

Re-envisioning the Future of Care in California:

The cost of doing nothing and
the case for universal access to aging and disability
care

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THE FUTURE OF CARE





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.

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Key Takeaways:

- Californians overwhelmingly want to receive support to live and age in their own homes and communities, but the ability to do so requires navigating a complicated patchwork of programs that are difficult to qualify for and vary in the level of support provided. Investments in aging and disability care are also widely popular among California voters.
- For Californians who do not meet the strict eligibility for Medi-Cal, there are few options for care, because Medicare provides limited long-term care coverage and private long-term care insurance is prohibitively expensive with a shrinking market presence. The out-of-pocket market cost for home and community-based care is more than \$80,000 annually.
- The largest Medi-Cal home and community-based services (HCBS) program in California available to low-income people, In-Home Supportive Services (IHSS), serves more than 700,000 older adults and people with disabilities. The program requires additional investments to meet the needs of the millions of Californians who will need aging and disability care by 2030.
- Investments in the paid care infrastructure would also take the financial strain off the 4.4 million family caregivers in California who currently provide supports and services for their family members because the current system does not support everyone.
- Adults over the age of 75 years with incomes as low as \$25,000 and as high as \$100,000 in California are particularly vulnerable to not receiving care. These older adults are more likely to be women, people with disabilities, and people of color, especially among Black, Brown, and immigrant communities. These older adults cannot afford the care they need, even if they worked full-time jobs their entire careers.
- Minimum wage, or barely above it, with minimal to no benefits is the current standard for private pay and state-supported direct care workforce, making it the largest low-wage occupation in the state. Good jobs for the 700,000 IHSS workers with 800,000 direct care workers in the private pay market are essential for recruiting and retaining workers to the field, meeting both current and future demand for services, and achieving universal access to aging and disability care.

- Ultimately equitable policies that support universal access to aging and disability care will require:
 - Exploring and adopting policies to expand coverage for long-term care to Californians who have incomes that exceed the current Medi-Cal eligibility limit.
 - Adopting policies that expand access to long-term care coverage beyond what is currently through Medi-Cal.
 - Ensuring that coverage expansions would ensure access to services and supports people need to remain living in and connected to their communities and be equitably available to all Californians who need care regardless of income, race, age, disability, sexual orientation, and gender identity.
 - Addressing the workforce crisis, so severe that many who can afford care are unable to find it due to the lack of care workers in California's communities, by using the buying power of the State in the care marketplace to increase pay, benefits, and improve working conditions, including the right to join a union.

Why This Matters:

- The cost of inaction is too high to warrant doing nothing. Meeting the needs of Californians now and in the future calls for universal access to aging and disability care, especially home and community-based care. This will ensure that every Californian is able to access the care they need when they need it.
- In California, family caregivers provide more than \$81 billion in unpaid care even as they themselves experience significant financial hardships, difficulties with their careers, and health challenges.
- The care workforce crisis continues to intensify without a plan to compensate, develop, and strengthen the workforce which provides the services and supports that people with disabilities, older adults, and family caregivers rely on. Ensuring these workers and their families can thrive and make ends meet is vital to California's communities.
- All Californians need and deserve to live, age, and work with dignity. If the state does not act, California will experience unprecedented pressure on underprepared and under-resourced public health systems, making it increasingly difficult for Californians to access the life-sustaining care they need.

The future of care in California depends upon affordable, accessible aging and disability care, support for family caregivers, and good jobs for direct care workers.

Introduction

We all have care in common. Each of us will need or provide care at some point in our lives. Home and community-based services (HCBS) are the essential supports that people with disabilities and older adults rely on to live and age with dignity in their own homes and communities. Aging and disability care remains undervalued and care workers remain underpaid despite the critical nature of these essential services. Decades of disinvestment in care infrastructure mean that family caregivers continue to shoulder the vast majority of the cost of long-term care and care recipients are unable to access the care they need. This is by design and is deeply rooted in persistence of structural racism, sexism, ageism, and ableism embedded in public policies today.

This brief focuses on the long-term care needs of older adults and people living with disabilities and examines what is at stake for family caregivers, direct care workers, and the state as a whole if California does not invest in the growing demand for long-term care. We also discuss recent polling that provides insight into Californian's current views about long-term care, and principles for developing policy solutions that lead to universal access for aging and disability care for every Californian.

Most Californians want to live and age in their own homes and communities but are not able to access the services and supports they need.

Home and community-based services (HCBS) assist people living with disabilities and older adults with day-to-day activities, providing critical support to family caregivers, and support for care recipients to live and age with dignity in their own homes and communities. The preference of the vast majority of Californians is clear: Most Californians – 72% – would prefer to live and age in their own homes, compared to just 2% who would prefer institutional care or skilled nursing facilities.¹ However, older adults and people with disabilities may need support with a range of day-to-day tasks in order to live independently in their own homes and participate fully in their communities. This includes tasks such as eating, dressing, support with communication, participating in employment, using transportation or assistance with cooking, cleaning, laundry, or shopping. As the people receiving services know best what support they need, it is crucial that they have access to

self-directed care, which gives them the power to exercise personal choice over how and where they would like to receive their care and who they would like to hire as their care provider, including a family member. Equally important for people who are unable to self direct their care is that they also have options for home and community-based care and are not forced into institutional settings.

