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California's In-Home Supportive Services Program: An Equity Analysis

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Hagar Dickman, Senior Attorney

INTRODUCTION

Medi-Cal-funded home and community-based services (HCBS) are essential for the ability of California's older adults and adults with disabilities with low incomes to live and age in the community. But, as in health care generally, HCBS programs are impacted by systemic racism, discrimination, and bias that can ultimately lead to disparities in health outcomes and quality of life of program users.¹ Policies and program rules that appear to be neutral can perpetuate existing inequities or result in unanticipated ones due to longstanding discrimination in health care and society more broadly. Such inequities can appear as disparities in access to these programs as well as in the quality of the services themselves.

In-Home Supportive Services (IHSS), administered by the California Department of Social Services (CDSS), is the state's largest Medi-Cal HCBS program. It provides consumer-driven personal care services to over 585,000 low-income older adults and individuals with disabilities annually, making it the biggest personal care system in the country.² As one of only two HCBS programs that California offers as a Medi-Cal State Plan benefit, IHSS is available statewide to any Medi-Cal enrollee who is aged, blind, or disabled, living at home, and who demonstrates a need for services.³ IHSS providers assist IHSS users with personal care activities such as ambulation, bathing, and dressing as well as with cleaning, meal preparation, and laundry.⁴ The program can also provide paramedical services, such as administration of medication, and protective supervision for individuals who require 24-hour a day supervision to remain living safely in the home.⁵

The IHSS program was signed into law fifty years ago in 1973.⁶ Over the last five decades, much work has gone into improving the IHSS program and making it more accessible to more people. The aim of this paper is to evaluate California's IHSS program to 1) identify policy choices that have helped to reduce inequities in the program over

its long history that could be implemented for other HCBS programs in the state; and 2) identify areas where more work is needed to increase equitable access and quality in the program.

To conduct this assessment, the paper utilizes Justice in Aging's [Equity Framework for Evaluating California's Medi-Cal Home and Community-Based Services for Older Adults and People with Disabilities](#) and examines the program's design and implementation using the framework's five domains: 1) Program Design; 2) Provider Availability; 3) Program Awareness and Enrollment; 4) Assessments and Authorization of Services; 5) and Provision of IHSS services. For each domain, the paper provides examples of policies, program rules, and decision points in IHSS that have addressed inequities, where policies could give rise to or reduce inequities, and suggestions for alternative formulations that could encourage more equitable outcomes.

This evaluation is not meant to be exhaustive. Instead, it serves as a starting point to both assess how California can better embed equity in the IHSS program to ensure all eligible individuals receive the services and supports they need to live in their community and to uplift specific policy choices that have proven to increase equitable access in the IHSS program for consideration for the state's other HCBS programs.

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HCBS EQUITY FRAMEWORK

The systemic drivers of health inequities—racism, ageism, ableism, classism, sexism, xenophobia, and homophobia—are embedded in law, policy, governance, and culture at the national, state, and local levels both in health care broadly and in HCBS. In our previous paper, [An Equity Framework for Evaluating California’s Home and Community-Based Services for Older Adults & People with Disabilities](#), we put forth an HCBS Equity Framework describing five HCBS domains in which inequities can arise: 1) Program Design; 2) Provider Availability; 3) Program Awareness and Enrollment; 4) Assessments and Authorization of Services; and 5) Provision of HCBS. The Framework calls for data collection as key to identifying and eliminating disparities within each domain. In this paper, we use this Framework to identify possible sources of inequities, as well as areas of strength and inclusion in California’s IHSS program.

HOME AND COMMUNITY-BASED SERVICES EQUITY FRAMEWORK

PROGRAM DESIGN. In the initial design of HCBS programs, inequities can arise from policies that establish who is eligible for HCBS programs, where programs are available regionally, and what services are offered by an HCBS program.

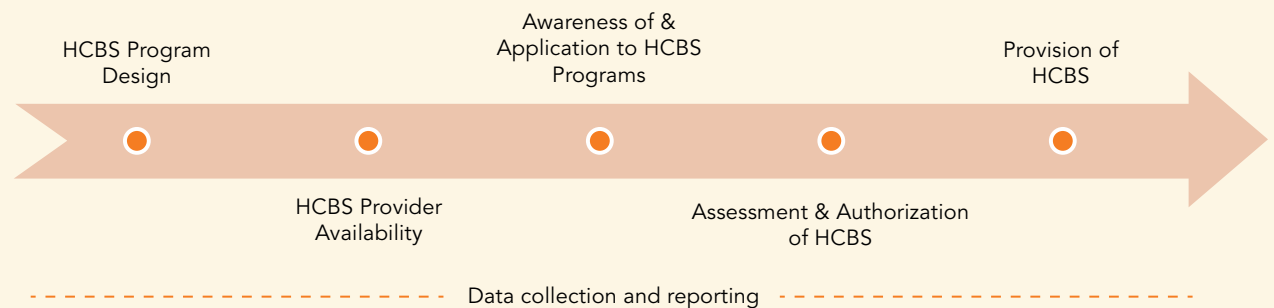
PROVIDER AVAILABILITY. Inequities in provider availability can arise from policies that dictate network adequacy, reimbursement rates, and provider investments, trainings, and supports.

AWARENESS AND ENROLLMENT IN HCBS. Inequities arise when information on program availability and eligibility requirements is not easily

available and application processes are overly burdensome.

ASSESSMENT FOR/ AUTHORIZATION OF SERVICES. Implicit bias can be built into service assessment and authorization processes that can lead to inequities in who is deemed eligible.

PROVISION OF HCBS. Inequities can arise in the provision of HCBS when the unique needs and lived experience of service recipients are not built into the accessibility of services and means of measuring quality of services rendered.



WHO IS ACCESSING IHSS: AN INCOMPLETE PICTURE

Comprehensive and intersectional data collection and reporting are essential to advance equity in all of health care, including in-home care.⁷ In December 2022, California took an important step towards providing essential data through the release of its first-ever Long-Term Services and Supports (LTSS) Data Dashboard.⁸ This dashboard publicly reports enrollment data for California's long-term care and HCBS programs, including IHSS, categorized by race, ethnicity, spoken language, and other demographics. In addition, CDSS publishes monthly IHSS Program Data reports that include an equity tab with public data on new applications, application denials, and allocation of hours by demographic groups.⁹ The data made available by the two dashboards are the most robust data available for any HCBS program in the state.

