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Building an Accessible Long-Term Care System for the Future

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We are dedicated to renewing the promise of America by continuing the quest to realize our nation's highest ideals, honestly confronting the challenges caused by rapid technological and social change, and seizing the opportunities those changes create.

About New Practice Lab

The New Practice Lab works at the intersection of ideas and on-the-ground experimentation to improve the design and delivery of policies focused on family economic security and wellbeing.

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Introduction

"Long-term care is a national healthcare crisis." - Dan Murphy, executive director, Northwest Regional Council, Area Agencies on Aging

The nation's long-term care system has struggled for many years, and those constraints are expected to deepen as our nation ages. One in five Americans is projected to be 65 years old or older by **2030**, outnumbering children for the first time in our nation's history. While seven in 10 will eventually require long-term care, currently, **more than 90 percent of Americans** are not insured for long-term care and do not have access to affordable, high-quality options for long-term services and supports.

In 2019, Washington State became the first in the United States to pass **legislation** that would enable a public state-operated long-term care insurance program. The **Washington Cares Fund**, borne out of this legislation, will provide a lifetime benefit of $36,500 per enrollee for certain medical, personal, and social services starting in January 2025. The fund will grow beginning in January 2022 as individuals working in Washington State pay 58 cents toward the fund for every $100 earned. The state is in the process of designing this program and wants to make sure that it is easy to access and supports the needs of those who will be its beneficiaries.

Many advocates also want to ensure that the Washington Cares Fund is easily accessible and supports the needs of its beneficiaries. Over an eight-week period in late March through May 2021, the New Practice Lab partnered with the **SEIU 775**, which represents over 45,000 home care and nursing home workers in Washington and Montana, to understand how individuals might navigate the fund. The goal of our research was to identify concrete ways for Washington State to implement the fund so that it is accessible to all and that it supports living-wage jobs for care workers.

In this report, we discuss our research methods, we present personas of individuals seeking long-term supports and services from the fund, and we offer a list of recommendations that, while intended for Washington State, we see as applicable to other states that will embark on offering similar long-term services to residents.

Method

Stakeholder interviews: We interviewed an array of leading advocates in adult care and social services. This includes representatives from **Washington State Department of Social and Health Services (DSHS)**, local **Area Agencies on Aging**, community-based organizations, SEIU representatives, and Tribal Government officials. Our 21 interviews helped us to understand the history of the Washington Cares Fund, the current long-term care administration within the state, and about the various communities that may be at risk of not being able to access the fund. Together, these interviews set the foundation for recruiting Washingtonians to further discuss the new long-term care fund and their overall view on long-term care.

Survey distribution: During our research period, we distributed an online survey to learn generally how Washingtonians are preparing for retirement (or not), who they rely on when they need help, and discover more about their thoughts on long-term care. We posted this survey in ***The Stand***, connecting us to many union workers. The survey was also posted in English on Craigslist for Seattle, Spokane, Tri-States and Yakima, and it was in Spanish on Craigslist Seattle and Yakima. From those surveys, there were over 120 usable responses.

Interviews with potential beneficiaries: From the survey, we selected 17 participants for in-depth interviews. Each individual represented a cross-section of backgrounds including age, gender, race, marital status and income levels; and they provided different perspectives on their long-term care planning.

Regular communication with our SEIU partners: On a weekly basis, our SEIU partners and research team met to review research findings gleaned from our interviews with stakeholders and potential beneficiaries. These sessions were immensely helpful for us.

Gaps in our research: The pandemic limited our ability to connect with individuals in person. Also, we were unable to connect with as many individuals as we would have liked, especially considering many working Washingtonians do not have easy access to the internet.

A 2018 survey by the city of Seattle found that **over 20 percent of households in Seattle** with income less than $25,000 annually did not have internet access. A recent *New York Times* article stated that **42 million Americans** live in areas where they cannot access broadband internet—particularly in rural communities, of which there are many in the state of Washington. We want to highlight that our research was digital-first and that this type of research is limited in the perspectives that it captures. Therefore, we recommend that future research teams broaden their outreach to better connect with those who are less digitally connected. With more time and with less social distancing, a research team might consider partnering with community-based organizations and conducting in-person intercepts.

Getting to Know the Beneficiaries

To understand how those who will benefit the most from the Washington Cares Fund, the team interviewed 17 potential beneficiaries who participated in our survey. Those potential beneficiaries represent the broad spectrum of Washingtonians, including those from various racial and gender identities, income levels, and marital status.