However, despite people's preferences, there are numerous barriers that prevent people from accessing the care they need including narrow financial eligibility requirements and additional barriers related to housing, location of available programs and services, language, and other accessibility needs, as well as difficulties finding workers to provide services in this underpaid workforce. The limits in the current system mean that many older adults and people with disabilities are not getting the care they need or are relying on family and friends to fill in the gaps. Older women of color are acutely affected by limited income eligibility - over 40% of older Black women live in poverty or near-poverty, compared to less than 20% of older white men.² The inadequacies in the system also leave potentially or already eligible people on waiting lists for months and years and subject to diminished quality of life and health challenges. It also impedes upon the civil rights of people with disabilities seeking to live in their own homes and participate in their communities. We discuss these and related challenges below.

Medi-Cal is the primary payer of long-term care in California but has strict income eligibility.

Medi-Cal is the primary payer of long-term care in California, including HCBS. While California is the first state in the country to eliminate the asset limit for Medicaid, the state's income limits keep many older adults and people with disabilities from accessing the program. Adults with earnings under 138% of the federal poverty level (FPL) can qualify based on income.³ Those receiving Supplemental Security Income (SSI) are also automatically eligible for coverage through SSI-linked Medi-Cal.⁴ People with disabilities in the workforce – even if they make as little as \$20 per month – can also qualify if they make under 250% of the FPL or \$3,158 per month for a single person.⁵

Older adults and people with disabilities who do not meet these income cutoffs can “spend down” to qualify through the Aged-Blind-Disabled Medically Needy (ABD-MN) Program, a “share of cost” program. This means participants must pay a certain amount of their income on medical costs – similar to a deductible – each month before their Medi-Cal coverage kicks in.⁶ Currently, people must spend down all but \$600 of their income before Medi-Cal pays. Although this threshold was intended to reflect the amount of money one would need to survive each month, it has not

been updated since 1989, rendering the ABD-MN program an unaffordable source of coverage for many.⁷ The threshold was set to be raised in January of 2025 to 138% of the FPL, from \$600 to \$1,677 per month, but implementation may be delayed due to budget constraints.⁸ In a state where housing alone costs around \$1,700 and the monthly cost of living typically reaches \$5,200 this leaves care recipients in an untenable situation.⁹ In 2023, barely 5,000 people were able to meet their share of cost among the more than 61,000 receiving Medi-Cal through this program.¹⁰

The lack of affordable, accessible housing results in additional barriers for older adults and people with disabilities seeking to live and age in their own homes and communities.

AARP's Livability Index ranks California 41st among states on the basis of affordability, accessibility, and availability of housing. The same index ranks California in the bottom third of states for high housing costs, housing cost burden, and availability of subsidized housing.

For those unable to afford housing without public assistance, the state does not provide a reliable safety net. The average wait time for a housing voucher is 32 months – over two and a half years. Californians over the age of 50 are the fastest growing unhoused population in the state, with older Black men at highest risk. Only 17% of Californians with disabilities who are eligible for housing assistance actually receive assistance.

In the absence of crucial state support, older adults and people with disabilities with the least income are left at significant risk as rents steadily increase, health outcomes worsen, and accessibility needs remain unaddressed. For example, efficiency apartments are unaffordable statewide for those surviving on SSI benefits — and in 25 out of 58 counties, typical rent is actually higher than the benefit amount. Older adults who are unhoused also utilize health care services at higher rates than younger unhoused adults due to health and aging challenges.

The limited supply of housing that meets the accessibility needs of people with disabilities creates additional challenges. Among the discrimination complaints received by the US Department of Housing and Urban Development from California, 54 percent were related to disability status.

Sources: AARP, "AARP Livability Index" / Sonya Acosta and Erik Gartland, "Families Wait Years for Housing Vouchers Due to Inadequate Funding," Center on Budget and Policy Priorities, July 22, 2021 / Patti Prunhuber, "California's Older Low-Income Renters Continue to Be Squeezed by Housing Unaffordability and Face a Growing Threat of Aging into Homelessness," Justice in Aging, March 13, 2024 / AARP, "LTSS 2023 State Scorecard Report," September 28, 2023 / Monica Saucedo, "Inadequate SSI/SSP Grants Leave Californians Unable to Afford Basic Needs," California Budget and Policy Center, January 2024 / California Department of Housing and Community Development, "People with Disabilities."

Californians who want to access Medi-Cal HCBS must navigate a complicated patchwork of programs.