Yet, significant limitations in the data exist. Most notably, while CDSS's IHSS Program Data report includes the total number of authorized users with accompanying demographic data, it does not include how many users actually access services with accompanying demographic data. The difference between authorized users and actual users is significant. In the 2021-2022 fiscal year, an average of 665,329 people were authorized to use IHSS per month, but only 586,627 actually received IHSS services.¹⁰ Also notable is the lack of race and ethnicity data for IHSS users. While statewide race and ethnicity data are unknown for 5% of IHSS authorized users, there is wide variation in the percent of unknown users between counties. For example, in Alameda County, 10% of authorized users' race and ethnicity are unknown.¹¹ Finally, sexual orientation and gender identity demographic data are not included in the dashboard for either IHSS users or providers and data cannot currently be stratified by different demographic categories to evaluate intersectional

IHSS BASICS

IHSS is made up for four programs available to older adults age 65 and older, people who are blind, or people living with disabilities who require support with activities of daily living. The four IHSS programs are: 1) Community First Choice Option; 2) Personal Care Services Program, 3) IHSS Plus Option; and 4) IHSS-Residual Program. The programs have some differences in eligibility criteria and different funding sources, but generally the IHSS user does not know or need to know which program they are enrolled in for the purposes of receiving services.

California's Medicaid agency, the Department of Health Care Services (DHCS), delegates administration of the IHSS program to the California Department of Social Services (CDSS). The day-to-day administration of the IHSS program is shared between county social services departments that CDSS oversees and regional Public Authorities. County social services departments process program applications and administer functional rankings and needs assessments to determine eligibility and allocation of service hours. Public Authorities are governing bodies operated by most counties that serve as the employers of record of IHSS providers. They implement training for participants and their providers, engage in provider recruitment, conduct background checks, and maintain provider registries. They also negotiate the terms of employment, such as wages and benefits, with provider unions.

Once found eligible for the program and approved for hours of service, most IHSS users are responsible for directing their own care including how and when care is provided as well as hiring, supervising, and, when needed, firing their own service providers. California statute also allows counties to enter into contracts with agencies through "contract mode" under which the agency employs providers directly. Currently, only San Francisco County uses contract mode for a limited subset of IHSS users who choose an agency to secure and manage their IHSS provider.

The type of services IHSS users may access are set by statute. Services include personal care, domestic or homemaker services, paramedical, and protective supervision. Individuals assessed may receive up to 283 hours per month depending on the IHSS program they are enrolled in and their level of need. IHSS users can hire a provider of their choice, with some limitations. There are two eligibility criteria to become an IHSS provider: one must be eligible to work in the United States and pass a criminal background check. (Cal. Welf. & Inst. Code § 12300 et. seq).

See, [In-Home Supportive Services \(IHSS\): A Guide for Advocates](#)

inequities. Demographic data are also not available for people who have been terminated from the program. These gaps in data make it impossible to determine who is utilizing the program and whether there are disparities in actual access to program services.¹²

While the currently available data do not allow for a review of actual access to services, the authorization data do provide some insight into whether there are disparities in applying for and being authorized for IHSS. For example, a preliminary review of statewide authorization data shows few disparities by race and ethnicity between the proportion of Medi-Cal enrollees who are potentially eligible for IHSS and those who apply for and are approved to receive IHSS. As shown in Table 1, Hispanic people make up 31.2% of older adults and individuals with disabilities enrolled in Medi-Cal and 30.6% of those authorized to receive IHSS, while Black, Asian and Pacific Islanders, and white IHSS users are overrepresented in the IHSS program compared to their proportion of the total eligible Medi-Cal population. This preliminary review suggests that the application and authorization processes for IHSS are not causing barriers to enrollment in the program for specific populations. Additional review, however, is needed of other IHSS user populations along with a review at the county-level where disparities may be masked by statewide data – particularly in light of the variation in completeness of race and ethnicity data at the county level.

Meanwhile, disparities do emerge in the authorization data by race and ethnicity for higher level of services – particularly among those receiving protective supervision, the highest-level services for individuals assessed as requiring 24-hour supervision to safely remain in their homes. For example, Black people make up nearly 14% of all IHSS users and of the total authorized hours, but only 10% of the population authorized to receive protective supervision. Meanwhile, white people make up 29.4% of IHSS users, but represent 31% of total authorized hours and nearly 34% of those authorized to receive protective supervision. This review suggests that the application and authorization processes for protective supervision may be causing inequitable access to this higher-level service. And again, because data are not available for utilization of protective supervision, it is not possible to determine if disparities are even more significant in actual receipt of protective supervision.

Future iterations of the state’s LTSS Dashboard and IHSS Program Data dashboard could be improved to provide a more complete picture of IHSS program access by:

- Reporting IHSS utilization data based on monthly IHSS caseloads with accompanying demographic data to evaluate disparities in actual receipt of services and not just disparities in who is approved for the program.
- Implementing targeted efforts to increase the completeness and accuracy of demographic data statewide and at the county level.
- Collecting and reporting sexual orientation and gender identity demographic data pursuant to state law.¹³
- Adding data on IHSS terminations and service reductions with accompanying demographic data.
- Using stratified data by multiple fields to analyze how different and intersecting factors affect IHSS authorization and utilization.
- Comparing allocated hours with actual utilization data by demographics and service type.¹⁴
- Stratifying disparities in types and quantity of services with disability data such as Alzheimer’s and dementia diagnosis or physical disabilities and institutionalization encounters to assess disparities in unmet need;
- Including average months a user is matched with a provider for both relative and non-relative providers to assess the length of time of provider and user relationships and quantify turnover rates; and

- Tracking average time between becoming an authorized IHSS user and actually receiving the services, as well as the percentage of unbilled authorized hours by demographic groups and relative versus non-relative providers.

As discussed in [An Equity Framework](#), these additional measures could uncover disparities in access and quality across the program.¹⁵

Table 1. Average IHSS Authorization, 2022

Race/Ethnicity	Total Medi-Cal 65+ or Disabled Individuals	Percent of total Medi-Cal 65+ & Disabled Individuals	Number of IHSS Authorized Users	Percent of total IHSS Authorized Users	Authorized Hours	Percent of Authorized Hours	Number of IHSS Users Categorized as Severely Impaired	Percent of IHSS Users Categorized as Severely Impaired	Number of IHSS Authorized Users with Protective Supervision	Percent of IHSS Authorized Users with Protective Supervision
AI/AN	10,063	.42	3,279	0.47	360691	0.46	968	0.41	315	0.46
Asian/PI	403,953	16.9	147,767	21.4	15187525	20	45,715	19.2	10211	14.9
Black/AA	220,839	9.3	96,216	13.9	10982737	13.9	32,828	13.8	6970	10.2
Hispanic	743,259	31.2	210,874	30.6	24628544	31.3	76,643	32.2	24475	35.7
Other	183,459	7.7	19,970	2.9	2201059	2.8	5,660	2.4	2682	3.9
Unknown	257,123	10.8	8,985	1.3	967395	1.2	2,426	1	1047	1.5
White	567,357	23.8	202,464	29.4	24443347	31	73,992	31.2	23119	33.7
Total	2,386,053		689,554		78771298		238231		68613	

Source: DHCS, *Aged, Blind and Disabled Medi-Cal Enrolled in 2022 Data* (provided by DHCS); IHSS averages calculated using equity data published by CDSS, [Program Data](#) (July 2022-Dec. 2022);

DOMAIN #1: PROGRAM DESIGN

Basic program design decisions, such as what services are covered by the program and how services are rendered, can give rise to inequities in IHSS access.

