”

CATHY MCMAUL, AARP
Washington State

10 years without interruption of five or more than six consecutive years. For a catastrophic disabling event, one has to have paid into the fund for at least three of the last six years. First payroll deductions begin January 1st, 2022 and the first claim for benefits can begin on January 1st, 2025.

The legislation also establishes the Long-Term Trust Services and Supports (LTSS) Commission, made up of legislators, administering agencies, and stakeholder representatives. The purpose of the Commission is to propose recommendations to the appropriate executive agency or legislature regarding issues related to long-term care and services. The Commission’s recommendations and decisions must be guided by the joint goals of maintaining benefit adequacy and maintaining fund solvency and sustainability. The Commission makes recommendations about implementing the bill such as criteria for determining who is a qualified individual, minimum provider qualifications, service payment maximums, actions needed to maintain Trust solvency, and monitoring of agency expenses.⁴

STATE-RUN SOCIAL INSURANCE PROGRAMS

Paid Family and Medical Leave, 2017

Covers up to 16 weeks of paid leave; benefit is 90% of wages capped at \$1,000/week; funded by a payroll tax of 0.4% of wages.

Long-Term Care Trust Act, 2019

Covers a range of supports and services up to a lifetime maximum of \$36,500; funded by 0.58% payroll tax.

Early Childhood Education and Assistance Program, expansion 2018

Goal is to move towards universal pre-K for low-income children; enrolling 90% of eligible children by 2023; program is overseen by Department of Children, Youth, and Families (DCYF) and implemented through contracts with school districts, educational service districts, community colleges, local governments, tribal organizations, child care centers and homes, and non-profits.



WASHINGTONIANS FOR A RESPONSIBLE FUTURE

Washingtonians for a Responsible Future

The fight for solutions to address the growing need for long-term care started at least a decade before the Long-Term Care (LTC) Trust Act was signed into law. There had been a constant push from various stakeholders to bring attention to the issues to legislators and the public. In 2014, legislators responded by convening the Joint Legislative Executive Committee on Aging and Disability to look at policy options and actions that the state can take to prepare for its aging population.⁵ For the coalition, it was a marker of success because it indicated that lawmakers had finally heard the calls for action.

Leading the fight was a determined coalition Washingtonians for a Responsible Future (WRF) that included organizations representing a diversity of sectors affected by the long-term care system: advocates for aging adults and people with disabilities, long-term care providers, labor,⁶ consumer rights organizations, administrative offices, and families. In addition to representing a diversity of interests, it combined the resources of larger groups, like SEIU 775, AARP of Washington State, and smaller groups like Puget Sound Advocates for Retirement Action (PSARA) and brought together their diverse perspectives and common interests to advocate for the LTCA. These groups were deeply engaged stakeholders that were both committed to their interests and to getting something meaningful passed.

The coalition was intentionally formed as a cross-sectoral body that harnessed the knowledge and power of stakeholders familiar with the issue. As will be described below, organizing and sustaining the group demanded long-term relationship building, perseverance, and trust. In fact, many coalition members have continued the work by participating in the implementation phase of the work via the Long-Term Care and Supports Commission (LTSS). Many of the collaborative members serve on the LTSS Commission and they are actively overseeing and improving upon the bill. For example, the LTSS is now recommending tribal employers to participate in the Trust and providing benefits to qualified workers with developmental disabilities.

Member organizations

AARP of Washington State
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

Source: "About Washingtonians for a Responsible Future." Washingtonians for a Responsible Future. <https://responsiblefuture.org/about/>.



A SHIFT IN CARE: LAYING THE FOUNDATIONS FOR THE LONG-TERM CARE TRUST

Washington's Long-Term Care System Ranks among the Best in the Nation

According to AARP's 2020 scorecard, Washington State's long-term care system ranks second in the country.⁷ There are three key factors behind its strong performance. The first is that the state has taken measures to help aging adults and those with long-term disabilities stay in familiar environments. Medicaid spending in the state is balanced between nursing homes and home-based and community-based care which allows care recipients to remain in their homes and in the community for as long as possible. Secondly, Washington ranks high due to efforts to streamline access points and increase coordination across multiple public agencies and private service providers which makes access to services and supports more accessible to those seeking care. The third factor reflects the leadership of SEIU 775: Washington is also a leader in supporting working family caregivers.