Medi-Cal offers HCBS through different Medicaid authorities including six different Medicaid waiver programs (1915(c)) funded using state and federal dollars and through the state plan (discussed more in the next section). Only those who require a nursing facility level of care are eligible for 1915(c) waiver programs.¹¹ These programs, described below, are limited in scope, with enrollment caps and waitlists, as well as restrictions based on geography (e.g., specific counties) and populations that meet a set of defined needs or criteria.¹²

- The [Assisted Living Waiver](#), available in just 15 counties, supplies comprehensive services to people in assisted living facilities and public subsidized housing.
- The [Home and Community Based Alternatives Waiver](#) provides care recipients statewide with care management teams that coordinate and connect them with HCBS.
- The [Medi-Cal Waiver Program](#), formerly known as the AIDS waiver, provides services such as case management, household services, transportation, and attendant care to people diagnosed with HIV/AIDS in 26 counties.
- The [Multipurpose Senior Services Program](#) supplies health care and social services to older adults so they can age safely at home. Currently available in 46 counties, California is seeking to expand the program statewide.¹³
- The [Home and Community Based Services for the Developmentally Disabled](#) (HCBS-DD) waiver is the largest of all HCBS waiver programs in the state, providing funding for services at regional centers, which are nonprofits that contract with the state to provide support for care recipients with developmental disabilities.¹⁴
- The [Self-Determination Program](#) supports people with disabilities who guide their own care and receive services at regional centers to meet their goals to live and age in their own homes and communities.

Medi-Cal HCBS is also offered through Medicaid demonstrations – special projects that allow greater flexibility in order to experiment with potential innovations to Medicaid. Like 1915(c) Medicaid waivers, these programs can limit eligibility by geography and population.¹⁵

- [California Community Transitions](#) (CCT) is available in 40 counties and helps those living in skilled nursing facilities move back into their communities.¹⁶
- [Program for All-Inclusive Care for the Elderly](#) (PACE), available in 15 counties, provides older adults with transportation to PACE centers that provide comprehensive services supporting their continued ability to age at home.
- Three more Medicaid demonstration projects – [Community Based Adult Services](#) (CBAS), [CalAIM Enhanced Care Management](#), and [CalAIM Community Supports](#) – provide HCBS for certain care recipients who are enrolled in Medi-Cal managed care plans.¹⁷

The Medi-Cal State Plan includes In-Home Supportive Services (IHSS), the largest self-directed program providing HCBS for older adults and disabled people.

Two kinds of HCBS services are offered as Medi-Cal State Plan benefits that must be made available to all eligible Medi-Cal enrollees in the state.¹⁸ The first is [the Health Homes Program](#), which provides resources such as intermittent skilled nursing care, home health aide services, and medical supplies and equipment to people who require the level of care found in skilled nursing facilities.¹⁹ The second is [In-Home Supportive Services \(IHSS\)](#), the state's largest HCBS program, which provides a range of personal care services to Medi-Cal recipients who would otherwise be unable to live safely in their own homes.²⁰ The underlying principles for policies to support long term care in California discussed below draw on the lessons, and growing demand for the services of the IHSS program.

IHSS, also the country's oldest and largest self-directed personal care program, was founded in 1973 as an outgrowth of a grassroots movement advocating for the freedom of older adults and disabled people to live and age in the community.²¹ A crucial aspect of this freedom is the ability of care recipients to self-direct their own care.²² Administered day-to-day through county governments, IHSS provides access to personal care services, paramedical services, and – for care recipients who need extra attention to live safely in their homes – 24-hour supports and services.²³ A unique, particularly popular feature of IHSS is that enrollees can self-direct their care by hiring their own family members if they choose: 72% of the 671,000 IHSS providers are related to their care recipients.²⁴ This functions as a mechanism both for paying the family caregivers whose efforts are usually left uncompensated and for providing direct financial assistance to families with older adults or people with disabilities.²⁵ Depending on which particular IHSS program they're enrolled in and how much support they're determined to need, care recipients can receive up to 283 hours of care monthly (typically a maximum of 66 hours per week). They can also use IHSS simultaneously with other HCBS services.²⁶

While IHSS is the largest HCBS program in California by far, serving over 750,000 care recipients, enrollment is increasing at a high rate and demand is outstretching program resources.²⁷ For comparison, the HCBS-DD waiver – the second largest – served 111,000 people with disabilities.²⁸ IHSS enrollment is consistently increasing every year, and will only continue to grow, both as the population continues to age – by 2030, a quarter of the Californian population will be older adults – and as Medi-Cal eligibility facilitates access and affordability by eliminating asset limits and providing Medi-Cal to all eligible California residents, regardless of immigration status.²⁹ Demand is already outstretching program resources: more than half of

California's counties, 32 out of 51, have shortages of IHSS providers, and each month tens of thousands of people are unable to secure access to the IHSS care they qualify for.³⁰ As discussed below, the lack of providers is also fueled by lack of high paying jobs for this critical workforce providing essential services.

Californians who are ineligible for Medi-Cal are left with few options for care, as Medicare does not cover the majority of services and private insurance is prohibitively expensive and limited in scope.