In 2023, over 700,000 people have been approved to use IHSS, representing at least 17 ethnicities and races and speaking over 30 languages.¹⁶ Unlike HCBS waiver programs, IHSS is included in the Medi-Cal’s State Plan and must be provided statewide to all eligible Medi-Cal participants without enrollment caps, geographic limitations, or waitlists.¹⁷ The state’s decision to make IHSS a State Plan benefit eliminates many of the inequity risks that the state’s HCBS waiver programs face. Accordingly, one significant and transformational policy decision California could implement to increase equitable access to HCBS would be to make all HCBS programs State Plan benefits.

However, while the IHSS program’s status as a State Plan benefit significantly reduces inequities in access, this single program design element does not protect against inequities arising out of other policy choices in program design.

A significant program design choice and hallmark of California’s IHSS program is its commitment to the consumer-directed model, in which IHSS users

retain the right to hire, supervise, and fire their providers as well as decide how, when, and where the services they receive are delivered. This program design element ensures that IHSS users maintain agency over their services and grants independence, choice, and autonomy to people with disabilities who are so often stripped of these rights by systems of care.

The IHSS program, however, is limited in its ability to adequately serve people who have a medical or cognitive condition that makes it more difficult for them to direct their own care.¹⁸ For example, people with Alzheimer's disease and other dementias often have difficulty directing their own care, limiting their ability to use IHSS, which places them at higher risk of institutionalization. In fact, national research shows that at age 80, 75% of people with Alzheimer's live in a nursing facility compared with only 4% of the general U.S. population at this age, demonstrating the current inadequacy of HCBS systems nationwide to support people with Alzheimer's and dementia in the community.¹⁹ This issue particularly impacts Black and Hispanic older adults and older women who are more likely to have Alzheimer's and dementia.²⁰ Similarly, people who do not have a relative that can serve as their IHSS provider may have difficulty finding and hiring a provider under a consumer-directed model; this can disproportionately affect LGBTQ+ users who are less likely to have family member support as they age.²¹

Counties have undertaken efforts to pilot and implement alternative models over the history of the IHSS program with varying success, including contract mode IHSS, where IHSS services are provided through an agency.²² This model and others could be evaluated and considered in the development of any statewide strategy to more equitably serve older adults and people with disabilities who have difficulty directing their own care.

Inequities can also arise when IHSS users are not engaged in policy decisions made by county IHSS Public Authorities. Public Authorities, as the employers of record of IHSS providers, implement training for participants and their providers, engage in provider recruitment, conduct background checks, and maintain provider registries.²³ They also negotiate the terms of employment, such as wages and benefits, with provider unions—decisions that have a direct effect on the provision of services. In line with the program's consumer-driven model, Advisory Committees provide input on Public Authority policy decisions; these committees are statutorily required to have 50% participation by people with lived experience who use or have used publicly or privately funded personal assistance services, including IHSS.²⁴ Consumer participation in these committees can

WHAT IS A HOME? TAKING ACTION TO REDUCE DISPARITIES IN IHSS ACCESS & ADDRESSING HOMELESSNESS THROUGH PROGRAM DESIGN

Prior to 2020, the IHSS program narrowly defined "home" as one's "own home." Because unhoused individuals do not have a home, they were denied access to the IHSS program. This narrow definition of home disproportionately affected Black people, who make up just 5% of the state's total population but 25% of the state's homeless population. The narrow definition of "home" also required access to local utility services, disproportionately excluding Native individuals living on tribal lands from IHSS.

Recognizing the inequitable impact of the narrow definition of home, California expanded the definition in 2020 to include alternative living situations, including RVs, temporary shelters, and those living in the residence of a family member. The directive from CDSS also now recognizes alternate sources of heat and water to ensure IHSS is accessible to those living on tribal lands or without access to local utility services.

While the expanded definition of home helps to address access for many people previously unserved by IHSS, the definition still excludes unsheltered people who make up 70% of the state's homeless population, 32% of whom are over 50 years old and are more likely to be living with disabilities and could benefit from IHSS (see more below).

Sources: California Budget & Policy Center, "[Who is Experiencing Homelessness in California](#)," (March 2023); *Welf. & Inst Code 18999.8*; CDSS, [ACIN I-19-20](#), (Feb. 25, 2020); United States Department of Housing and Urban Development, "[The 2022 Annual Homeless Assessment Report to Congress](#)" (December 2022); California Interagency Council on Homelessness, "[Action Plan for Preventing and Ending Homelessness in California](#)," (Sep 2022).

ensure the needs and priorities of individuals who use the IHSS program are reflected in the administration of the program. But when barriers exist that keep some communities from participating, or when counties fail to consult with or support Advisory Committees, inequities can arise in whose needs are incorporated or considered. For example, when meetings are held in person without a remote option, people who experience barriers attending in person do not have an opportunity to provide input on policies that may impact them.

When IHSS users are not engaged in policies regarding program design, inequities can also arise regarding how well the program is meeting their unique needs. For example, the IHSS program has a defined set of covered services that does not currently include coverage for reading an IHSS user’s mail or other paperwork. This limits the IHSS program’s assistance for people with visual impairments, individuals with limited English proficiency who may require translation or interpretation assistance, and disproportionately impacts people who have fewer family supports to help with this task, such as LGBTQ+ individuals, and people living alone. IHSS also does not currently cover assistance with mobility outside the home for non-medical ambulation, such as for non-prescribed exercise or for social visits,²⁵ while assistance to medical appointments is a covered service.²⁶ This policy decision to not cover any non-medical ambulation assistance limits the program’s ability to support people with disabilities to live in the most integrating setting and access their communities.

The table below provides examples of how program design elements may contribute to inequities in access to IHSS, and describes opportunities for California to mitigate inequities through policy change.

IHSS POLICY ELEMENT: PROGRAM DESIGN	EQUITY EVALUATION	POLICY OPPORTUNITIES
Enrollment Caps/ Geographic Limitations	Unlike other HCBS programs in California, IHSS is a State Plan benefit and is available to all eligible Medi-Cal users without enrollment caps or waitlists, reducing inequities in access.	California could make all HCBS programs state plan benefits to reduce inequities in access that occur when programs are limited by region and number of slots available. See, California’s Assisted Living Waiver: An Equity Analysis .
Consumer Direction	Disparities arise when eligible people are not able to access services because they have difficulties directing their own care. This disproportionately impacts Black and Hispanic people who are twice as likely as white people to have Alzheimer’s or dementia and may not be able to hire or manage a provider, as well as IHSS users who do not have family members serving as their IHSS provider.	California could explore creating targeted alternative personal assistance models for people who have difficulty directing their care and have no access to relative caregivers, such as contract mode IHSS. Alternative models must still allow for consumer direction and cannot replace or erode the robustness of the current consumer-directed model.