As part of this research, the team developed "personas" to highlight the varied segments of the potential beneficiary population and their perceptions of long-term care. A persona helps depict the experiences, motivations, and goals of a beneficiary group, as well as the barriers that different people face when engaging in a particular process. For our report, personas offer what aggregate data cannot: firsthand insight into how the long-term care system can support the needs of beneficiaries, and identifiable areas of improvement.

There are many personas that were explored in our research, but the team narrowed it down to the following four key personas—note that people from varied genders and ethnicities fell within each of these different groups. While demographic characteristics are important, we found that they were not the most salient in determining an individual's orientation towards long-term care.

Personas: Four Types of Beneficiaries

"Mothers to the World"

The "Mother to the World" is driven to meet her loved ones' needs rather than her own. She views the world through a caretaker's lens. Ironically, she can fall into a pattern of neglecting her own needs because she is laser focused on caring for her loved ones. While she may be providing long-term care to others, she might not have much in place for when she will need long-term care for herself.

While the job of a family caregiver is not necessarily gender specific, this task historically has fallen on the shoulders of women. The average family caregiver is a **49 year old woman providing 20 hours of unpaid care for a parent**, according to Caregiving.com. Also, women provide **more hours of care per week for a family member than men**. More than half of the women who care for a loved one say they felt like they **did not have a choice**, and are more likely than male caregivers to be unemployed and experience stress.

The Mother to the World has a lot of responsibility; she takes care of her elderly parents, and she takes care of her own children. Sometimes, she is also the main caretaker of her spouse/partner. Through this experience, she understands long-term care and knows how to advocate for the ones that she loves and is able to navigate the system to find the resources they need.

However, the emotional and financial toll of caring for the people that she loves can leave her exhausted and, at times, even in poor health. She might be planning her own retirement, but this tends to come after caring for her family members. Her caregiving duties may have kept her from collecting benefits that come with full-time employment: a 401k, a pension, and social security. She is very capable and knowledgeable, but still, her retirement years can look precarious because she might not have anyone able to care for her and few resources saved up.

“Planners”

The “Planner” trusts that hard work today can lead to rewards in the future. They desire to live and enjoy life to its fullest, but they are also realistic; they have experience in caring for a loved one such as a parent or grandparent. They also have seen firsthand that at a certain point in life, most people face changes and need care. Their caretaking experience gives them a sense of what type of care they will need and what circumstances they need to prepare for later in life—this knowledge shapes their lives.

The Planner contributes early and often to an array of savings accounts: employer-based 401Ks or pension plans, college-tuition savings accounts for their children, and possibly other investments, depending on resources. They’ve made career choices based in part on benefits packages and they read through all the plans before choosing which one will serve them best. While they may have debts related to home mortgages, student loans, and credit cards, they are paying them down every month. Coupled with a steady income and career growth, they have created enough stability in their life that they can focus on future plans, which can vary based on their resources.

Those “Living in the Here and Now”

Someone “Living in the Here and Now” focuses on today, rather than on the future, simply because their vision of the future is worrisome. They do not know how they will have the resources to meet their needs when they can no longer work. They live with challenges such as unstable work, mounting debts, or a chronic illness that can make life feel overwhelming.

For most of their life, they have had limited financial resources, earning well below Washington State’s household median income of $78,687. Those interviewed who fell within this persona worked as gig workers, entrepreneurs, or full-time employees, but for low wages. They were of varying ages and ethnic backgrounds and lived in cities across the state.

They may also feel a sense of hopelessness, and the very thought about their future becomes overwhelming. This makes it challenging for them to take the initial steps of planning for their future, because thinking of the future is stressful.

Those "Facing Life's Hurdles"

Life throws all of us a curveball at times. The "Facing Life's Hurdle" persona is in a moment of change. They seem to have their whole life ahead of them—career and personal life. Then, an unexpected shift in their life changes it all—be it a sudden debilitating illness, an injury, or a divorce. Whatever the reason, suddenly they face new obstacles. They're forced to pivot in their present life and plan another path that lands them searching for long-term care options.

Unlike the Living in the Here and Now persona, who rarely has enough bandwidth for future planning, Facing Life's Hurdles has a network to tap into for support, such as family, friends, and their surrounding community—but not all. There are those who have to navigate the system on their own, resulting in the need for a supportive advocate through community-based organizations who can connect them to resources. That includes searching for a caregiver, moving into a nursing home and possibly transitioning into Medicaid.

Findings: How People Think about Long-term Care

Many are planning for retirement, fewer are planning for costs associated with long-term care.