Since Medicare does not adequately cover long term care needs, 77% of older adults and 50% of adults with disabilities ineligible for Medi-Cal must instead pay the market price for HCBS or rely on family members and friends to fill in gaps.³¹ In California, the median market cost for care is \$83,512 each year.³² This is well out of reach for the majority of Californians. Home and community-based care in California would cost 80% of the median annual income for heads of households who are 65 years and older.³³

The Older Americans Act does help to provide some support and services to people who are financially ineligible for Medi-Cal through Aging and Disability Resource Centers and Area Agencies on Aging. Such supports include personal care services, home modifications, nutrition services, respite for family caregivers, and more. The availability of these services varies from region to region, however, and are not a substitute for comprehensive long-term care coverage.

Private insurance does not address these economic challenges or gaps, and in many cases, makes care even more unreachable for care recipients. The cost of long-term care insurance policies rose over 35% in the last decade nationally, and that, along with inflation and the rising cost of care, acts to severely erode the value of a daily fixed reimbursement rate in the private care marketplace.³⁴ Long-term care insurance companies meanwhile are increasingly unable to perform in California, with multiple lawsuits by consumers in recent years leading to class action settlements over increasing premiums and other rate hikes.³⁵ For these reasons alone it is unsurprising that only 4.2% of Californians over 40 have long-term care insurance that would help defray these costs.³⁶ Given these conditions, almost half of Californians (44%) – including higher rates of Black and Latinx residents – lack confidence in their ability to afford HCBS for themselves or their family.³⁷

By 2033, almost 90% of California's older adults 75 years and older with incomes between \$25,000 - \$100,000 – those who struggle to afford private home care, but

have incomes too high to qualify for Medi-Cal – will not be able to afford private assisted living without selling their homes.³⁸ Even after selling their homes, almost half will still not have enough money to make ends meet.³⁹ This would lead to additional racial inequities in intergenerational wealth building; nearly half of this group are likely to be people of color.⁴⁰

The 13% of older Californians whose incomes place them just above the threshold for Medi-Cal eligibility are especially vulnerable.⁴¹ These Californians – more likely than their higher-income counterparts to be women, immigrants, and people of color – also have a particularly strong need for HCBS because they are more likely to live alone and are more likely to be people with disabilities.⁴² NORC, using a more expansive definition of this cohort, finds that by 2033, there will be more than 1 million older Californians stuck just above the Medi-Cal eligibility threshold.⁴³ 57% will have mobility limitations and 48% will have at least three chronic conditions.⁴⁴ Almost half (46%) of this group will be people of color.⁴⁵

The inability to obtain care has serious consequences for the health and wellbeing of older adults, people with disabilities, and their families.

Out of the 14% of Californians who attempted to get home-based support for themselves or a family member in the past year, 35% were unable to do so due to a myriad of factors including cost, inadequate housing, complicated enrollment processes for programs, and the inability to obtain a caregiver.⁴⁶ These barriers are compounded when program rules and application processes do not take into consideration the specific needs of individuals and populations causing disparities in access and inequities in health outcomes.

With IHSS, for example, barriers to accessing the program start with the application, which is only available in English and 3 of the 18 Medi-Cal threshold languages.⁴⁷ IHSS program rules also keep some of the most at risk of hospitalization and institutionalization from accessing the program. The program has a narrow definition of “home,” which excludes 70% of unsheltered people from the program, disproportionately impacting communities of color.⁴⁸ IHSS provider shortages particularly impact those without family caregivers, who are more likely to be women, LGBTQ+, and immigrants without status. Because counties have not engaged in adequate planning to ensure all eligible IHSS recipients receive their care and the state has not required them to do so, each month, tens of thousands of IHSS recipients go without needed care.⁴⁹

Having unmet needs can significantly impact the health and safety of older adults and people with disabilities. When individuals cannot get the care they need, their

basic needs go unmet – needs like eating, getting out of bed, taking medication, interacting with the community, and wearing clean clothes. This drives increased rates of hospitalization and institutionalization and impacts care recipients' dignity and wellbeing. Given that the highest levels of unmet need are reported by Black Californians, unmet needs are a reflection of, and further perpetuate, systemic inequities in health outcomes.⁵⁰ Overall, nearly two-fifths of care recipients either need more help or receive no help at all.⁵¹

Insufficient public investment in aging and disability care means that unpaid family caregivers carry the costs of the services and support their family members need to live and age in their own homes and communities.

The majority of aging and disability care in California is provided by unpaid family caregivers because of limited eligibility for Medi-Cal, insufficient and cost prohibitive private long-term care insurance, and unmet needs alongside growing demand for aging and disability. One in ten people in California, or 4.4 million people, provide caregiving support for their family members.⁵² The AARP estimates that California's family caregivers provide more than 4 billion hours of care each year for a total economic value of around \$81 billion.⁵³ The lack of support for family caregivers creates financial pressures, difficulties with employment, and additional health challenges for caregivers.

