

The Future of Care:

Addressing Long Term Care Needs for Californians

Michele Mattingly

January 6, 2025

**THE
FUTURE
OF CARE**



JUSTICE IN AGING
FIGHTING SENIOR POVERTY THROUGH LAW

seiu 2015

UDW



Caring Across Generations is a national campaign of family caregivers, care workers, disabled people, and aging adults working to transform the way we care in this country so that care is accessible, affordable and equitable—and our systems of care enable everyone to live and age with dignity. Our mission is to change our culture and policy in America to value and support caregiving. To that end, we seek to transform cultural norms and narratives about aging, disability and care; to win federal and state-level policy change; and to create a powerful coalition across the millions of us who are touched by care.



United Domestic Workers AFSCME 3930 is a union for home care workers, by home care workers. We look after loved ones in our families, as well as community members who need our assistance. Many of us left paid, full-time jobs to do this work, and we frequently work more hours than we are paid for. Our union allows us to fight for better working conditions collectively and, as a result, we have experienced many victories for home care over the past several decades, starting with the creation of California's In-Home Supportive Services program (IHSS) in 1973. Today, we are led by a group of dedicated members committed to protecting the IHSS program for our clients, making improvements to IHSS that positively impact the lives of clients and providers, and raising wages and expanding benefits for IHSS home care workers.



Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources. Since 1972, we've focused our efforts primarily on those who have been marginalized and excluded from justice such as women, people of color, LGBTQ individuals, and people with limited English proficiency.



SEIU 2015 is California's Long Term Care workers organization that will unleash the collective power of long term care workers, their families, and their communities, harness the power of technology, and build a broad movement to disrupt the unjust status quo in order to bring lasting transformational change towards a more just society for all. Through the work of our members, by building partnerships, and embracing innovation and education, SEIU Local 2015 long term care workers will have achieved quality jobs that deliver livable wages, retirement security, respect, and the right to a union for all.

Acknowledgements

The author thanks the team at Justice in Aging, UC Berkeley Labor Center, and Caring Across Generations for their review and contributions to this report.

Introduction

Long-term services and supports (LTSS) are the services and supports provided to people for whom aging, chronic illness, or disability limit their ability to care for themselves. LTSS can be delivered in an institutional care or skilled nursing facility, or in the home. Almost three-quarters of Californians express a preference for receiving LTSS, should they need them, at home.¹ Yet, there are numerous barriers that prevent people from having the ability to do so, like navigating a complicated patchwork of programs that are difficult to qualify for and vary the level of support provided. Californians need and deserve to live, age, and work with dignity, and building a comprehensive system for long-term care in the state will help meet growing needs.

More than half of Californians aged 65 and older or those living with disabilities report difficulty with routine activities such as managing their medications or shopping for groceries.² Meanwhile, nearly one in five says that they need assistance with bathing, dressing, or other personal care activities.³ Inequities persist by race and ethnicity, with Black Californians reporting difficulty with routine activities and personal care 1.3 and 1.9 times more than the population average, respectively.

While the vast majority of Californians want to stay in their own home, they are not confident about being able to afford to receive care there. Forty-four percent of adult Californians surveyed in 2022 said they were “not too” or “not at all” confident they would have the financial resources to pay for home-based care for themselves or a relative as they age.⁴ Again, the results vary when broken down by race and ethnicity, with 52 percent of Black Californians and 50 percent of Latinx Californians unsure of their ability to afford home-based care.

When contemplating how they will pay for long-term care, many people mistakenly assume that Medicare will cover the cost. Nationally, 45 percent of people aged 65 and older believe that long-term care will be paid for by Medicare.⁵ In fact, Medicare does not cover non-medical long-term care.⁶

Private long-term care insurance is prohibitively expensive for many—premiums have increased by 35 percent in a decade, while rising health costs and general inflation have eroded the value of the benefits.⁷ The failure of insurance carriers’ actuarial models to account for longer life spans and accompanying health costs has led firms to exit the market, with the number of carriers offering policies

44%

of adult Californians surveyed in 2022 “not too” or “not at all” confident they would have financial resources to pay for home-based care for themselves or a relative as they age.