Of the 121 individuals surveyed, more than three-quarters said that they were over age 40, and more than half (60 percent) reported that they were building assets for retirement:

- Over 50 percent reported having retirement accounts such as 401ks, IRAs and others
- Over 50 percent reported having personal savings
- 37 percent said they had a pension
- 30 percent said they owned their home

However, more than half (58 percent) said they have not begun planning for future long-term care needs, while only a third (33 percent) said that they had begun planning, and another 9 percent were not sure. When asked if they owned long-term care insurance through their employer or with a private insurance company, 43 percent said no and 20 percent said that they were not sure. Thirty-seven percent said that they owned a long-term care plan but these answers may have been inaccurate. While employers across the country are increasingly offering the option to purchase long-term care insurance through a group plan, the national rate of long-term care insurance ownership is **at roughly three percent**, indicating that most employees do not pay into long-term care plans offered by employers. We wonder whether some individuals who answered that they own long-term insurance plans thought that they had plans when in fact they did not. We also wonder how common it is for individuals to mistakenly think that they will have access to long-term services and supports when they need them.

“Many people who haven't already gone through the process [don’t make] long-term care top of mind,” said the legislative and campaigns director for SEIU 775. “They're thinking about paying bills now and getting their kid into childcare, whatnot.”

Indeed, life’s circumstances—credit card bills and other expenses—preceded any planning for the future among potential beneficiaries. “It’s pointless to save money when you have high-interest loans,” said a female interviewee, 36, who worked as an independent contractor for a dog-walking and pet-sitting service business in Seattle.

Those with low wages and unsteady work are less likely to plan for their retirement.

Research has shown that most people will require long-term care at some point in their lifetime, and those numbers are growing. But few have the financial means to plan for their future care needs—most of all, the ability to even focus on affording a long-term care plan. The Washington Cares Fund was designed to benefit all working people in the state, alleviating the strain of the high cost tagged to long-term care insurance and the limited coverage for services.

In our survey, the income brackets broke down as the following:

- Below $45,000
- $45,000–$75,000
- $75,000–$100,000
- Above $100,000

Nearly half of those surveyed (43.2 percent) stated that they earned below $45,000 a year. These are the individuals for whom the Washington Cares Fund would benefit the most—workers who do not earn enough to save for the costs of long-term care.

In our survey, women between ages 20 and 77 accounted for more than half of our respondents (67 in total) in the lower income tier. Many had experience in caring for a loved one with long-term care needs, and a select few had started planning for their future care. This correlates with a recent report highlighting that **women** in the nation.

“Money is hard to come by sometimes,” said a female interviewee, 41, who works in janitorial services in Spokane. She serves as the sole caregiver for her mother, while managing her own health issues, including bouts of anxiety that have forced her to take short-term disability. “By the time I'm ready to retire, it still won’t be enough, but what can I say—it is what it is.”

In her union job, she felt stable and valued with her employer-based 401k and other benefits; she also relies on her employer’s online benefits service for information and resources available to her. Friends from church also are a resource for her to turn to in times of need, she said. When asked how she would utilize a $36,500 benefit, she listed having food delivered and house cleaning. In short, “it could help me not starve; and if something went wrong, I wouldn’t immediately end up homeless.”

She is not alone among our interviewees, many of whom felt overwhelmed by life’s circumstances—combined with, most of all, thinking about their health in coming years.

“It's the planning ahead for an uncertain future. I can look at the calendar, and yes, I will get older and I will get more infirmed, and I will have to plan around that,” said a male interviewee, 58, who is a front-desk security guard in Seattle and deals with a chronic health issue. “But day to day, I do my best to avoid that thought. It’s overwhelming.”

When asked what he would do with his $36,500, he said he would pay his wife a stipend to provide in-home care, as well as find a professional caregiver who would help with house cleaning and other chores.

People have varied definitions of long-term care.

“What is long-term care? Is it for a hospice, or a retirement home? What is the difference between short-term and long-term care?,” asked a male interviewee, 54, who was a software trainer in Spokane.

Several years prior, he had to stop working in order to care for his mother during her final months. He was among the more than 60 percent of our survey respondents who said they had experience helping a friend or family member with long-term care. His questions highlight that even those who experience being a family caregiver, still do not know what services fall within long-term care as defined by the Washington Cares Fund.

Our interviews with survey respondents revealed there was no common understanding of what long-term care meant. Each of our interviewees experiences with long-term care were diverse. When we asked our interviewees how they viewed long-term care, they often shared their own personal experiences of caring for someone, or of being cared for by someone.

For instance, some talked about providing in-home care for parents with dementia, while others have helped family members choose and move into a senior living residence. Some served as their loved one’s prominent advocate, ensuring that service providers were delivering on contracted services and properly billing the family for those services. There were individuals who were hit with a life-changing event—an injury or illness—that has left them relying on their family or spouse for care. And while they’re working, some had chronic health issues that meant they needed support in terms of minor medical care.