IHSS POLICY ELEMENT: PROGRAM DESIGN

EQUITY EVALUATION

POLICY OPPORTUNITIES

Community Contribution to Program Design	Disparities in consumer participation in IHSS governance bodies lead to policy decisions that do not reflect the needs and preferences of excluded populations.	Public Authorities or other IHSS governing boards should recruit participants with lived experience from diverse communities to ensure participation in advisory boards reflects the diversity of their respective counties. Public Authorities could audit their recruitment and participation policies to identify and address potential hurdles or disparities in participation for specific communities. Public Authorities could also evaluate what barriers exist to participation and make efforts to address those barriers such as providing a virtual or remote option.
Program Benefits	The IHSS program has a defined set of benefits or services. Inequities can emerge in which services are included or omitted.	CDSS could regularly review program benefits in consultation with a diverse representation of IHSS users and providers to evaluate whether additional covered benefits that address inequities in access or quality should be authorized under the program.
Availability of IHSS to Unsheltered Individuals	Seventy percent of California’s homeless population is unsheltered and cannot access IHSS under current program guidelines, many of whom are adults over 50 years of age, from communities of color, and are more likely to be living with disabilities.	CDSS could explore models of IHSS that could better serve people who are unsheltered including, for example, the Alameda County IHSS and Homelessness Building a Bridge Pilot. ²⁷ CDSS could also reduce barriers that people experiencing homelessness face in applying for IHSS and maintaining eligibility. ²⁸

DOMAIN #2: PROVIDER AVAILABILITY

Inequities in provider availability can arise from policies that dictate network adequacy, reimbursement rates, and provider investments, trainings, and supports.

For every hour an IHSS enrollee needs services, there must be a provider to deliver those services. Disparities arise in access to IHSS when there are not enough participating providers to meet the need of program participants. Unfortunately, California’s IHSS program has routinely struggled with maintaining an adequate number of providers over the course of the program’s history, and continues to have a provider shortage today.²⁹

Past IHSS provider shortages have driven policy changes that have helped to increase access to the program. For example, while some family caregivers were paid under California’s IHSS program early in the program, the 2004 IHSS Plus Waiver expanded the ability of parents to serve as IHSS providers for their adult children and allowed spouses to act as IHSS providers for older or disabled adults for some IHSS services.³⁰ Later, federal law changed to permit states to allow “legally responsible relatives” to act as IHSS providers.³¹

Following these changes, the IHSS program saw a steep increase in relatives serving as IHSS providers, increasing from 43% of IHSS providers in 2000 to 70% of IHSS providers in 2023.³² For many IHSS users, these policy changes have resulted in the availability of a stable provider who can meet their unique needs. However, for those without a relative caregiver, provider shortages remain a significant barrier to the program, disproportionately impacting

LGBTQ+ users who are less likely to have relative caregivers, women who are more likely to live longer than their spouse, and IHSS users whose family members are undocumented and cannot be hired to be providers due to federal employment laws, so that they must either hire non-family members or require their family members to provide care without pay.³³

Currently, 30% of IHSS users hire non-relative providers through IHSS registries maintained by the regional Public Authorities or through other listings (e.g., Craigslist). These IHSS users often cannot find a provider for significant periods of time or cannot find a provider to work all of their authorized hours when there are provider shortages. Research from Los Angeles County, for example, found that one in six users who did not have a provider were still unable to find one eight months later.³⁴ Gaps between authorization and actual use of those hours can also indicate provider shortages. Data show that from 2015 to 2019 the number of IHSS hours that were approved but ultimately not provided to IHSS users increased from 33,000 to 40,000 hours per month.³⁵ Moreover, in 2019, IHSS provider turnover was estimated to be at 33% annually, or approximately 180,000 providers, which has been exacerbated by the COVID-19 pandemic.³⁶

Underutilization of provider registries can also indicate provider issues. For example, as of October 2022, all counties were required to make available a backup provider registry available to IHSS users separate from the registries maintained by the Public Authorities.³⁷ Unfortunately, only 118 IHSS users across all counties accessed their county's backup system in its first three months to find a provider.³⁸ Underutilization may indicate that local backup provider registries are not widely available and accessible, which may be attributed to lack of awareness of the backup program by users, or lack of providers enrolled on backup provider registries.

Provider shortages can be addressed. For example, research has shown that high provider turnover is a result of low wage policies combined with emotionally and physically challenging work with few benefits.³⁹ Conversely, when wages and benefits are increased, provider participation and retention improve. For example, a study comparing Alameda County and San Francisco County provider levels found that Alameda's wage limit and lack of benefits beyond basic health insurance led to worker shortages, while San Francisco's increase in wages and benefits led to an almost 40% growth in its provider workforce over a three-year period.⁴⁰ Not only do increased wages and benefits lead to a more robust IHSS workforce and increase access to the program, it also ensures that IHSS workers, who are predominately women, people of color, and immigrants, receive wages that are adequate to provide for their basic needs and decrease their risk of aging into poverty.⁴¹

IMPROVING PROVIDER AVAILABILITY: IHSS CAREER PATHWAYS

Career Pathways is a CDSS initiative intended to 1) reduce provider turnover, incentivize providers to work with people with complex care needs, and improve quality of care; 2) advance health equity and reduce health disparities for IHSS users; and 3) assist in the development of a culturally and linguistically competent workforce.

The state used \$295 million of one-time federal funding through the America Rescue Plan Act to create Career Pathways. The initiative provides one-time incentive payments for providers that complete their choice of trainings from a catalog of options and who remain with the same IHSS user for a six-month period. Among the courses available to providers are those dealing with specialized or complex health conditions, dementia and Alzheimer's care, harm reduction, and provision of person-centered care.

At this time, no courses are offered on the provision of care for LGBTQ+ consumers, or more generally on cultural competence and humility. Only some classes are available in languages other than English, so not all IHSS providers can enroll in all courses.

CDSS is expected to release an interim report on the outcomes of this program to the state legislature in 2023 and a final report in 2024. CDSS does not intend to continue this program after federal funding is exhausted in September 30, 2024.

While state regulations require counties to develop a plan for providing IHSS services to all county participants and empower CDSS to create a plan for those counties that do not submit one, a 2021 report by the state Auditor’s office found that “for at least 20 years, Social Services has neither enforced the legal requirements that counties develop and submit annual county plans nor created county plans for counties that did not do so. Social Services’ responsibility to ensure proper planning is clear; moreover, this lack of attention to planning increases health risks for individuals who should receive care but do not.”⁴²

Lastly, disparities also arise in the length of time IHSS users and IHSS providers work together. Research shows the relationship between a family member provider and IHSS user is “three times as likely to endure when compared to relationships in which providers are professional caregivers or otherwise acquainted with their users.”⁴³ Practically, this means that IHSS users without a relative caregiver do not have the continuity of care in their IHSS services that those with a relative caregiver experience. A lack of a stable provider can lead to unmet long-term needs which research has found to significantly impact the health and safety of IHSS-eligible individuals including increased incidence of hospitalization and institutionalization.⁴⁴ Infrastructure investments can help to increase the workforce and aid retention, while trainings and resources for IHSS providers like those provided under IHSS Career Pathways (see text box) can help to address issues that arise in non-relative relationships.