Washington Shifted Its System to Support Aging and Long-Term Disability at Home

Since the 1990s, there has been a dedicated effort to shift the long-term care system from a more institutional care-focused financing mechanism into more comprehensive and flexible community-based long-term services and supports. The Medicaid waiver from the Centers for Medicare and Medicaid Services (CMS) allows Washington State to allow home- and community-based services and addresses the need for financial flexibility and expanded eligibility.⁸ These changes have been essential in covering more people and in protecting them from having to spend down their resources in order to qualify for Medicaid. Meanwhile, the private long-term care insurance system does not work for most people as many elderly are unable to cover long-term care premiums and have to drop their policies putting further financial strain on the state's Medicaid system. Without action, the increasing demand on the Medicaid system would become greater than its resources thus requiring a new revenue source to lessen the demand on the general fund.

“ We spent 20 years rebalancing our caseloads so that we have skilled nursing facilities, assisted living facilities, adult family homes, independent living situations, and in-home care. We have a robust system that let us build the Long-Term Care Trust program so that the benefit is meaningful. ”

LAURIE JINKINS, *Speaker of
the House of Representatives*

The Paid Family and Medical Leave Act Paved the Way for the Long-Term Care Trust Act

When we interviewed people involved with the LTC Trust Act, almost everyone saw the 2019 passage of the Paid Family and Medical Leave Act as paving the way for the Trust Act's revenue source. The Paid Medical and Family Leave Act, which was endorsed by many advocating for the LTC Trust Act, established a payroll-financed program for workers recovering from or supporting a family member with serious health conditions, dealing with a military deployment, and benefiting younger families with a newborn or newly placed foster or adopted child.⁹ Washingtonians for a Responsible Future was able to build on knowledge, messaging, relationships, and organizing used to benefit younger families to look at the needs of older individuals and families.

The Infrastructure for Expanded Long-Term Care was Already in Place

By the time the campaign for the Long-Term Care Trust was underway, the state already had a robust infrastructure in place to support the expanded beneficiaries and expansion of benefits. According to one interviewee: "figuring out qualifying vendors, figuring out appropriate rates, having a payment system, having a way of evaluating whether or not a benefit is necessary for supports like wheelchair ramps or medication management or adult day health or the various other benefits that we in Washington State have already established as state benefits decades earlier." The additional administrative costs to implement the Act are kept to a minimum because it builds on the existing infrastructure.

Government-Provider Collaboration and Coordination is Essential

Essential to meeting higher demand was having the infrastructure to manage and deliver services. Collaboration between the Department of Social and Health Services (DSHS) and area service providers was instrumental to passing something actually useful and feasible. The decentralized system of LTC was more localized/grassroots rather than centralized with the state, which helped to identify and address gaps and needs in the Medicaid system. An agreement with a strong community partner, WA Area Agencies on Aging (AAA), provides many of these services. It does the assessment of caregivers and all the in-home case management. It is funded through the state on unit-based use. Other groups and networks provide important services including: referrals, options for counseling and assistance, eligibility assistance, and transition support. Also, Washington's rural geography has required that delivery of care be more decentralized because there are fewer local healthcare resources available in the state's rural areas. The desire to age in place may be that much more necessary in those regions.

“ Our Paid Family and Medical Leave Act, which passed in the previous session, introduced us to a social service program that could extend benefits in a way that was not burdensome to business. ”

LAURI ST. OURS, *Washington Health Care Association*

“ The Trust Act is as cheap as it is administratively because we're piggybacking on the DSHS-approved vendor list, the Medicaid payment system through Provider One, and all of the infrastructure and IT that's already in place for a long-term care system. It's already decided what to cover. For us to just say now we have a new payment source for those benefits, that's easy. ”

KATE TUDOR, *Washington Association of Area Agencies on Aging*

Washington has a History of Strong Labor-Community Alliances

Lastly, one foundational aspect of the campaign lies in the state’s history of strong labor-community alliances, particularly with the leadership of SEIU 775. Having the power of organized labor connected closely with community and other constituent/membership groups was a key factor in the campaign. Having a well-trained caregiving workforce is important to delivering quality services – and SEIU 775 has successfully advocated for better wages and benefits for the caregivers it represents.