2023 CHCF California Health Policy Survey

¹ Lucy Rabinowitz Bailey et al. The 2023 CHCF California Health Policy Survey. <https://www.chcf.org/wp-content/uploads/2023/02/2023CHCFCAHealthPolicySurvey.pdf> Accessed 9-12-24.

² Kathryn G. Kietzman and Lei Chen. Unmet Needs for Help at Home Fact Sheet. <https://healthpolicy.ucla.edu/publications/Documents/PDF/2022/Unmet-Needs-for-Help-at-Home-factsheet-aug2022.pdf> Accessed 9-12-24.

³ Kietzman and Chen.

⁴ Bailey et al.

⁵ Liz Hamel and Alex Montero. The Affordability of Long-Term Care and Support Services: Findings from a KFF Survey. <https://www.kff.org/health-costs/poll-finding/the-affordability-of-long-term-care-and-support-services/> Accessed 9-13-24.

⁶ U.S. Centers for Medicare and Medicaid Services. Long-term care. <https://www.medicare.gov/coverage/long-term-care> Accessed 9-12-24.

⁷ Jordan Rau and JoNel Aleccia. Why Long-Term Care Insurance Falls Short for So Many. <https://kffhealthnews.org/news/article/dying-broke-why-long-term-care-insurance-falls-short/> Accessed 9-13-24.

having declined by about 90 percent.⁸ Insurers also overestimated the number of policyholders who would let their policies lapse before actually needing long-term care.⁹ As well as raising premiums, insurance companies have made it harder to qualify to purchase a policy—a chronic condition such as diabetes can greatly reduce one's odds—and they have adopted more stringent examination of claims.^{10,11}

More than two million Californians do have access to long-term care through Medi-Cal, the primary payer of long-term care in the state.¹² This includes coverage for both nursing facility care and home and community-based services (HCBS). HCBS programs entail a wide range of services which enable people to receive care without having to enter a facility. These services include skilled nursing care delivered in the home and assistance with personal care such as bathing, dressing, and eating. Outside of the home, HCBS programs provide services through community-based resources such as senior centers, meal programs, adult day care programs, and assisted living.

"Californians need and deserve to live, age, and work with dignity, and building a comprehensive system for long-term care in the state will help meet growing needs."

In-Home Supportive Services Program (IHSS) in California

The state's largest HCBS program is the In-Home Supportive Services Program (IHSS), which currently serves more than 750,000 Californians.¹³ It is also the country's oldest and largest self-directed personal care program and the state's largest public workforce. A critical component of IHSS is that enrollees can self-direct their care by hiring their own family members if they choose. In fact, 72% of the 671,000 IHSS providers are related to their care recipients.¹⁴ This functions to both pay the family caregivers whose efforts are usually left uncompensated and to provide direct financial assistance to families with older adults or people with disabilities.

While providing vital services that allow Californians to stay in their homes and self-direct their own care, HCBS programs also save the state money, since, as would be expected, it

⁸ Rau and Aleccia.

⁹ Rau and Aleccia.

¹⁰ Portia Y. Cornell. Medical Underwriting In Long-Term Care Insurance: Market Conditions Limit Options For Higher-risk Consumers. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5127198/> Accessed 9-13-24.

¹¹ Rau and Aleccia.

¹² Department of Health Care Services. Medi-Cal Monthly Eligible Fast Facts. October 2023. <https://www.dhcs.ca.gov/dataandstats/statistics/Documents/FastFacts-July2023.pdf> Accessed 10-21-24.