The table below provides examples of how provider availability may contribute to inequities in access to IHSS, and describes opportunities for California to mitigate inequities through policy change.

HCBS POLICY ELEMENT: PROVIDER AVAILABILITY	EQUITY EVALUATION	POLICY OPPORTUNITIES
Network Adequacy	Disparities may arise when some counties do not have sufficient IHSS providers to serve the needs of their IHSS users, resulting in reduced utilization of allocated service hours.	Today, there is no network adequacy standard for the IHSS program. CDSS could develop and implement a network adequacy standard informed by demographic data, which could help identify local provider shortages and disparities in access. The state could set an initial adequacy standard for how many providers each county must have on its general and backup provider registries for its county-level IHSS population and then track disparities between allocated and used service hours, stratified by race, ethnicity, and language, for example, to identify unmet needs and adjust the network adequacy standard accordingly.

**HCBS POLICY
ELEMENT: PROVIDER
AVAILABILITY**

EQUITY EVALUATION

POLICY OPPORTUNITIES

**Infrastructure
Investments**

Infrastructure investments can reduce inequities when they are targeted to address unmet needs of underserved populations. But when investments are limited or difficult to access, they can continue to perpetuate systemic inequities.

The Career Pathways program is an effort to grow the caregiving workforce and improve provider retention.⁴⁵ Although federal financing of this initiative will end in 2024, California could seek permanent funding to continue this and other initiatives that address the needs of special populations such as those with Alzheimer’s and dementia and LGBTQ+ individuals. Continued investment would improve counties’ ability to grow their workforce so that they can meet increasing needs. The state could track whether these investments translate to growth in the workforce and a reduction in provider turnover, and look into other strategies to address provider shortfalls.

The state could track and report the demographic characteristics of providers enrolled in Career Pathways and those who complete the training courses to identify and address disparities in access.

**Backup Provider System
Registries**

Inequities can arise when provider registries, including backup provider registries, are not fully implemented across all counties and there are not enough providers to address user needs. Workforce shortages may be exacerbated for the Backup Provider System when providers are not aware of the program and how to enroll.

California should enforce the current statutory requirement that all counties establish a Backup Provider System. CDSS could ensure that providers are aware of the Backup system and how to enroll through the provider orientation process. The state could also require counties to submit a plan to CDSS on provider recruitment, and report on their progress on a quarterly basis. County efforts and outcomes could be monitored so that CDSS could identify systemic and regional barriers and implement appropriate strategies to increase worker enrollment in the program in all counties.

Wages

Inequities in access can occur when wages are too low to attract participating providers. Recruitment and retention efforts are less likely to succeed when IHSS wages do not reflect a living wage.

Indexing pay increases to a local living wage can lead to an increase in workforce. To meaningfully address the workforce shortage, the state and counties could consider potential pathways for increasing wages to regional living wage levels, using for example, [a living wage or self-sufficiency calculator, subject to annual cost of living increases](#). Wages could be evaluated bi-annually to ensure that they are adequate for attracting enough providers to fulfill the need for services regionally.

DOMAIN #3: AWARENESS AND ENROLLMENT

Inequities arise when information on program availability and eligibility requirements is not easily available and application processes are overly burdensome

Individuals cannot apply for programs they are not aware of, and disparities can arise when awareness about a program and information about how to apply is not readily available and widely known. Fortunately, unlike many other HCBS programs in the state, IHSS is well-known, in part because the five-

decades old program is a State Plan benefit available to anyone who is eligible. And, unlike other HCBS programs, IHSS program information is widely available on the CDSS website and made available through local county social services offices, Aging and Disability Resource Centers, Area Agencies on Aging and local Departments of Aging, and through Medi-Cal managed care plans.

Yet, even when awareness of a program is widespread, disparities in who applies and enrolls can arise when those in need of services face administrative burden, confusing or complex application processes, and language access limitations. Simple and centralized program information and applications are key to preventing and reducing disparities in who can enroll in IHSS, especially in light of research that has shown that application processes that are overly burdensome or complex disproportionately impact people of color.⁴⁶ For those users with digital access and fluency, the information and program materials for the IHSS program are easily available in a centralized location—CDSS’s IHSS website.⁴⁷ Unfortunately, these forms cannot be signed and submitted online, requiring users to print them out or obtain them directly from their county social services office.

In addition, the application procedure is different for each county. While some counties allow submission by mail, in person, by phone, or by fax, others require applicants to file a request through a referral worker, either by phone or through an online form. For example, counties like San Mateo and Kern require applicants to first submit a referral form online or by phone prior to filling out an application, and await a follow-up from a county IHSS intake worker.⁴⁸ A system that requires affirmative outreach by a county worker is more vulnerable to the severe county worker shortages and can lead to additional delays for applicants receiving services.⁴⁹ A referral system can also create additional hurdles for people with disabilities or cognitive impairments and their caregivers who may have difficulty with the additional steps of communicating with the county rather than being able to directly submit an enrollment application online, by phone, in person or by mail.

State-mandated forms that have been tested for vision accessibility, readability, and language access are also important in ensuring program equity. While IHSS forms are standardized by CDSS and used uniformly across the state, not all forms are accessible to the diverse population of IHSS users and applicants. For example, IHSS applications on CDSS’s website are available in English and only three of the eighteen Medi-Cal threshold languages, and forms are not available in large print or braille, creating additional hurdles to access for individuals with limited English proficiency (LEP) or visual impairment. Forms for higher-level services such as paramedical services or protective supervision are available in English only and on a separate consolidated forms library.⁵⁰ These forms are also difficult to find or missing altogether from county websites. Inaccessible forms and program materials can drive disparities in who gets access to the program. Making all program and service information and forms available to all users of all abilities, and ensuring they are easily accessible through a variety of channels would make the program enrollment more equitable by reducing disparities in who is able to access the IHSS program and ensure those with LEP, visual impairments, and other access barriers can easily enroll.

The table below provides examples of how lack of awareness and challenges in program enrollment may contribute to inequities in access to IHSS, and describes opportunities for California to mitigate inequities through policy change.

HCBS POLICY ELEMENT: AWARENESS OF AND ENROLLMENT IN HCBS PROGRAMS

EQUITY EVALUATION

POLICY OPPORTUNITIES

Application and Program Forms

Administrative burdens disproportionately impact marginalized communities, particularly communities of color and individuals with LEP. A non-streamlined IHSS application process that requires applicants to submit multiple forms to access different services and are not translated in all of Medi-Cal’s threshold languages creates administrative burdens and confusion about how to access different services covered by the program. This also puts additional burdens on individuals with LEP to access IHSS. Lack of availability of large-print and braille forms and information creates additional burdens on individuals with vision impairment who must ask for assistance to access information otherwise available to the public.

CDSS could standardize all IHSS forms statewide to ensure consistency in accessibility across all counties, with all applications and program forms translated into Medi-Cal’s threshold languages and made available in large print and in braille. CDSS could require all counties to accept IHSS applications directly through online, in-person, and telephonic submissions without intermediary referral lines or processes. CDSS could also streamline the IHSS application process to include an evaluation for higher-level services without the need for additional paperwork.