KEY LESSONS FROM THE CAMPAIGN FOR THE LONG-TERM CARE TRUST ACT

Washingtonians for a Responsible Future (WRF) used a myriad of strategies to achieve a victory for long-term care recipients, their families, and those who provide their care. In this section, we highlight key lessons from their strategies that may be useful in other states attempting to reach a similar goal.

Building a Broad-Based Coalition with Diverse Capacities

Creating and leading a successful campaign required a clear vision, coupled with tireless coalition building, educating, organizing, research,¹⁰ and policy development. According to several interviewees, the strength cultivated within the coalition was due to having members who represented all sides of the issue. WRF's leading labor organization, SEIU 775, brought a long-term vision, the perspectives of a diverse workforce of caregivers, and a strong set of organizational resources, such as financial contributions and relationships with legislators. AARP of Washington State brought the interests of their membership of aging adults as well as national recognition and resources. Smaller organizations, like Puget Sound Advocates for Retirement Action (PSARA) and Washington's Area Agencies on Aging (AAA), bolstered the group with their community connections and deep understanding of the issue's impacts on Washingtonians. Just as important were statewide administrative office representatives with experience and insight on actuarial studies and implementation.

An important step that the coalition took was reaching consensus on the core mission around a shared philosophy and viewpoint. It was a process to make explicit the implicit assumptions by putting them on paper, stating a clear goal, and deciding what success would look like. This gave coalition members clarity over terms like "long-term care" versus "long-term supports and services", and eased tensions between those who advocated for institutional care over home- or community-based care and vice versa.

In addition to members who joined the coalition on behalf of their organization, contract workers were hired to accomplish goals critical to the campaign. This included gathering stories from WA residents about

“ Any one of the groups - labor providers, citizens, legislature - coming to this issue separately might have raised awareness. But that all the groups focused on this as the next step for Washington is really what made this happen. There was a common interest that was initiated by some actions by SEIU [775] and it snowballed into what we ended up with in the bill. ”

DAN MURPHY, Northwest Regional Council

their experiences with long-term care and preparing those residents to tell their stories to the legislature. The same contract workers would also inform residents about the numbers of people across the state experiencing similar issues, thus connecting their individual stories to a larger systemic issue.

The lack of racial and ethnic diversity in the coalition, however, was admittedly a missed opportunity. According to interviewees, involving grassroots organizations rooted in low-income Black, immigrant, and Indigenous communities and other low-income communities of color was a weakness in the coalition. Attempts to bring in more diverse organizations were met by resistance and questioning whether their constituencies would be truly represented in the legislation at that point in the campaign. Some pointed out that an equity mindset that considered the barriers to participation in the coalition – such as transportation, staff availability, etc. – was necessary to support the participation of smaller yet highly important organizations.

Working through Conflict within the Coalition

What seemed like a major obstacle was an opportunity to further refine the proposal in a way that could gain more support by important partners like AARP.

LAURI ST. OURS, Washington Health Care Association

Despite efforts to build consensus and trust towards a common goal, there was one disagreement that brought the campaign to a halt. When the bill first made it to the floor for a vote, in the 2018 legislative session, there was a pivotal fissure in the coalition related to a goal set out by AARP. The organization's membership was explicitly requesting support for family caregivers, which was not a group initially identified as beneficiaries in the bill. Taking a stand on this issue ultimately led to AARP pulling their support from the bill. As one of the most well-known and active proponents of the issue, its decision eventually led the legislature to vote against it. According to multiple interviewees, the issue arose due to communication issues where the interests of AARP's membership did not seem clear, but also from the fact that other stakeholders did not seem to take the time to understand to the organization's interests.

Understandably, this event created a gap in trust that took time and labor to rebuild. As a result of quick thinking and work from bill proponents, Dan Murphy and Kate Tudor, with support from Representative Laurie Jenkins, the coalition secured funding for a stakeholder group to convene in between legislative sessions to rework the bill. The group convened in the "Lost Summer of 2018" – as one interviewee fondly remembered it – as was mandated by the legislature. The group met as many as 10 times that summer through a process skillfully facilitated by key members such as Dan Murphy from Northwest Regional Council, Madeleine Foutch from SEIU 775, and Representative Laurie Jenkins.