Each of these varied experiences, in short, have informed their views on what long-term care is and what it will mean for them in the future.

People think about long-term supports and services differently than long-term care.

During the course of this research, our interviewees used the terms long-term care as well as long-term supports and services. Long-term supports and services seemed to be the preferred choice among our interviewees when referring to in-home care provided by a trained professional.

Stakeholders stated that depending on the audience, one term might be preferred over another. Our team wanted to understand how potential beneficiaries would react to these different terms, and whether there might be useful insights. Will potential beneficiaries be more likely to hire union members for one versus the other?

Below is a snippet of what our interviewees and stakeholders had to say:

- "'[Care]' almost has a little bit of a . . . slightly patronizing connotation to me . . . [but] 'care' is more humanizing than . . . services and supports." - A female interviewee in Seattle, 30, who recently began relying on her family to help her with daily living after contracting COVID.

- "Long-term services and supports feels more accurate [when talking about home and community-based services]. There's less of a connotation of a group home setting. It also seems broader, and that there's a range of things you may need and not all are nursing home needs."- A Seattle-based independent contractor, 36, who watched her mother care for her grandmother.

- "Long-term care sounds caring. I would say while I care about feeling loved, I want someone who knows how to do the work. Long-term services and supports sounds safer."- A Seattle-based bookkeeper, 68, who cared for her mother living with dementia.

- "Care seems like a full-time job, but the term services and supports sounds like a one-time thing."- A Spokane-based freelancer, 45, who recently took care of an uncle.

- "For me, I guess, they're not different. We're used to hearing long-term care. I don't have a negative connotation about it."- A Kent-based manufacturing analyst, 37, who is part of a large and tight-knit family.

- “When you say long-term services and support you feel a sense of relief. Like ‘oh, you know, I'm gonna have some support here!’ And long-term care sounds like Medicaid . . . like, ‘okay, I'm going to have to jump through these hoops.’”- A government employee of a federally recognized tribe expressing her own view.

- “[My community] would take support and relief. ‘Services and support’ language is important in these communities.” - An Adna-based administrator, 42, who added that her rural, faith-based community viewed ‘care’ as more personal.

- “Many Asian communities come from third-world countries that don’t have the same resources as the U.S. [They] typically don’t have paid caregivers - family takes care of [you]. When we get older, there’s that unwritten rule that as a child, you were taken care of by your parents and your grandparents; [and] when you're old enough, you return that caring to your elders. So when they come here, the reaction is: ‘I can get paid to take care of my grandma?’ It’s a new concept to grasp.” - A representative from a community-based organization serving older adults in the Asian, Asian-American and Pacific Islander community.

Those who leaned toward informal caregiving were open to learning about professional care and caregiving training.

Most of our interviewees stated they would turn to family for care, especially when it came to what they deemed to be simple tasks. That included delivering food or taking them to the doctor. For some, it was ingrained within the traditions of family or community—family takes care of family and the community comes together to support one another in times of need. “I don't feel like taking care of family is work,” said a female interviewee, 41, who is the main caregiver for her mother in Spokane.

Another interviewee echoed that point and shared the following: “I imagined my long-term care is me staying in this house; and you make changes to the physical structure of your house to be able to be mobile. You have family come check on you. If it gets really bad, you have family stay with you. That's our history. That's our tradition, “ said a female interviewee who lived in the small, rural town Adna, Washington.

However when the team delved further, many interviewees likely were convinced otherwise—having a professional caregiver or at least professional caregiving training may be essential at times. For instance, the so-called small task of taking a loved one to the doctor may require professional support if that loved one has mobility issues and needs to be lifted in and out of the car. If the loved one has a specific disability, there are professional skills that would be required.

It is possible that communities rely on informal caregiving to do so, at least in part, because it is what they know and they have less access to information about finding a professional caregiver. The same interviewee who said that caregiving was her community's tradition followed up with our research team to share that our conversation possibly shifted her perspective. She was alerted by another community member about someone in critical need of care. In her email, she contended that she would still help informally, such as preparing some meals for that person; but "I will [also] refer them to public resources that I know are available."

Findings: How Potential Beneficiaries May Navigate the Washington Cares Fund

In-home support, training, and adaptive equipment were the types of long-term support that people believed they would need.

"There's a lot of planning that will happen around access assistance and navigation assistance." - Bea Rector, director of Home and Community Services Division Aging and Long-Term Support Administration Washington State Department of Social and Health Services (DSHS)

Understanding how potential beneficiaries will access the Washington Cares Fund and navigate the long-term services and support systems as a whole is critical to our research. In the survey, the team purposely did not share much information about the Fund to determine how many Washingtonians were familiar with the new benefit. The survey showed that nearly 63 percent were not aware of the Fund, while 31 percent said they were familiar with the Trust Act, while the rest said "maybe."