CDSS Education & Training

Persistent county worker shortages and high turnover rates can lead to an understaffed, undertrained, and over-strained workforce. Because applicants and program users rely on county personnel for information about IHSS services, an undertrained and stressed workforce puts additional burdens on applicants and program users to navigate the program and get accurate information. This has a disproportionate impact on underserved and marginalized communities that may not have access to external support or advocacy needed when program information is incomplete or erroneous.

CDSS could work with counties to identify drivers of county shortages, support counties in creating recruitment strategies, and consider necessary financial investment in county workforce. Part of any workforce growth plans should include investments in a robust training program that goes beyond eligibility matters and includes cultural competency, language access and disability rights issues including the provision of reasonable accommodations. Bi-annual retraining, as well as county-specific trainings should be provided to counties experiencing high levels of employee turnover or where disparities are identified through ongoing monitoring.

Managed Care Member Materials

Under California’s CalAIM initiative, most Medi-Cal users in the state now receive their care, including many long-term services and supports, through managed care, while IHSS continues to be administered by counties and the local Public Authorities. As Medi-Cal users communicate more with the managed care plans regarding long-term services and supports and other non-medical supportive services, differences in how managed care organizations assess and refer members to IHSS versus other non-IHSS personal care services, can drive disparities in who hears about the IHSS program and how to apply.

The state could require Medi-Cal managed care plans and Medicare Dual-Eligible Special Needs Plans to inform plan participants of the IHSS program in plan materials, and take an active role in identifying potential program participants and referring to them.⁵¹ The state could track the number of plan members that enroll in IHSS to identify potential disparities in participation between plans, and monitor plans’ IHSS communication materials for accessibility to ensure that potential enrollees are aware of the program and how to enroll.

DOMAIN #4: ASSESSMENT AND AUTHORIZATION OF SERVICES

Implicit bias can influence service assessment and authorization processes that can lead to inequities in who is deemed eligible for services.

Implicit bias can influence the IHSS assessment and authorization processes, which can lead to inequities in both who is deemed eligible for services and the extent of services an individual is authorized to receive. For example, inequities in the allocation of hours can arise when implicit bias impacts needs/functional assessments conducted by county social workers. To receive a particular IHSS service, applicants must be unable to perform the task themselves and be unable to safely remain living in their home without the service.⁵² To determine whether an IHSS user meets these criteria, IHSS social workers use a uniform assessment tool during a home visit to observe and identify what services an IHSS user needs and assign a level of need using a Functional Index Range from 1, where the applicant can perform the task independently, to 5, where the applicant is unable to perform the task at all.⁵³ The assigned rank determines the number of hours allocated for a particular service based on the program’s Hour Task Guidelines which set the average amount of time it takes to complete a task.⁵⁴

Because the rank received for each service determines the hours assessed, biases in ranking translate into biases in hour allocations. Biases in ranking can also translate into disparities in who gets approved for higher-level services. For two of the four IHSS programs, people who are assessed as severely impaired (because they require at least 20 hours a week of assistance to carry out activities such as dressing, bathing or ambulation) are eligible to receive up to 283 hours of assistance, while those that are assessed as non-severely impaired can receive up to 195 hours.⁵⁵ Approximately 34% of California’s IHSS users are rated at the severe impairment level. As discussed above in the “Data Snapshot,” Asian users are underrepresented, while white and Hispanic users are slightly over-represented in the severe impairment category. It is unsurprising then, that Asian users have a disproportionately lower share of IHSS allocated hours, whereas white and Hispanic users have a disproportionately high hour allocation. (Table 1)

Implicit bias in required physician assessments can also drive disparities in the type of services for which users are approved to receive. For example, a physician certification declaring that “the applicant or recipient is unable to perform some activities of daily living independently and that without services to assist the applicant or recipient with activities of daily living, the applicant or recipient is at risk of placement in out-of-home care” is required to be eligible for the program. Implicit bias in the physician can translate to disparities in program access. Similarly, to access protective supervision in IHSS, a treating physician must assess the memory, judgement, and orientation of an applicant.⁵⁶ Implicit bias in the physician can impact who is diagnosed with a cognitive impairment. For example, research has shown that Black patients are twice as likely to have Alzheimer’s disease compared to white patients, but Black patients are 65% less likely to be diagnosed at their first visit despite showing severe symptoms.⁵⁷ As noted previously, IHSS data shows that Black people make up only 10% of those authorized to receive protective supervision—three percent less than Black individuals receiving IHSS services overall, demonstrating a possible disparity in access to specialized services that could be related to implicit bias in these services’ assessment processes.⁵⁸ Future iterations of the state’s LTSS Data Dashboard showing the number of hours per service by demographic categories such as race/ethnicity and spoken language would help the state and interested parties identify whether there are disparities in the amount and quality of services allocated between groups.

California regulations specify that physician certification is not solely determinative of protective supervision eligibility, and counties are instructed to consider other evidence including social worker observations and medical records.⁵⁹ Advocates recommend applicants gather additional evidence to either support or contradict a physician’s assessment, including the submission of an incident log that documents the need for supervision.⁶⁰ Such documentation can help to mitigate the effects of implicit bias of medical professionals.

Implicit bias can also be mitigated through robust training combined with monitoring for disparities and through the use of standardized assessments and other tools. For example, CDSS has created a Social Worker Assessment Field Handbook, which outlines guidelines for determining functional rank and hour allocations including factors that assessors should consider in their evaluations, with corresponding high, middle, and low hour allocation per rank.⁶¹ CDSS also provides an “IHSS Assessment Narrative Tool” allowing for documentation to support social worker assessments. However, the Narrative tool is optional and individual counties can create their own tool. Finally, assessments are based on social worker observations and rankings and do not solicit applicant input. Consumer engagement can reduce disparities and provide an opportunity for assessments to reflect actual rather than perceived need.

The table below provides examples of how program assessments and authorization may contribute to inequities in access to IHSS, and describes opportunities for California to mitigate inequities through policy change.

**HCBS POLICY
ELEMENT:
ASSESSMENT AND
AUTHORIZATION**

EQUITY EVALUATION

POLICY OPPORTUNITY

**Function/Needs
Assessments**

Program authorization requires a physician certification of need for the service. IHSS functional and needs assessments are also based on social worker observations of consumer needs. Both physician certification and social worker assessments are vulnerable to the effects of bias on determination of need. Implicit bias in function and needs assessments can drive disparities in who is found eligible for IHSS, what services are authorized, and the extent of services authorized.