“The bill benefited from all of the slowing down and the stakeholder work that we did.”

KATE TUDOR, Washington Association of Area Agencies on Aging

What resulted was an iterative process with representatives from all kinds of citizen groups and agencies. Through these meetings, the group decided on recommendations about what services could be provided under this Act, the qualifications of who could provide and receive these services, and recommendations about how family could become providers. Despite losing the bill in 2018 and enduring a grueling summer of work, interviewees agreed that this work ultimately resulted in a better bill for Washington residents.

Organizing, Organizing, Organizing

You can't underestimate the impact of SEIU [775] and organized labor to help catalyze the beginnings of a campaign. SEIU [775] has been part of Washington's long-term care system since about 2001. A lot of the community-based providers are a part of organized labor, which creates both an action base and a political base.

DAN MURPHY, Northwest Regional Council

Meeting with and organizing everyday people in every corner of the state impacted by long-term care issues was critical to the campaign's success. SEIU 775 organized, educated, and activated their own members around the issue. There also arose a need to connect with and organize more community members beyond the union's membership. As previously mentioned, the coalition hired a dedicated organizer who went into communities to meet new people affected by long-term care issues and to gather their stories.

What eventually emerged in these small community meetings was awareness-building amongst residents who often did not know that their neighbors were enduring similar issues. The process thus embarked on a leadership development effort with those residents so that they were not only connected to a community, but also brought into the LTC Trust Act campaign. Some residents were eventually prepared to tell their story to neighbors as a form of relational organizing and to legislators as a form of testifying for the bill. One interviewee shared that she was even able to encourage friends from Eastern Washington - a traditionally conservative area - to contact their legislators about their own long-term care and caregiving needs.

According to interviewees, the campaign yielded a core group of spokespeople who engaged community members, the legislature, and the media. Interviewees shared that the leaders that emerged from the community were special in that there was a large degree of selflessness in their decision to tell their stories. Those who testified often shared very

“ We did a lot of power building and leadership development with our grassroots base, including our membership, but also expanded out to other people. As a coalition we hired a full-time organizer who went to different places, making connections with people who had been impacted and let down by the system and really having a core set of leaders who are able to tell their personal story and also reach out within their communities to try to get more action and engagement...Having that core dedicated voice of real people who would be the spokespeople, who would show up, was key. ”

MADELEINE FOUTCH, SEIU 775

personal and painful stories about being unable to afford services for their aging loved ones or about wanting to age with dignity in their homes. This vulnerability took place despite the fact that many testifiers and their loved ones are not likely to qualify for these services since they will only begin to be collected in 2022 and administered starting in 2025.

Bolstering Efforts with Reputable Data and Analysis

It was critically important to have the actuarial work done to provide some level of assurance to the financial committees of the legislature, particularly about the actuarial soundness of this proposal, about the services, and about the reduction in Medicaid spending that one could potentially experience based on this program.

LAURI ST. OURS, Washington Health Care Association

Several members of the coalition pointed to the power of the actuarial studies in the campaign. Knowing that the issue was gaining attention and reaching urgency, the State Legislature required Washington's Department of Social and Health Services (DSHS) and Aging and Long-Term Support Administration (AL TSA) to commission the report in 2015. The studies concluded that the Trust Act was financially feasible and even better than the alternative of continuing to rely on Medicaid and private insurance for those requiring long-term care. The study looked at different scenarios of a fully public option and public-private option—which revealed that a public option was the way to go to both save money and have a more meaningful and expansive reach.¹¹ Scenarios demonstrated how the Medicaid system would eventually not be able to meet rising demand. In the end, it demonstrated the need for a new source of revenue that would lessen the demand on the state's general fund.