¹³ Hagar Dickman. California's In-Home Supportive Services Program: An Equity Analysis. June 2023. <https://justiceinaging.org/wp-content/uploads/2023/06/CA-IHSS-Program-An-Equity-Analysis.pdf> Accessed 10-21-24.

¹⁴ Caitlin Barr, Amanda Ream, and Jaimie Worker. Re-envisioning the Future of Care in California. https://caringacross.org/wp-content/uploads/2024/05/Re-Envisioning-the-Future-of-Care_-The-cost-of-doing-nothing-and-the-case-for-universal-access-to-aging-and-disability-care-new-1.pdf Accessed 5-28-24.

costs more for care to be delivered in a nursing facility. The average annual per person cost of a nursing facility, for example, is more than four times that of IHSS.¹⁵

The reach of Medi-Cal home and community-based services, however, is limited – not everyone can access these critical supports. There are 6.6 million older adults and people with disabilities in California,¹⁶ but only one in three is eligible for long-term care through Medi-Cal due to income eligibility limits, which restrict enrollment to those with annual incomes of less than \$21,000 or 138 percent of the Federal Poverty Level (FPL). The majority of the remaining 4.4 million older adults and people with disabilities, while ineligible for Medi-Cal, live on less than \$60,000 a year.¹⁷ With the Medi-Cal threshold so low, low-income older adults and people with disabilities who do not qualify for the program must choose between accessing essential long-term care and paying for essential needs like food and rent.

Further, even those who qualify for Medi-Cal do not necessarily receive the services to which they are entitled. A 2021 California State Auditor report on IHSS cited state and county failures that have resulted in tens of thousands of recipients not receiving timely care.¹⁸

With the inadequacies of the private market for long-term care insurance and the limitations of state-provided programs, the majority of long-term care in the state is provided by unpaid family caregivers.¹⁹ It is estimated that the 4.4 million unpaid caregivers in the state provide over four billion hours of care annually with an economic value of approximately \$81 billion.²⁰

Given the lack of accessible and affordable LTSS, it is not surprising that 40 percent of older adults and those with disabilities in California say they have unmet needs when it comes to long-term care.²¹ The number of Californians with unmet LTSS needs can only be expected to grow as the state's population ages. The Department of Finance projects that nearly a quarter of Californians will be 65 or older by 2040.²² It is therefore imperative that California take steps to ensure that all residents who need it can receive long-term care. The state needs a system of accessible, affordable LTSS with stable financing. Four key components of making LTSS for all a reality include reforming Medi-Cal's Share of Cost policy, expanding Medi-Cal's Aged and Disabled Program, creating a long-term care social insurance benefit, and investing in the direct care workforce.

Reform Medi-Cal Share of Cost

The Medi-Cal Aged, Blind and Disabled – Medically Needy Program (ABD-MN) is designed to provide Medi-Cal coverage to those who are aged, blind, or disabled yet have incomes

¹⁵ University of California Labor Center analysis of CA Department of Social Services and CA Department of Health Care Services data.

¹⁶ Department of Health Care Services. October 2023. National Opinion Research Center. Understanding California's Middle-Income Older Adult Population. October 3, 2022. <https://www.norc.org/content/dam/norc-org/documents/standard-projects-pdf/NORC%20Forgotten%20Middle%20CA%20-%20Findings.pdf> Accessed 10-21-24.

¹⁷ National Opinion Research Center. October 3, 2022.

¹⁸ California State Auditor. In-Home Supportive Services Program. <https://information.auditor.ca.gov/pdfs/reports/2020-109.pdf> Accessed 7-29-24.

¹⁹ Barr, Ream, and Worker.

²⁰ AARP Public Policy Institute. Number of Family Caregivers, Hours, and Economic Value of Caregiving, by State, 2021. <https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-state-estimates.doi.10.26419-2Eppi.00082.009.pdf> Accessed 9-16-24.

²¹ Kietzman and Chen.