CDSS could require uniformity in all assessment tools across the state. The state could also create and implement robust implicit bias, cultural competency, reasonable accommodation training, and training on utilization of non-medical supporting evidence for IHSS eligibility social workers to reduce implicit bias in function and needs assessments.⁶²

CDSS could also include IHSS users in the function and needs assessment to ensure the type and amount of support reflects user needs. CDSS could adapt a guideline similar to Disability Rights California's [IHSS Assessment Criteria Worksheet](#) that uses guided questions that engage consumers in providing accurate assessments of their need. When used uniformly, guided questions can help reduce disparities in allocation of hours by standardizing what social workers must consider in placing applicants at a particular rank. CDSS could also inform applicants of opportunities for input in the assessment such as providing additional evidence including incident logs and additional medical evidence to support needs.

While CDSS reports monthly hour allocations by county, the state could also provide data on annual hour allocations. CDSS could affirmatively monitor and identify racial, ethnic, geographical, and other disparities that may arise in the number of hours allocated to IHSS users per service, and intervene to address disparities with targeted oversight and training where appropriate.

Protective Supervision

A preliminary look at statewide data shows that a disproportionately high number of white users are allocated protective supervision, while Black users' allocations is disproportionately low. Because this service is specifically intended for individuals with impairment in memory, judgment, and orientation, those with Alzheimer's and dementia may benefit from protective supervision most. Because Black and Hispanic populations have a greater incidence of Alzheimer's and dementia, under allocations of protective supervision is further indication that these populations appear to be underrepresented.

CDSS could review tools and methods used to assess users and applicants for protective supervision. Counties could actively assess users with Alzheimer's or dementia diagnoses. To counter the disparities in medical diagnosis that delay identification of Alzheimer's among Black and Hispanic patients, counties could also evaluate individuals who have a self-reported impairment and look to non-medical supportive evidence to evaluate the need for protective supervision.

DOMAIN #5: PROVISION OF SERVICES

Inequities can arise during provision of HCBS, including the quality of services rendered and the adequacy of the services in addressing a recipients' unique needs.

Disparities can arise when IHSS users are unable to find providers who can address their specific care needs. California's statewide IHSS workforce shortages, discussed in Domain 2 above, disproportionately impact individuals with more complex needs. For example, in a 2020 survey, 94% of the 51 participating counties reported they do not have enough caregivers to provide recipients' approved services in part because there are too few providers who can provide care for "recipients with specific or challenging needs."⁶³ Disparities in who can find a provider can lead to disparities in health outcomes, including increased institutionalization among those with unmet needs. County planning and state oversight are key for reducing these disparities.

Factors such as language access, culturally competent care, and workforce training can also drive inequitable receipt of care. Language access is fundamental to high-quality person-centered care, whereas language asymmetry between IHSS providers and users can negatively affect the quality of care an IHSS user receives.⁶⁴ California's IHSS data show significant gaps between the primary language of users and providers. For example, there are approximately 52,000 more Spanish-speaking IHSS users, 7,200 more Mandarin-speaking users, and 9,650 more Farsi-speaking users than providers who speak those languages. (Table 2; see Appendix 1 for complete user language data). While this data likely includes IHSS providers who speak English and another language, the data warrant further analysis to determine whether and where language gaps may lead to lack of service access. Similarly, program users who do not have family caregivers may experience difficulty in accessing culturally competent care. While provider training programs can help address cultural competency gaps, IHSS provider trainings are optional and may not address the unique needs of specific population.

Table 2. Top Ten Spoken Language of Providers and Users (Averages July-Dec 2022⁶⁵)

SPOKEN LANGUAGE	PROVIDER (598,423)	USERS (689,554)	% DIFFERENCE
English	411,691	362,290	14
Spanish	76,491	128,231	-40
Armenian	15,805	38,443	-59
Vietnamese	13,850	29,314	-53
Cantonese	18,840	27,764	-32
Russian	6,256	15,729	-60
Farsi	4,386	14,052	-68
Mandarin	6,659	13,946	-52
Korean	5,693	12,255	-53
Tagalog	3,672	10,780	-65

Finally, IHSS service quality may be difficult to measure in a consumer-driven system, particularly among the 70% of recipients whose providers are relatives.⁶⁶ Access to quality care can be monitored by identifying unmet needs and adverse outcomes experienced by IHSS users. California has implemented several mechanisms, but most are focused on fraud prevention, not quality of service delivery.⁶⁷ For example, the federally mandated Electronic Visit Verification is used to verify that non-live-in caregivers provide the services claimed on timesheets⁶⁸ and the Uniform Statewide Protocols is used to monitor for program fraud.⁶⁹ The state's Quality Assurance program does require counties to review cases quarterly and identify administrative errors and critical incidents that may affect service provision or health risks to recipients, the results of which are made available annually on the State's All-County Information Notification page.⁷⁰ But the focus on this program is to measure the quality of county IHSS administrative work rather than on the quality of care. Adding monitoring on outcomes – such as incidence of hospitalization, institutionalization, and other health outcomes, stratified by demographic groups – to routine case reviews can help counties and the state identify potential disparities in quality and adequacy of care.

The table below provides examples of how service provision may contribute to inequities in access to IHSS, and describes opportunities for California to mitigate inequities through policy change.

IHSS EVOLUTION IN QUALITY OF CARE: HISTORICAL EXPERIMENT

Although measuring quality of services delivered in California's consumer-driven model has been an ongoing challenge for the state, efforts to do so have driven positive changes since the program's inception.

In 1991, the Little Hoover Commission, California's government oversight body, reported that the IHSS program suffered from operational fragmentation between state, county, and recipients that resulted in a lack of accountability for poor service delivery. The report in part found that persistently poor quality of care was unresolved due to the state's reluctance to take on the role of an employer.

This report and other program evaluations have led to significant changes in the IHSS program that have aimed to address fragmentation and quality issues over the years. For example, Public Authorities were created to increase accountability for quality of care outlined in the Little Hoover Report by assigning them the role of employers of record for collective bargaining purposes and making them responsible for creating provider registries and offering provider trainings.

Later, the state implemented standardized county-level case reviews overseen by CDSS to ensure that caseworkers "appropriately apply the supportive services uniformity system and other supportive services rules and policies for assessing recipients' need for services to the end that there are accurate assessments of needs and hours." Cal. Welf. and Inst. Code § 12305.71.

Such efforts have improved consistency in the delivery and quality of services across the state.

Sources: Little Hoover Commission, Report 113, "[Unsafe in their Own Home: State Program Fails to Protect Elderly from Indignity, Abuse and Neglect](#)," (Nov. 1991) at 15; California State Auditor, "[IHSS: Since Recent Legislation Changes the Way Counties Will Administer the program, the Department of Social Services Needs to Monitor Service Delivery](#)" (Sep. 1999); Cal. Welf. and Inst. Code § 12305.71.

HCBS POLICY ELEMENT: SERVICE PROVISION

EQUITY EVALUATION

INTEGRATION OPPORTUNITIES

Quality Measures

Quality measures seek to identify uniformity in hourly assessments and program allocation, and to identify potential fraud or administrative error. Unfortunately, demographic information, unmet needs, and health outcome monitoring is absent from the IHSS Quality Assurance program.