The idea of financial responsibility did well to assuage the concern of fiscally conservative legislators who worried that the Trust Act would be either too expensive or ineffective. Having hard data that showed the opposite was invaluable backing for coalition members in direct contact with legislators. In addition to a strong financial basis for the bill, the Trust Act appealed to those who desire a stronger, more robust social safety net. This information was collected and used before the bill was drafted, thus informing the direction of the bill entirely. Actuarial studies, according to one legislative champion, made that decision very clear. Other options would simply cost more and did not guarantee to address the issue of unaffordable and inaccessible long-term care.¹²

Not many people in the state are covered by private insurance plans – or are able to keep their coverage. Premium payments inched higher and higher until many had to eventually opt out. Even though some WA residents had paid into their insurance plans for years in anticipation of requiring long-term care services, they have ultimately had to abandon their plans and receive no benefits

Source: <https://www.kuow.org/stories/washington-becomes-first-state-to-offer-public-health-insurance-option-long-term-care-benefit>

// You've got to pass this or our Medicaid system will go bankrupt in a couple decades. //

The Trust Act showed savings to the Medicaid program because people would have the equivalent of their Medicaid benefits covered by the Trust for six months or for a year. It had real actuarial implications of saving hundreds of millions of dollars through the state Medicaid system.

Deploying Narratives for Every Corner

Communicating the issue of long-term care to resonate with different audiences was a crucial advantage to the campaign. The high costs of paying for long-term care services out-of-pocket created an urgency to the problem that not only brought light to the issue, but spoke to the minds of both fiscally- and socially-concerned stakeholders. Interviewees shared that they had heard of and spoken to Washington residents who were having to spend down their savings to get access to Medicaid benefits or have their loved ones abandon jobs to care for them. Throughout the campaign, it was relatively easy to demonstrate how people all over the state were affected or would eventually be affected – either by reaching the age where they require care themselves or having a loved one that requires care.

There were moral arguments to the effort as well. Protecting some of the most vulnerable in their time of need via a social safety net program resonated with many. Having residents go to the Capitol prepared with their personal testimonies was particularly impactful for legislators. One interviewee who shared her testimony to the legislature shared that it was the one strategy she was tasked with and it was the one that she saw as impactful. She testified a few times and saw caregivers, professionals, and others testify alongside her. By putting many different faces to the issue – ranging from recipients of care, relative caregivers, and professional caregivers – the campaign was able to prove that this issue is not only a moral one, but one that affects all types of Washingtonians.

Another narrative used by the coalition was about the workforce required to meet the rising need for long-term care services. SEIU 775 led the charge in sharing the labor perspective for a living wage, training, and secure and safe jobs. Their membership revealed that many caregivers at the time were underpaid or providing this type of care for free to family. Many caregivers, they shared, were immigrant women providing an essential service with insecure working conditions, long hours, and low wages. As a result of engaging with her constituents, one interviewee and legislator shared that she saw the labor side of the issue to be a clear immigrant issue. She heard of immigrant women often serving as underpaid caregivers and that there are not enough training resources for them or others looking to provide care for loved ones.

“ Having personal stories from across the state that showed geographic breadth, pairing those stories with the research and the numbers, and having a narrative backed up by the fact that this is not just one person. It is actually a wave of thousands of people who are going to need this care. Then adding to that, having one of our 800,000 unpaid caregivers tell their story about being an unpaid caregiver. That combination was powerful. ”

SEIU 775

“ Getting out those stories was something that could give a face to all the policy organizing. Being able to put a face to and understand the human suffering behind what those numbers mean. ”

COURTNEY NEUBAUER,
Organizer at Washingtonians for a Responsible Future

Last is the fiscal responsibility argument, based in the actuarial study detailed above. This narrative demonstrated that the bill would end up saving dollars down the road and free up Medicaid to care for other needs. Supporters of the bill also shifted from the notion of a “tax” to a wage-earner “premium.” This messaging not only skirted the challenges of it being seen as a pro-tax proposal in an anti-tax climate but it also neutralized potential opposition from employers. Other economic arguments around the loss of productivity among a generation of workers sandwiched between caring for parents and children helped to bring employers along.

Some interviewees thought that emphasizing the \$36.5k lifetime benefit was a strong message for the Washington residents who had invested in private insurance options for decades and eventually had to give it up due to high premiums. However, there was also an understanding about the benefit that, as helpful as it will be for many, it will ultimately not be enough to cover every need. To address this shortcoming, the coalition used a larger framing that emphasized that this campaign was not about just one bill, but part of a larger legislative effort to accomplish true change for caregivers and those requiring long-term care.

Securing Legislative Champions

Representative Jinkins is the embodiment of collaborative leadership and fostered a sense of openness and encouraging all voices at the table.