Survey participants were also asked the following question: ***If Washington State provided $36,500 in long-term care benefits, what type of professional services and support do you anticipate you will need?***

Here's what the team learned from survey respondents:

- 75 percent said they would need professional support at home
- 53 percent said they would need training, pay, and support for family members who can provide services and support
- 51 percent would need adaptive equipment and technology (i.e. wheelchair ramps, medication-reminder devices, etc.)
- 46 percent said they would need professional services and support at a facility
- 46 percent would need rides to the doctor
- 36 percent they would need home-delivered meals
- 26 percent said they would need home-safety evaluations

Based on these responses, it seems people want to stay in their homes as long as they can. “Generally, people like to keep doing as much as they can for themselves,” said Dan Murphy, executive director of the Northwest Regional Council, Area Agency on Aging. “They want to stay home if they can, they want to control how the money is used on their behalf, and they want to age with dignity.”

Employers will play a key role in educating beneficiaries about the benefit.

For many Washingtonians, their first experience with the fund simply will be a new tax deduction in their paycheck. Who will they go to first with questions about this new deduction? Most likely, it will be their employer.

As we noted earlier in this report, more than three quarters of our survey respondents said that they had a 401k and/or a pension through their employer; and another 62 percent said they have an employed base healthcare plan. What’s more, about 20 percent of our survey respondents shared that they lean on their employer for information when planning for retirement. Together, this highlights howemployers play a key role in providing important information to the state’s working population.

“I'm a CPA. It took me several readings... to understand the difference between a Health Savings Account and Flexible Spending Account, and specifically, like, what is covered under which one,” said a male interviewee, 47, who deals with employer benefits programs at his company in Federal Way. “Even now, I'm more familiar with it, but I still have to go to our HR sometimes and ask."

Those employed by tribal employers may face a different path towards accessing the Washington Cares Fund than those working for employers that are regulated by Washington State and required to participate in the Fund.

For companies employing low wage workers, they may decide that any deduction from their employees’ earnings would be too much. For tribes that already offer care-related benefits to their members, they may look to see how the benefits covered by the Fund are different.

A representative from a federally recognized tribe in Washington State emphasized how important freedom and flexibility is for tribal employers as well as for workers. “When looking at the [fund], [companies are] going to see what the benefits are and see how it affects their employees overall,” she said. “It really depends on how it's packaged, and how much flexibility there is in it.”

Low-wage workers are among the targeted beneficiaries for the fund. They are the individuals who will have the least resources to pay for future long-term care.

Those with any savings will be the ones who have to make the difficult choice on whether or not they want to spend down their assets to qualify for Medicaid.

Local community-based organizations (CBOs) will be instrumental in ensuring access to benefits.

Many Washingtonians rely on community-based organizations for help in navigating government programs and for support in maintaining the government benefits that they use. Our survey showed that 15.4 percent of respondents relied on community-based organizations (CBOs) for healthcare services, and another 32.8 percent would turn to their neighborhood organization or church in an emergency.

The CBOs serve as the first point of contact for the most vulnerable communities in urban and rural areas. **Churches and CBOs are the single thread that ties people with caregivers and services by offering the necessary information based on their care needs.** The CBOs also have the reach and connection within communities of color and the growing immigrant population; they're aware of the cultural nuances and traditions, when it comes to expectations about services and supports.

"Washington State, being multi-ethnic, you have to think how you're going to come across those ethnic groups, and really introduce them to this option that exists," said Julia Weinmaster, state director for All Ways Caring Homecare in western Washington. One challenge that she noted was reaching communities that distrust government institutions.

A representative from a CBO serving older adults in the Asian, Asian-American, and Pacific Islander community echoed this point. He also stressed that CBOs focused on supporting specific communities can support the development of diverse outreach programming. "One of the (challenges) is how information is disseminated," he said, adding that his department alone supports clients who speak up to 10 different languages and dialects. "It's great that it's out there, but people don't know it's out there. You know, so that's one piece of it. And then the other piece of it is like, okay, step one is letting them know what's available. A second step is okay; now that they know it's available, how do they access it?"

He, along with many CBOs, raised concerns about beneficiaries' digital literacy and their ability to access information about the fund via a computer or their smartphone. "We're assuming everybody knows how to navigate the Internet, has internet access, has a smartphone or a computer at home."

Most of all, the CBOs also shared that they already provide support for Medicaid recipients. Therefore, closely working with the CBOs and other such service providers would offer potential beneficiaries a smooth transition from the fund to Medicaid.