Caregiving responsibilities cause financial stress for almost half (44.4%) of California caregivers. While only 1 in 11 Californian caregivers were paid for any of their caregiving, national data shows that the 78% of caregivers who had expenses related to their loved ones' caregiving spent more than a quarter of their income on their loved ones' caregiving needs.⁵⁴ More commonly experienced by women caregivers, this pressure rises in intensity among Black, Latinx, Asian, and the most underpaid caregivers.⁵⁵ As a result, caregivers may have to curtail their spending, dip into personal savings, or cut back on retirement contributions. Nationally, nearly 8 in 10 caregivers report having routine out-of-pocket expenses related to looking after their loved ones and the typical annual total spent on caregiving is \$7,242.⁵⁶ The strain is even greater on Latinx, Black caregivers, and on younger caregivers, who have had less time to work and build up resources.⁵⁷

These financial pressures are heightened by the difficulty of juggling caregiving responsibilities with one's own career. Nationally, about a third of caregivers report two or more work-related strains, such as having to change their schedule or take leave, which leads to an average annual outlay of \$10,525.⁵⁸ Over half of California caregivers (53.4%) must balance caring for their loved one with the commitments of a full-time job.⁵⁹ An additional 9.7% work part-time.⁶⁰ The fact most California

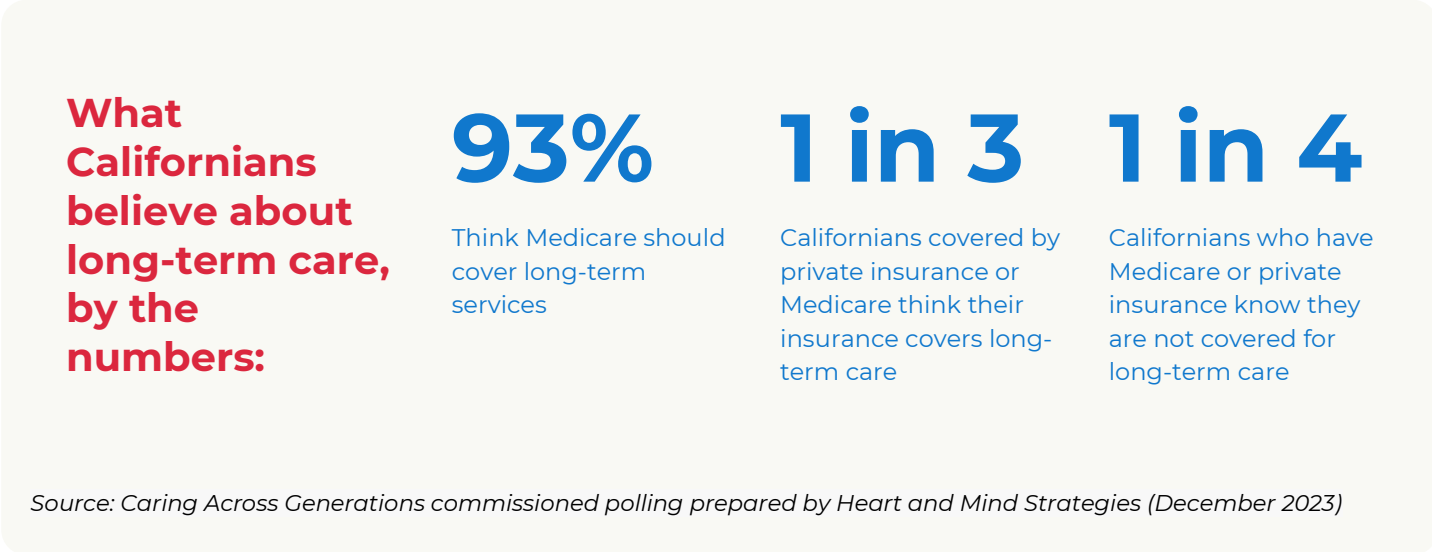
caregivers do not live with their care recipient makes this even more logistically challenging.⁶¹ Fewer than 1% of California caregivers used employment-based leave benefits – such as temporary, sick, or vacation leave (2.8%) or paid family leave (0.7%) – to help support their caregiving.⁶²

Recently introduced legislation would address some of the current barriers which contribute to the low uptake of employment-based leave, but not all bills have been passed by the legislature and signed into law. The current wage replacement rate for paid family leave benefits is too low for many to afford.⁶³ This wage replacement rate is set to increase to 90% for the lowest paid workers beginning in 2025 following the passage of the Equitable Paid Family Leave and Disability Insurance Benefits (SB 951, Durazo).⁶⁴ Also, the state's paid family leave program does not cover care for chosen family and extended family members such as aunts, uncles, and cousins, excluding caregivers and care recipients who rely on relationships with neighbors, friends, and other loved ones.⁶⁵ Finally, family caregivers lack certain job protections. Family caregiver status is not a protected class under California law, and workers may encounter discrimination on the basis of their status as a caregiver but have little recourse.⁶⁶ These difficult trade-offs and barriers can have long-term ramifications for caregivers' career advancement and lifetime earnings.