CATHY MACCAUL, AARP Washington State

Coalition members who already had established relationships with legislators moved strategically to identify those who could lead their fight at the Capitol. The combination of knowledge and relationships coming from the coalition cultivated a sense of legitimacy within the legislature that the coalition used to their advantage. The first time the bill was proposed in 2018, it was co-sponsorship by then-Democratic Representative (now Speaker) Laurie Jinkins and Republican Representative Norm Johnson. Having bipartisan support on this issue was helpful to organizers and lobbyists trying to secure the votes necessary for the bill to pass. When the bill did not pass in the 2018 legislative session, it made the role of legislative champions all the more important.

Through both rounds of the bill, current Speaker of the House Laurie Jinkins was the champion who stood by the issue until it crossed the finish line. During the campaign, Jinkins, not yet the House Speaker, was a Representative with extensive experience in healthcare administration who also faced long-term care issues with her own family. Interviewees shared that having a champion in the House with the experience of a loved one requiring long-term care helped colleagues realize that this issue is not

CHAMPION IN ACTION

To support the negotiation and collaboration process that would take the summer of 2018, coalition members worked quickly after the failed vote to craft and propose language to the state’s budget proposal that would allot money for a stakeholder group to convene and propose a new bill in the next session. State Representative and legislative champion Laurie Jinkins worked with coalition members to come up with a \$100,000 line item in the budget proposal. This funding assigned AAA to be the neutral convener of the group between SEIU 775 and AARP WA State and all other members with the goal of writing a bill that satisfied all coalition members. The result of that group was the bill that eventually passed the 2019 legislative session.

theoretical – it is, in fact, a real issue impacting the lives of Washingtonians daily. The Speaker was also an indispensable facilitator of coalition meetings as the group labored through a rewrite of the bill for the 2019 session.

Judy Warnick was one of the only Republicans in Washington State’s Senate to vote in favor of the bill. For Senator Warnick, it was through her work in the state’s budget and finances that she formally entered the long-term care debate. In looking at the numbers herself, she realized that there was a grave lack of funding for seniors requiring long-term care services. However, it was a combination of personal issues with older family members needing care, talking with constituents about their struggles obtaining care for loved ones, and sitting in budgetary discussions that did not allocate substantial funding to the issue that led to her overall support for this particular bill. In addition to the clear urgency of the issue, she shared that it was the tenacity of organizers and lobbyists that made the difference this time around. Senator Warnick described their campaign as one that took the time to develop relationships, trust, and continued interest among legislators on both sides of the aisle.

Former Speaker of the House Frank Chopp was another champion who played a unique and vital role in the issue. Representative Chopp was a critical “insider” whose organizing background became apparent as a Democratic majority ultimately voted in favor of the bill when it came before the House. He was supportive in ways that did not alienate potential votes from across the aisle. It was important to him that the coalition had the diverse expertise and capacity to determine and argue the specifics of the Trust Act.

Strong legislative leadership became invaluable to the coalition as it took time to rewrite the bill for the 2019 session. Coalition members looked to them for their continued support and to keep momentum for the bill alive in the legislature. This was especially true when the coalition had to navigate difficult political dynamics, such as having the House Republican co-sponsor for the 2019 bill ultimately vote “no” on the issue. Despite political challenges, the bill’s champions and the legislators who heeded their words supported the bill in the end and shared in the win alongside committed organizers, lobbyists, and advocates in the coalition.

ADDRESSING THE BUSINESS SECTOR

Business interests were addressed early in the campaign process. Educating business that this bill would enact a worker, rather than employer, premium removed the potential threat this posed to the sector. This lack of opposition by business was helpful to organizers as they could focus on other stakeholders. Interviewees perceived business interests as either a neutral or even slightly supportive group when it came to passing the bill.

Knowing Non-Negotiables and Negotiables

Those crucial conversations about what belongs in statute language versus what you leave out of statute language to allow the room to have those conversations down the road because trying to get to agreement on prescriptive implementation language within the tight timeframes of a legislative session would have likely meant the bill wouldn't pass.