Bea Rector shared that sentiment: “We really want to make sure that we leverage the best of what Medicaid has to offer as well as the Older Americans Act and the many state-funded programs that have been developed over the decades, leverage those so that they're available in the trust.”

Self-employed individuals will have a greater burden to collect a long-term care benefit (fix).

The size and composition of the “gig economy” varies, including the size of the workforce, hours worked, and basic demographics (such as race, gender, and immigration status). Nationwide, gig workers also have often been misclassified within payrolls, excluding them from protections and benefits afforded full-time employees. Black and Latinx adults are significantly impacted by this misclassification, considering they represent a significant share of those working in the gig economy—and most work for online platforms.

In a 2018 **Edison Research poll**, almost a third of Latinx adults aged 18 and over (31 percent) earned income through the gig economy, while 27 percent of Black adults and 21 percent of White adults earn income through gig work. For Black and Latinx adults, the poll also showed that gig work served as a primary income source.

Additionally, a **Pew Research Center report** showed that some 14 percent of Black adults and 11 percent of Latinx adults had earned money in the last year from online gig work platforms, while five percent of whites have done so.

Among our interviewees, three were self-employed, and all stated they were interested in participating in the fund. One interviewee asked: “What does [the fund] do for the entrepreneur who, you know, isn't paying into this system? Is there an option for entrepreneurs and self-employed people to benefit from this type of program?”

Beyond wanting to opt-in, these interviewees said that being automatically registered in the program would relieve them of new administrative burdens. They stated that they already had so many other moving parts to keep track of in their lives.

Many raised concerns about the instability of their work. A male interviewee, 54, based in Spokane, shared that he’s only recently been in a stable job in technology—in the course of a 30-year career, he has lived in three countries and held 10 jobs. A female interviewee, 36, who has worked as an independent for the last five years in Seattle, recognizes that payroll taxes (i.e. social security, medicare, and unemployment) are not being taken out of her check. With that, she has to find other avenues to build her nest egg—but that will come after she and her husband pay off their credit card debts.

Everyone values training for caregivers.

Washington State has set a precedent in leading the nation with progressive policies. That includes voters approving a 2016 ballot measure to raise Washington's minimum wage and establish a paid sick leave program.

The state also has an extensive history of delivering an array of long-term services and supports, spending nearly three-quarters (73 percent) of its long-term services and supports budget on home health and personal care. That compares with 59 percent on a national average.

"Strong federal and state partnerships to leverage federal funding from the Center for Medicare and Medicaid Services and the Administration on Community Living providing Older American Act funds and many of the grants used to test models of care over the years have been key to the development of the LTSS [long-term services and supports] system," according to **Washington State Plan on Aging**.

As noted earlier, the state's long-term services and supports system currently ranks second in overall performance within the nation, based on the **fourth edition of the Long-term Services and Supports State Scorecard**. The high ranking reflects Washington's keen focus on delivering quality and affordable care to older adults, people with disabilities, and family caregivers. That begins with a solid, well-trained workforce.

For instance, home care aides are required to take **75 hours of basic training** within the first 120 days of their start date; and they must earn their certification as a home care aide within their first 200 days of their start date. Aides also are required to take continuing education courses and training. The base pay is above minimum wage at nearly $17 an hour, including benefits.

Maintaining a qualified workforce, as well as building upon that workforce, will be key as the number of those needing long-term care doubles, advocates and state officials said. It will also secure Washington as a leader in the nation.

Aurora Castillo Garcia, 28, discovered her passion for becoming a full-time certified home care aide while caring for her mother-in-law. She is among individual providers interviewed who have participated in the training programs provided through SEIU 775. She, along with others, expressed the value of such training to be better equipped to care for a loved one. "It gives me gratification to help others," she said. "Before, I felt like I didn't have a skill, but now I have passion about what I do. This is where I belong."

Among the potential beneficiaries interviewed, many had relied on informal caregiving (unpaid caregiving) and expressed that they also saw the value of training. They want to learn skills to better care for their loved ones and, generally, families want to know that their loved ones are being cared for appropriately.

“I’d be open to training,” said a female interviewee, 42, who lives in a rural community in eastern Washington State. Within her community, informal caregiving is a tradition—neighbors and families step in to help one another when necessary. “I’ve seen family members become certified nursing assistants to work in local nursing homes or assisted living facilities on a part-time basis, but then utilize that training to take care (of family) without being paid.”

Some interviewees said upon their need for long-term care that they would prefer a trained caregiver—be it a family member or not. “The training component would help to alleviate caregivers' fears of not being capable of aspects of care that they might not have thought about,” said a male interviewee, 53, from Des Moines.