Unpaid caregiving also negatively impacts caregivers' health. A substantial body of research shows that family members who provide care to people with chronic or disabling conditions are themselves at risk. Emotional, mental, and physical health problems arise from varied and complex caregiving situations.⁶⁷ In recent years, one in seven California caregivers endured a physical or mental health problem due to caregiving.⁶⁸ Women and caregivers providing more than 30 hours of care per week were more likely to develop a health issue.⁶⁹

The majority of Californians support public financing and investment in long term care, particularly home and community-based care.

According to a 2023 poll, respondents in California overwhelmingly believe that Medicare should cover long term care services: 93% indicate 'yes.'⁷⁰ However, Californians misunderstand how the current long term care system works. 1 in 3 people insured by Medicare or private insurance incorrectly believe that their insurance covers long term care, both for nursing homes and for in-home care. Only 1 in 4 Californians who have Medicare or private insurance know they are not covered for long-term care. Opposition to the Medicaid spend down requirement for long term care service is also strong with 63% not in support.⁷¹ The gap between what Californians believe about public coverage for aging and disability care and



the reality comes as a shock for many and their families as they near the end of their lives or experience disability and must navigate the cost of their care. This confirms what earlier national polling revealed: that 88% of Americans would prefer to receive care at home as they age, and more than 6 in 10 support a variety of policies that would facilitate aging at home, including a government-administered long-term care insurance program similar to Medicare.⁷² In California, a 2022 study found that 85% of care recipients surveyed strongly supported the creation of a statewide long-term care insurance program funded by a 1% tax on income.⁷³ Overall, most Americans think that Medicare, health insurance companies, and Medicaid should cover the costs of long-term care.⁷⁴

Good jobs for direct care workers are essential for achieving universal access to aging and disability care.

All of California’s direct care workers need and deserve high-quality union jobs with family-sustaining wages and benefits. Direct care workers include personal care aides and home health aides, including direct support professionals and IHSS workers, and certified nursing assistants. Currently, home health and personal care

aides are the largest low-wage occupation in the state, composing over 4% of the total workforce. IHSS workers constitute an estimated three-quarters of the occupation.⁷⁵ Raising pay for these workers to be able make ends meet and take care of their families addresses the workforce recruitment and retention crisis, and reduces the need for care workers to depend on the social safety net which also needs ongoing, robust investments to support California's communities. Research also suggests that stabilizing the home health care workforce could improve the quality of care, strengthen economic growth, and allow family caregivers to return to the workforce.⁷⁶

The COVID-19 pandemic only further demonstrates the need for high quality home care across the state, yet little has improved for California's direct care workers. The majority of IHSS workers are women of color, disproportionately Black, Latinx, Asian, and immigrant women.⁷⁷ Caregivers in the IHSS program receive pay that is at or near minimum wage, an average of \$17.95 per hour.⁷⁸ This means that caregivers are paid significantly less than a living wage in each county and many workers employed full time qualify for public assistance themselves.⁷⁹ Also, while these workers comprise one of the largest public workforces in the state, at 700,000 care providers, they have no retirement program and may access just five sick days per year as a result of a statewide policy change for all workers, depending on the number of hours worked as of 2024.⁸⁰ Family caregivers, who are the majority of public providers, have no access to unemployment insurance or social security benefits that are readily accessible to all other workers.⁸¹

Conditions in the private sector are even worse. Nationally, California is ranked 48th for competitive wages among workers providing aging and disability care.⁸² These 800,000 care providers – most of whom are women of color and half of whom are immigrants – are paid minimum wage on average, with a median annual income of less than \$22,000, and with even fewer protections.⁸³ More than a third of this workforce lives at or near poverty level, more than a quarter pay over 30% of their income on housing-related costs, and nearly half rely on public assistance to make ends meet.⁸⁴ A report from UCLA Labor Center that interviewed 500 homecare workers and 100 consumers found that nearly two-thirds of homecare workers do not earn enough to cover their basic daily expenses, and about 3 in 4 workers reported they did not have any type of personal retirement savings.⁸⁵ The majority of these workers are paid through informal methods like cash or check, leaving them vulnerable to losing their access to unemployment insurance, paid family leave, and disability insurance.⁸⁶ Consumers reported paying \$21 per hour, but workers reported earning only \$14.50, another common home care marketplace issue, where agency fees drive wages down even further.⁸⁷ Wages are more competitive in the fast food industry and adjacent healthcare industries, intensifying workforce shortages in the most underpaid industries.⁸⁸ Additionally, misclassification and wage theft remain persistent issues for home care workers in

the private sector.⁸⁹ Despite the passage of California's [AB 5](#) in 2019, making it illegal to classify home care providers as "independent contractors," the California Department of Labor continues to prosecute groundbreaking cases of misclassification and wage theft.⁹⁰