BEA RECTOR, *Washington State Department of Social and Health Services*

Coalition members had to negotiate the monetary amount of the benefit provided through the Trust Act. There was also extensive discussion about what the funds could be used for, who could access them, and if residents had the option to opt-out of paying into the Trust. The coalition finally agreed on a \$36,500 lifetime long-term care benefit that would be held in the Trust by a 0.58% premium on the wages of working residents. Despite the seemingly low premium, coalition members still had to think creatively about how to convince legislators who were opposed to any form of a premium. One effective strategy in negotiations was putting a dollar amount on the annual cost of the premium. One interviewee shared:

One of the things we emphasized was that this was a \$36,500.00 lifetime long-term care benefit and explaining how the premium was paid and that the premium was .58% on wages. So it would be roughly \$290 for somebody making an average of \$50,000 a year for a \$36,500 long-term care benefit. People saw value in that and saw that it was doable.

What later emerged as an issue for coalition members was the possibility of an opt-out option. In order to get the support necessary to pass the bill in the State Senate, an opt-out option was included. This allows residents the option of opting out of paying the premium, which could destabilize the financial viability of the program. Legislative champions and coalition members worked diligently to make sure the issue was resolved. That solution came after the passage of the Trust Act with Senate Bill 6267, titled "Modifying the long-term services and supports trust program by clarifying the ability for individuals with existing long-term care insurance to opt out of the premium assessment and making technical corrections." It was approached - and won - as a simple technical modification. The coalition's lobbyists, who had become trusted faces on both sides of the aisle, also worked to gain support for the bill.

Without the passage of SB 6267, Washington residents can opt out of paying the premium until 2022. This, some interviewees highlighted, is an issue that they warn against agreeing to. The reason that this still poses a threat to the Trust is because it is possible that only those people who know or believe they might need long-term care in the future are the only ones paying into the fund, which could create the possibility for an eventual high demand but low revenue base. Given this consideration, LTSS Commission members recommend that other states do not allow an opt-out option, including for those who are self-employed.

“ A non-negotiable was that the benefits have to be meaningful. We defined meaningful by: the average length that someone needs for long-term care and how much care, on average, people need. ”

SEIU 775



THE ROAD AHEAD

A reminder that once a bill is passed, there is an immense amount of work that happens to actually execute on a bill. There's nothing set in stone about the bill serving all of the people that we wanted to serve.

SEIU 775

Next Steps in the Campaign

Looking forward, there is still work to be done to improve upon the landmark legislation. Soon after its passage, there were efforts to secure financing of the Trust through a ballot measure (WA Senate Joint Resolution 8212) in November of 2020. The Joint Resolution passed in both the state Senate and House for a constitutional amendment allowing the investment of public funds "for long-term care services and supports to be invested by governments as authorized by state law, including investments in private stocks." This would bring higher yields to offset impacts on tax payers and ensure sufficient funding. However, the ballot did not pass in the 2020 general election for various reasons including uncertainty about the stock market and a divided political environment.

Coalition partners and others remain committed to strengthening and protecting the LTC Trust Act. They believe with stronger public education on the topic they will be able to pass a similar ballot measure in a future election. In addition, based on their priorities and the recommendations of the LTSS Commission, they are proposing HB 1323 that will allow tribal employers to participate in the Trust and provide benefits to qualified workers with developmental disabilities. It also offers a clear opt-out option for private long-term care insurance policy holders to forego the benefit and a clear process or mandate for self-employed individuals to opt-in.

“ Caregiver shortage is also a threat that looms largest, which means that continued progress in making direct care a good wage and benefitted career is critical.”

DAN MURPHY, Executive Director of the Northwest Regional Council

“ I would love to see this happen on the national scale. I think that is really ultimately how this is solved. We can't go state by state, and we're attempting to bridge this gap, but a year worth of benefit is actually - it's meaningful, but it's not enough, and it should be a part of our social safety net nationwide.”

SEIU 775

In addition to the legislative amendments and additions, there is the continued fight to educate the public about how the Trust is a viable alternative to private insurance options. Additionally, coalition members continue to shine a light on how caregiving can be a viable and dignified work option. A shortage of caregivers and home care workers is expected. Organizing for living wages for all caregivers, better working conditions, training and opportunities for career advancement remain critical to the sector. For immigrant caregivers who are already in the U.S., there is a need for visa and naturalization programs, as well as pathways to live and work here safely.