Another interviewee who once worked as a caregiver to those with disabilities echoed that view: “More training is needed. Most people don't know how to handle what life throws at them.”

Long-term care is already complex—new long-term care benefit programs will add to that complexity.

It became clear very quickly that navigating long-term care is complicated, service providers often make billing errors, insurance plans often refuse to pay for services that seem like they're covered in the plan, and so on and so forth. All beneficiaries need a strong advocate on their side—be it to how to access the benefit, manage their funds, gain training or even learn about long-term care. All will need an advocate.

From our interviews, we heard many stories about family members providing unpaid caregiving, often spending many hours per week. Their tasks ranged from negotiating bills to interviewing staff at assisted living residences. One interviewee calculated that she provides her mother at least 102 hours of care a month, including preparing meals, giving her showers, and handling household chores. A Seattle-based interviewee said she spent 10 hours a week helping her grandmother, who lived across the country with the search for a senior living community.

“I knew my grandmother couldn’t do it on her own, and she felt like she couldn’t live in her apartment on her own anymore. So what are grandchildren there for?”

She is fluent in various languages, which helped her to learn from frontline staff—the CNAs, dining staff, and housecleaning—about the communities and their services during her tours. “I also was able to communicate with these workers and ask them how they were being treated. Were they getting paid well enough? If they were not, that place was out."

The new benefit may be vulnerable to exploitation.

The fund benefits are intended to be flexible. However, this creates new risks for consumers who suddenly have $36,500 to spend. During our interviews with community-based organizations, union representatives, adult care advocates, and potential beneficiaries, all called for rules and oversight to protect beneficiaries from being taken advantage of by a variety of actors they might do business with.

They also spoke about the risk of long-term care providers misrepresenting their services, employers failing to properly deduct fund contributions from their employees' accounts. A female interviewee from Seattle was worried that family members providing care might be abusive without much oversight. "It's a beautiful idea, but I could see this getting abused," she explained. "If it comes with training or a social worker checking in, then [it could work better]."

As mentioned above, state officials plan to leverage the best of Medicaid, as well as the Older Americans Act, within implementation of the Fund. That implementation process should include the approved services from registered providers and the licensed certifications and continued training of caregivers. Advocates agreed with that approach, stating it would mitigate the pitfalls that may arise as beneficiaries navigate the long-term services and supports system.

Beneficiaries will interact with many different service providers and each will come with benefits and risks. "I'm concerned that facilities are going to require a certain amount of (the benefit) to be used in their facility before they will accept the person on Medicaid," said an advocate who supports assisted living and nursing home residents.

A male interviewee from Federal Way, 47, knows firsthand the need to be that voice for your loved one. He and his sister helped their parents move into a retirement community, during which they faced many struggles with the community's leadership regarding the contract and payment for various services. He became the key advocate for his parents, ensuring that they were not taken advantage of while living in the community. Outside of talking to family friends, parents' doctors, and their case manager, he had to hire a lawyer. That time sticks with him.

"Even as diligent as I thought I was, I still got some unexpected surprises throughout the process," he said. "(Looking back), I probably would have involved our (extended) family into more of the details."

Along with other interviewees, he called for the state to put in more protocols that will make continuing care retirement communities be more financially accountable to consumers in providing proper care and services. He also called for community-based organizations, the state, and unions to provide educational seminars on financial management and understanding of the various factors involved with long-term care costs. That would help mitigate the possible misuse of the benefit.

Recommendations

The following recommendations are for the SEIU 775 as it sets strategies regarding the implementation of the Washington Cares Fund and the rule-making process. While we frame these recommendations in the context of Washington State, we believe that they can provide guidance to other states across the country as they implement similar legislation.

Advocate for consumer protections.

Beneficiaries of the fund are going to have flexibility with regard to how they spend their allocation. They will also have limited in-person support as DSHS prepares to develop a digital-first strategy for outreach, education, and navigation. They will not necessarily have caseworkers like Medicaid recipients, and some may not have a support system to rely on in terms of family and friends. Safeguards need to be developed during the rule-making process to curb possibilities for profit-driven actors to take advantage of Fund beneficiaries. Applying similar training and standards requirements that exist for Medicaid providers to the Washington Cares Fund is one possible safeguard that should be considered during rulemaking.

Ensure that beneficiaries are positioned for a smooth transition to Medicaid.

Many beneficiaries of the Washington Cares Fund will eventually transition to Medicaid, and that process should be smooth for them as well as for their doctors and caregivers. Those with experience managing long-term care service delivery are experts in how to best make this happen. Listen to what they have to say and consider supporting their recommendations.

In outreach, use language to meet people where they are—particularly in communities that heavily rely on informal care.