²² Hans Johnson, Marisol Cuellar Mejia, and Eric McGhee. California's Population. <https://www.ppic.org/publication/californias-population/> Accessed 9-16-24.

exceeding 138 percent FPL. Through the program, individuals may pay for a share of their medical costs in a given month before Medi-Cal coverage begins. This arrangement is commonly referred to as Share of Cost, and the portion of medical expenses that enrollees pay is analogous to a monthly deductible.

In determining enrollees' share of cost, an allowance is made for an individual's monthly living expenses, known as the Maintenance Needs Allowance (MNA).²³ However, the MNA in California has not been updated since 1989 and is only \$600.²⁴ It is unrealistic to expect \$600 to cover an individual's monthly rent, utilities, food, and other living expenses. In 2023, only 8% of the more than 60,000 Californians enrolled in the program were able to routinely meet their share of cost and have their remaining monthly health expenses covered by Medi-Cal.²⁵ Reforming Medi-Cal share of cost would mean more Californians in need of long-term care can get the support they need without exhausting all of their resources.

In 2022, the Governor and legislature committed to raising the MNA to 138% FPL on January 1, 2025.²⁶ However, funding to do so was excluded from the final 2024-25 State budget.²⁷

Expand the Medi-Cal Aged and Disabled Program

As discussed previously, about one in three Californians aged 65 and up and those living with disabilities are enrolled in the Medi-Cal Aged and Disabled Program. The income eligibility limit for the program is presently \$1,732 monthly or \$20,784 annually for a household of one.²⁸ Increasing the income limit to 400 percent of the FPL (\$4,860 monthly or \$58,320 annually) would make LTSS accessible to Californians who are currently priced out of private care yet ineligible for Medi-Cal. Expansion can be carried out incrementally, as illustrated below. The state previously expanded the program in 2020, when the income limit was raised from 123 percent to 138 percent of the FPL.²⁹

Incremental expansion of Medi-Cal's Aged & Disabled FPL Program would make LTSS accessible to nearly **2 million older and disabled Californians**.³⁰

²³ Disability Benefits 101. Medi-Cal Frequently Asked Questions.

https://ca.dbi01.org/ca/programs/health_coverage/medi_cal/faqs.htm Accessed 9-24-24.

²⁴ Justice in Aging et al. AB 1900 (Arambula) Fact Sheet. Accessed 9-23-24.

²⁵ California Department of Health and Human Services. Population Distribution for Medi-Cal Enrollees by Met and Unmet Share of Cost.

<https://data.chhs.ca.gov/dataset/population-distribution-for-medi-cal-enrollees-by-met-and-unmet-share-of-cost-soc/resource/b8087144-5456-48fa-8d53-68d9f62ed896> Accessed 10-21-24.

²⁶ Karen Fletcher. Medi-Cal's Share of Cost Program's Monthly Maintenance Need Level to Rise to 138% FPL in 2025. Aug. 4, 2022.

<https://cahealthadvocates.org/medi-cal-share-of-cost-programs-monthly-maintenance-need-level-to-rise-to-138-fpl-in-2025/> Accessed 10-21-24.

²⁷ Karen Fletcher. An Update on Medi-Cal Share of Cost Reform. Sept. 5, 2024.

<https://cahealthadvocates.org/an-update-on-medi-cal-share-of-cost-reform/> Accessed 10-21-24.

²⁸ Covered California. Program Eligibility by Federal Poverty Level for 2024.

<https://www.coveredca.com/pdfs/FPL-chart.pdf> Accessed 8-19-24.

²⁹ Karen Fletcher. Medi-Cal's Senior Penalty Ends December 1st – Yes!

<https://cahealthadvocates.org/medi-cals-senior-penalty-ends-dec-1st-yes/> Accessed 9-23-24.

³⁰ Table created using UC Berkeley Labor Center preliminary estimates based on 2023 Medi-Cal enrollment data, December 2023 IHSS monthly program data, and analysis of disability rates and health insurance unit income-to-poverty threshold ratios in March 2022 CPS ASEC microdata.