Long-Term Care Trust Act-Related Legislation and Initiatives

ESJR 8212	Constitutional amendment to allow the Long-Term Care Trust Fund to be invested by the Washington State Investment Board; failed to pass on the 2020 ballot; is likely to be placed on the ballot again.
SJR 8200	Passed in 2020 with senate with bipartisan support for viable long-term investing
HB 1323	Futher defines details for workers enrolled, including self-employed, in the Long-Term Care Trust and outlines the roles for those who will collaborate to manage the program.

Recommendations

Ultimately, what is needed is a national program. In the absence of federal action, states can prepare by rebalancing their long-term care approach in a way that supports people aging at home and having a workforce that is able to work in dignity and with compensation. In this section, we offer a summary of recommendations for states that are interested in a similar program.

- 1. Do not have opt-out options - even for self-employed individuals - to ensure the viability of financing the fund.** Be prepared to continue to fight for garnering resources needed to support the benefit. Ultimately, what is needed are strategies to address anti-tax sentiment among the general public and to further advocate for the essential services and support needed for *all* Washington residents and families.
- 2. Establish a Long-Term Services and Supports Trust Commission to oversee the implementation of the program.** Ensure multi stakeholder representation on an oversight body that has the authority and respect of legislators and the sector. Having this body in place will help to ensure that the program is able to achieve its purpose and improve upon the original legislation.
- 3. Ensure the state agency rules are clearly defined and assigned.** Get in the weeds by understanding the costs, systems and obstacles to accessibility to the benefit.
- 4. Start with easier qualification allowing more access to long-term care benefits through a 1115 waiver from CMS.** Decreasing the income thresholds to qualify for benefits and having community-based services covered by Medicaid will allow more people to participate and more providers to be compensated for their time.

- 5. Cultivate partnerships among agencies and organizations for a robust infrastructure and smooth administration.** Partner with agencies such as the Department of Social and Health Services, Association of Area Agencies on Aging (state and local), and community-based long-term care providers. Having a decentralized infrastructure helps to advocate for local needs and to provide services tailored to individual and family needs.
- 6. Acknowledge long-term care as an economic engine as well as a service.** This means that it is important to prepare and support the growing care workforce. Funding should also include resources for counseling, training, respite, and other services that will help family and professional caregivers provide quality care.
- 7. Be prepared to push through the legislature or at the ballot box as leverage.** Passage of any legislation will likely be an iterative process requiring ongoing negotiations and organizing. Building capacity to engage in integrated voter engagement is necessary for building power in both arenas.
- 8. Be prepared for the next fight.** It pays off to work through differences that are inevitable, even when there are common interests. Reach consensus on the core mission and focus less on tensions and disagreements. The expertise, relationships and experience gained through the campaign can be carried over into improving the policy and participation in oversight.
- 9. Be intentional in centering the people not at the table yet with much to gain.** Addressing the generation gap and the full generational spectrum with attention to race/ethnicity, nativity, ability, and gender will be increasingly important. Pay attention to capacity and resource differences among coalition partners who may be more local and grassroots. Smaller community partners may not have the staffing to dedicate to the coalition work so creating a way to include them throughout the process and in key decisions is critical.
- 10. Keep vigilant of who is missing who needs to be at the table.** Balancing the need to check in with groups not at the table with rushing to the next thing requires intention and discipline. Bring in diverse voices early – of workers, those with disabilities, and others – and invest in the leadership from communities of color.



CONCLUSION

State solutions for long-term care can help build momentum towards a national program. While each state has its own context and landscape, all share similar stresses and strains on the systems of care. Having a concrete model of what it can look like to meet the growing demand and make it affordable to more families, helps to make a feasible case. And even with their success, the work in Washington is not done: changing demographics, with a growing population of people of color will require revisiting the Act to ensure equitable access to benefits.

Washington opens the country up to what is possible when stakeholders come together across sectors and concerns about social insurance programs. The human narrative that touches all families at some point, paired with the coalition strength, technical expertise, and state/local infrastructure, helped build the political and public will to care enough to tackle this intergenerational and complex issue together. It wasn't a quick fix, but with perseverance it was possible to secure a brighter future for the home care sector and for families to age with dignity.

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