The Californian direct care workforce is rapidly aging alongside the general population. Two-thirds of care workers statewide are more than 40 years old and 37% are more than 55 years old.⁹¹ As this workforce ages into needing care itself, the state's care infrastructure will become even more strained without better wages and benefits to attract younger workers. PHI predicts that from 2020-2030 California will see 232,500 more direct care jobs (27% growth) resulting from increased demand.⁹² But counting the job openings that will arise from workers switching occupations or leaving the labor force, that number balloons to a total of 1.4 million (1,414,200) unfilled jobs.⁹³ The rise in direct care jobs would be even more dramatic – with up to 3.2 million potential job openings by 2030 – if the industry expanded to cover all Californians with unmet needs for HCBS.⁹⁴

Fair pay and benefits are the path to addressing the direct care workforce crisis, securing a future for caregivers and California's aging and disabled populations. Across the country, most home care workers are paid through the Medicaid program, and state Medicaid agencies set payment rates for care providers. State policy therefore has a powerful impact on home health care workers' wages. In some states, such as Washington, the state Medicaid agency negotiates with worker unions to set rates at more adequate levels and increase reimbursement rates at set intervals and to create workforce standards that can shift conditions for the larger marketplace where consumers who are not eligible for Medicaid seek access to care.⁹⁵ However, currently in California, in addition to private employers who use public assistance programs such as CalFresh and Medi-Cal to supplement poverty wages, the state acts to pressure IHSS wages downwards further through a complex and uneven county-level collective bargaining system in the public sector. In a 2021 report, the state auditor warned that this approach could cause significant problems with recruitment.⁹⁶ Low wages lead to high turnover and a recruitment crisis in both the private and public sectors.⁹⁷

Recent legislative proposals and policy recommendations begin to demonstrate potential paths forward to shift how workers can come together to negotiate wages and benefits and increase investments in aging and disability care. [AB 1672](#), the In-Home Supportive Services Employer-Employee Relations Act of 2023-2024, intends to shift collective bargaining in California's public home care program to the state level, away from the current complex and unequal county-level bargaining system that creates additional challenges for recruitment and retention of workers. Approaching collective bargaining at the state level rather than county-by-county supports 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.⁹⁸ Additionally, the [California Long Term Care Insurance Task Force](#), created by AB 567 in 2019, concluded with a [feasibility report](#) to the Insurance Commissioner, Governor, and Legislature outlining recommendations for establishing a culturally competent statewide long-term care insurance program in California. The creation of this program would lead to additional state investment in the affordability and accessibility of home care, and the potential to raise standards in the industry overall as a result of state investment.⁹⁹

Overall, unions have a powerful impact on wages. Unionized direct care workers receive significantly higher wages and benefits, benefiting both union and non-union workers. They were less likely to be infected with COVID-19 during the pandemic and people receiving supports and services typically experienced superior health outcomes¹⁰⁰ United Domestic Workers/AFSCME and SEIU Local 2015 are the two unions which represent IHSS providers. With more than 700,000 care providers and growing with California's aging and disability demographic shift, IHSS providers are the largest single unionized workforce both in California and in the country. The union IHSS providers are also the nation's largest number of organized women workers, and women of color, exerting a significant presence on caregiving and aging and disability issues in policy making in Sacramento and Washington, D.C. Labor unions act to raise wages and improve standards through collective bargaining, and to oppose cuts to the program and advocate for improvements that benefit consumers and providers such as expansions of the program in recent years to undocumented Californians. Unions also create upwards pressure on wages by acting to raise reimbursement rates through federal policy and advocacy. Ultimately, a unionized caregiving workforce creates good jobs and long-term sustainability in the home care marketplace.

The failure to invest in aging and disability care ultimately results in increased costs to the state and employers while compromising the health and well-being of care recipients and care workers.

Medi-Cal has seen critical general fund increases in recent years, including in most the 2024-2025 budget to support the elimination of the asset limits and Medi-Cal expansion for Californians regardless of immigration status.¹⁰¹ However, additional investments are needed to address decades of underinvestment and growing demand for aging and disability care, especially home and community-based services. For the IHSS program specifically, steady increases in enrollment are accompanied by steady increases in program costs, which are financed using a

combination of federal, state, and county funds.¹⁰² The program will be strained further by the end of federal pandemic relief and recovery dollars. California Governor Gavin Newsom's most recent budget predicts IHSS General Fund costs will increase by \$200 million.¹⁰³ Already the impacts of underinvestment are becoming evident due to underfunding for county-level administration, delays in services and long wait times, insufficient services for those with higher levels of need, and a lack of flexibility for those who are unable to self-direct their own care when compared to those who are able to self-direct their care. With the majority of IHSS dollars going directly toward worker wages, additional resources, particularly when paired with other critical policies to support good jobs for these workers, would go a long way to effectively leveraging public dollars to support good jobs and high quality services and supports for older adults and people with disabilities.