In interviews, we asked participants their perspective on the term long-term care versus long-term services and supports. "[My community] would take support and relief," said an interviewee from a small, rural community where informal caretaking is tradition. "'Services and support' language is important in these communities," she emphasized.

Language choices made a big difference in whether she thought her community members would accept professional help from someone who is not part of the family. For some people, there's no stigma attached to paying a professional for care. But for this particular interviewee and for those in her community, hiring a caregiver might mean failing at one's familial duties.

In another circumstance, a community-based advocate who supports African-American seniors said that the individuals seeking support through her organization choose not to use government services. These are individuals who lived through the Great Depression and worked in jobs, often paying a low wage, in order to purchase a home that they could pass along to their children. For them, relying on public programs—like Medicaid—means giving up everything that they have worked hard to build (because the income restrictions for eligibility are so low), making Medicaid signup not an option.

"They don't trust the state; [and when they think of services and supports], they see it as the state coming in and taking their house."

This mindset has continued in the generations that have followed, and that generation could benefit immensely from the Washington Cares Fund since, unlike Medicaid, it comes without income restrictions. However, to change their perspective on using public programs, outreach strategies will need to take into consideration their real mistrust in government, and this may mean working in partnership with CBOs that represent them.

The fund may create an opportunity to change the way that people think about long-term care, particularly in communities that are used to caregiving as unpaid labor by family members. That's a big deal. However, Washingtonians come from diverse cultural backgrounds, and in order to change perspectives, messaging should meet beneficiaries where they are.

Offer a simple process for those beneficiaries who will have to opt-in.

Gig workers, freelancers, and entrepreneurs will not have employers to automatically facilitate their participation in the fund. The gig worker, freelancer, and entrepreneur interviewed for this report stated that they would choose to opt-in to the fund. This leaves the team to speculate that many of these workers will choose to opt-in as they often have unstable and low wages and will commonly not have access to long-term care resources otherwise. It's also likely that their lives might have many moving parts that make administrative work hard to maintain. The fund's website has set up **a page for workers who will need to opt-in**. To bolster participation in the fund and equitable access to the benefit, Washington should be proactive in spreading awareness of the benefit, and simplifying the process to opt-in and contribute. Also, since employers from tribal nations have different concerns than those regulated by the state, Washington should allocate resources to ensure that employers and employees from tribal nations have the information that they need to make decisions about participating in the fund.

Make the program's digital analytics open to the public.

The fund's commission will be responsible for reporting on program participation and related demographics. Given that DSHS plans to focus on developing web-based services, the data analytics of the fund's website should be used as an accountability and tracking tool to evaluate equity and accessibility to the fund benefits.

Fund commissioners should have access to these analytics to help them gather data for their reporting responsibilities. Even better, data analytics for the fund's website should be publicly available so that communities not represented by the commission might still have an opportunity to participate in continuously increasing equitable delivery of fund benefits. Many CBOs will inevitably support the Fund by providing education, outreach, and navigation services. Making these data available to everyone would help CBOs and others direct their efforts. The Fund might even consider offering monthly presentations to go over insights from the site's analytics as a way to involve and inform CBOs of who the fund is reaching and where there are gaps in service.

Open data practices are becoming increasingly mainstream within government due to the value that they provide in increasing civic participation and reducing administrative burdens related to public record requests. See the federal government's **Digital Analytics Program** to get a sense of how others in government are opening up their website analytics to improve government service delivery.

Clearly state what services are covered and what are not.

As mentioned above, we have discussed the need for consumer protections—it's critical that services provided by the fund focus on the safety and protection of beneficiaries. Once DSHS has set which services it will fund, those services will need to be made clear to consumers.

Long-term care, in general, is not a well understood term—people have varying understanding of the services that it entails. To manage beneficiary expectations, DSHS should clearly state the types of services and supports that the fund. Also, DSHS should be concise about the services that the fund will not cover—and why they're not covered. It is also an opportunity for officials to identify services that properly protect beneficiaries as they age or face unexpected health crises. Making this distinction also will reinforce beneficiaries' understanding of what they are responsible for securing on their own.

Conclusion

Washington has set a precedent in leading the nation in providing care for its residents. The state's long-term services and support system currently ranks second in overall performance within the nation, based on **the fourth edition of the *LTSS State Scorecard***. While the Washington Cares Fund has raised an array of questions about the future of public-benefits programs, the fund serves as a clear microcosm of what can be achieved across the nation. By creating this program, Washington has set the tone for future legislation on a federal and state level.

We've discussed design decisions that Washington State might consider to increase the accessibility of the Washington Cares Fund for the wide array of Washingtonians. These recommendations are broadly applicable to other states developing long-term care fund programs as well.