Federal Poverty Level	A&D FPL Program participants	Participants estimated to use LTSS benefits
138%	2.2 million (status quo)	—
150%	+219,000	84,000
220%	+626,000	118,000
300%	+555,000	86,000
400%	+540,000	80,000

Establish an LTSS social insurance benefit

A key step in ensuring accessible LTSS with stable financing is creating an LTSS social insurance benefit, as the State of Washington did in 2019.³¹ A long-term care social insurance benefit would be a transformational public investment that would expand the affordability and accessibility of long-term care.

The state's Social Disability Insurance and Paid Family Leave Programs are financed by a payroll tax paid by those employed in California. An LTSS benefit for Californians would be financed the same way. Depending on the benefit design option, the payroll tax would be between 0.6 and 3.0 percent, split between employers and employees.³² These rates correspond to a limited lifetime benefit of \$36,000 to \$144,000. All vested adults aged 18 and older would be covered. Portable benefits would allow vested participants to access LTSS if they need to do so after moving away from California.

Creating an LTSS social insurance benefit would require a constitutional amendment via ballot initiative to invest the funds in treasuries, bonds, stocks, and equities. It could also be done via a two-thirds vote of the legislature, in which case the program would require a higher tax rate because funds could only be invested in treasuries.

Invest in good jobs for care workers

Good jobs for direct care workers are essential for achieving universal access to aging and disability care. Direct care workers include personal care aides, home health aides, direct support professionals and IHSS workers, and certified nursing assistants. IHSS workers constitute an estimated three-quarters of the occupation, and make near minimum wage, an average of \$17.95 per hour. Those caring for family members have no access to benefits like Social Security retirement or unemployment insurance.³³ This means that the

³¹ WA Cares Fund. Long-Term Services and Supports (LTSS) Trust Commission. <https://wacaresfund.wa.gov/about/commission> Accessed 10-21-24.

³² Oliver Wyman. California Assembly Bill 567: Oliver Wyman Actuarial Report. https://cahip.com/images/downloads/ca_ab_567_oliver_wyman_actuarial_report_2023_12_15.pdf Accessed 10-21-24.

³³ Barr, Ream, and Worker.

caregivers underpinning the majority of California's long-term care infrastructure are unable to make ends meet, and meet and are often on public assistance themselves. Stabilizing the direct care workforce by paying workers family-sustaining wages and benefits will help address the workforce recruitment and retention crisis.

One path toward that end is passing statewide collective bargaining for IHSS workers. Currently, California employs a complex and uneven county-level collective bargaining system in the public sector, which puts downward pressure on IHSS wages and creates additional challenges for the recruitment and retention of workers. Shifting towards a statewide system of collective bargaining would support state implementation and oversight regarding agreed-upon wages, health benefits, retirement benefits, training, and any necessary funding to bolster the workforce and improve the quality of care older adults and disabled people receive.

People can experience disability at any stage of life, and, with age, the chance of needing long-term care greatly increases. One study found that 70 percent of adults who survive to age 65 develop high levels of LTSS needs.³⁴ Inequities based on race, gender, and education lead to higher levels of need among people of color, women, and people with barriers to higher levels of education. With so many Californians presently facing unmet LTSS needs and nearly one in four residents projected to be 65 or older in 2040, action is needed now. We must begin by strengthening existing programs and infrastructure, including significant and sustained investments in the LTSS workforce. As we do so, we can lay the groundwork for a long-term care social insurance benefit. In taking these steps, we will ensure all Californians, regardless of income, have access to the long-term care that allows them to live in safety and dignity.

³⁴ Richard W. Johnson. What Is the Lifetime Risk of Needing and Receiving Long-Term Services and Supports? <https://aspe.hhs.gov/reports/what-lifetime-risk-needing-receiving-long-term-services-supports> Accessed 9-13-24.