Without these investments, the state and other employers face numerous direct and indirect costs due to turnover and worker shortages. National data indicates that the direct care sector experiences an average turnover rate of 77% for homecare workers.¹⁰⁴ State-specific data also indicates that California has shortages across the direct care workforce, not only among IHSS providers but also other direct support professionals, personal care attendants, and home health aides, as well as staff in institutional care facilities and skilled nursing facilities.¹⁰⁵ California was also one of 43 states that reported permanent closures of home and community-based service providers.¹⁰⁶

Direct costs due to turnover for employers include paying overtime to remaining staff, hiring temporary workers to fill immediate vacancies, advertising new job openings, screening and interviewing potential hires, and training new workers.¹⁰⁷ National data suggests that direct care workers have exceptionally high rates of workplace injuries due to overexertion and understaffing.¹⁰⁸ Understaffing could result in unsafe work environments and an increase in worker injuries, which generate costs in the form of lost days of work and worker's compensation.¹⁰⁹

There are indirect costs to employers as well. The continual overreliance on overburdened staff, undertrained temporary workers, and inexperienced new hires could result in lower productivity and lower quality of care which – in addition to compromising the health and well-being of California's older adults and disabled people – may also lead to fines, penalties, or malpractice claims for employers.¹¹⁰

Turnover also results in significant costs to the state. As the quality of care and working conditions deteriorate, care workers are injured more frequently and the overall health and well-being for older adults and disabled people worsens. This results in higher Medicare and Medicaid costs.¹¹¹ Additionally, if demand for HCBS is not met, more care recipients will be funneled into skilled nursing facilities – which, apart from being far less popular, are also more expensive.¹¹² In California, the

market price for HCBS is \$83,500 compared to \$147,800 for a nursing home facility – approaching double the cost.¹¹³ Recent national research indicates that states that increased Medicaid funding for HCBS ultimately saw Medicaid savings due to reduced reliance on institutional care.¹¹⁴

On the other hand, increasing the quality of these crucial jobs would bring substantial economic benefits by reducing costs associated with turnover, increasing pay indirectly for workers in related sectors, and encouraging economic growth by spurring spending in local economies. Several studies across industries demonstrate that when pay increases, turnover decreases, reducing the costs associated with training and hiring new workers.¹¹⁵ These workers also experience higher levels of productivity and are better positioned to deliver high quality services.¹¹⁶ Pay increases for direct care workers would also create ripple effects in the form of indirect pay increases for workers in related occupations as employers adjust their pay rates.¹¹⁷ Additionally, workers in traditionally underpaid sectors also tend to spend more of their income immediately for day-to-day needs (e.g., food and transportation) and other goods and services which benefits the local economies and encourages economic growth.¹¹⁸ For example, one recent report estimates that if direct care workers were paid a living wage, California would see a boost of \$3.6 million in economic output¹¹⁹

In these ways, increasing investments in direct care workers creates numerous economic benefits while also delivering higher quality services for the older adults, people with disabilities, and the family caregivers who rely on them.

Principles for developing policy recommendations for universal access to aging and disability care, support for family caregivers, and good jobs for direct care workers

The cost of inaction is far greater than the cost of doing nothing, the costs of not addressing long-term care needs will continue to show up in the state's economy. Californians need and deserve universal access to aging and disability care so that older adults and disabled people can live and age with dignity and family caregivers have the support they need. The following principles provide should be used as a guide for developing equitable policies on the path toward universal access:

Affordable, accessible and high quality aging and disability care and support for family caregivers

- Ensure access to aging and disability care, regardless of income, eliminating disparities based on race, gender, disability, access needs, and LGBTQ+ status;

- Prioritize self-directed care, allowing people receiving care to guide priorities and goals for their own care;
- Allow care recipients the option to hire their family members as care providers if they choose;
- Address family caregiver needs by including access to robust respite services;
- Support the direct care workforce providing aging and disability care with access to culturally affirming training; and
- Include disabled people at all ages, people currently living with disabilities, and current retirees in the program.

A strong care workforce, with good, union jobs for all care workers with family sustaining wages and benefits, including healthcare and retirement benefits as well as strong workplace standards that support respect and dignity for all care workers

- Invest in the care workforce through significant improvements to wages, benefits and working conditions, including the right for workers to join together in a union and collectively bargain to make these improvements;
- Acknowledge the labor of undocumented workers currently doing care work in the private pay market and improve their working conditions by enforcing labor laws, and investing in their work; and
- Eliminate exclusions for domestic workers in labor policies to guarantee a minimum standard for worker rights and protections.

Equitable, sustainable financing mechanisms that value care as a public good and reflect the true cost of care

- Secure public funding needed to guarantee the sustainability of Medicaid programs in California, and to improve access for all;
- Create new public investment to expand affordability of care that Californians need through a social insurance program, where everyone pays and everyone gains access to some amount of care, such as the year of care most Californians will need at the end of their lives; and
- Build a more, equitable tax system to generate revenue and support the pressing needs of all of California's communities.

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