Quality measures for IHSS could be based on unmet needs and assessment to determine whether the program meets the needs of users. California could refer to the quality measure methodologies recommended in the recently published CMS HCBS Measure Set, including recipient surveys such as the National Core Indicators-AD survey.⁷¹

Language Access

Gaps between LEP IHSS users and providers who speak the same language create disparities in who is able to access care, which could impact health outcomes such as hospitalization and institutionalization rates. The recent expansion of Medi-Cal to immigrant populations may exacerbate language gaps.

The state could work with counties to identify language gaps between providers and program users, and employ worker recruitment strategies including incentive programs to address these gaps.

Training

While trainings are available through the Career Pathways Initiative, the training program is an optional incentive program that is set to end by March 2024. Currently, no cultural competency, LGBTQ+, or implicit bias trainings are available in Career Pathways or other provider trainings.

CDSS could consider implementing a permanent provider training program, similar to the Career Pathway program. Because IHSS is a consumer-driven program, the types of trainings a provider takes may be done in consultation with the consumer. Trainings should include cultural competency, dementia and Alzheimer's care, and LGBTQ+ competency trainings.

CONCLUSION

California's IHSS program is the nation's largest personal care program and serves as a model for consumer-driven services. Over its fifty-year history, the state has succeeded in increasing equitable access to the program through changes in laws, policies, and guidance that could be considered in other Medi-Cal HCBS programs and services including making all HCBS State Plan benefits, investing in workforce training, expanding access to people experiencing homelessness, creating oversight and accountability, and collecting and reporting robust demographic program data. Meanwhile, opportunities to create a more equitable IHSS program can be pursued. By evaluating the IHSS program design, provider availability, assessment and authorization processes, enrollment and outreach efforts, and provision of services along with improved data collection and analysis, California can better ensure the IHSS program is equitably available to all who need it.

APPENDIX

Spoken Language of Providers and Users, Averages July-Dec 2022⁷²

SPOKEN LANGUAGE	PROVIDER	USERS	% DIFFERENCE
English	411,691	362,290	14
Spanish	76,491	128,231	-40
Armenian	15,805	38,443	-59
Vietnamese	13850	29,314	-53
Cantonese	18840	27,764	-32
Russian	6256	15,729	-60
Farsi	4386	14,052	-68
Mandarin	6659	13,946	-52
Other Non-English	3516	12,592	-72
Korean	5693	12,255	-53
Tagalog	3672	10,780	-65
Arabic	3033	7,772	-61
Cambodian	1248	5,383	-77
Hmong	899	2,811	-68
Lao	496	2,382	-79
Other Chinese Languages	1829	1,229	48
Mien	230	825	-72
American Sign Language	128	631	-80
Punjabi	18	530	-97
Thai	189	452	-58
Portuguese	127	382	-67
Declined/No Valid Data	45141	349	n/a
Ilocano	73	333	-78
Samoan	72	198	-64
Japanese	123	192	-36
Other Sign Language	36	190	-81
Hindi	<11	145	*
Turkish	22	90	-76
Italian	22	66	-67
Polish	30	65	-54
French	51	63	-19
Hebrew	28	45	-38
Ukrainian	<11	28	*

**Provider numbers are too low.*

ENDNOTES

- 1 Christ, Amber and Dickman, Hagar, [“Equity Framework for California’s HCBS Programs.”](#) (December 2022); see also UCLA Center for Health Policy Research, [“Demand for Aging and Disability Services Is Increasing in California: Can We Meet the Need?”](#) (Nov. 2022).
- 2 CA Senate Office of Oversight and Outcomes, [“Examination of the Impact of SB 1104: The 2004 Quality Assurance Initiative.”](#) (March 24, 2009); 42 C.F.R. § 440.220(a)(3); 2023-24 Governor’s Budget, [Caseload Projections](#), California Department of Social Services (CDSS).
- 3 Cal. Welf. & Inst. Code §12300
- 4 IHSS Manual of Policies and Procedures (hereinafter, “MPP”) § 30-757.
- 5 *Id.*
- 6 See CDSS, IHSS Training Academy, [History of the IHSS Program](#), (last visited 5/22/2023).
- 7 Christ, Amber and Huyenh-Cho, Tiffany, [“Using Data for Good: Toward More Equitable Home and Community-Based Services in California’s Medi-Cal.”](#) (Dec. 2021).
- 8 DHCS, [Data Dashboard Initiative](#) (last visited 05/22/2023).
- 9 CDSS, [Monthly IHSS Program Data](#) (last visited 05/23/2023).
- 10 2023-24 Governor’s Budget, [Caseload Projections](#), California Department of Social Services (CDSS),
- 11 CDSS, [IHSS Program Data](#), July 2022-December 2022.
- 12 Public Counsel, [“Examining Racial and Ethnic Inequities Among Children Served Under California’s Developmental Services System: Where Things Currently Stand.”](#) (May 2022) at 4.
- 13 Cal. Gov. Code §8310.8
- 14 California’s Auditor makes this data available by county level but not stratified by demographic groups. See Auditor of the State of California, [IHSS Program Appendix B, Report Number 2020-109](#).
- 15 Christ, Amber and Dickman, Hagar, [“Equity Framework for California’s HCBS Programs.”](#) at 13.
- 16 CDSS, [IHSS Program Data](#), (Jan-Apr. 2023).
- 17 Cal. Welf. and Inst. Code §12300; 42 U.S.C. 1396a; 42 CFR §430.25; 42 CFR §441.515.
- 18 California Department of Health, [“Alzheimer’s Disease and Related Dementias Facts and Figures in California: Current Status and Future Projections.”](#) (January 2021) (estimating that at least 5% of IHSS users had dementia or Alzheimer’s); Dopp, Carola, Drenth, Hermijntje, Verkade, Paul-Jeroen, Francke, Anneke, and Van Der Heide, Iris, “Interventions for Improving Self Direction in People with Dementia: A Systemic Review,” *BMC Geriatrics*, (March 20, 2021).
- 19 Alzheimer’s Association, [“2023 Alzheimer’s Disease Facts and Figures.”](#)
- 20 *Id.*
- 21 Sage, [“LGBTQ+ Older Adults Fear Discrimination in Long Term Care, Need Protection.”](#) (Aug. 16, 2021), (stating that “LGBTQ+ older adults are “more likely to live alone, be socially isolated, and have less family support, disproportionately leading to a reliance on long-term care.”)
- 22 See for example, San Francisco IHSS Public Authority, [“IHSS Continuum of Choice and Support,”](#) May 2017; and California State University, Sacramento, [“Tulare County IHSS Demonstration Project: An Evaluation of Managed Care,”](#) Aug 1995, available upon request.
- 23 Cal. Welf. And Inst. Code §12301.6
- 24 Cal. Welf. And Inst. Code §12301.6
- 25 22 CCR §51183(a) (limiting ambulation to “walking or moving around (i.e. wheelchair) inside the home, changing locations in a room, moving from room to room to gain access for the purpose of engaging in other activities. Ambulation does not include movement solely for the purpose of exercise.”)
- 26 22 CCR §51183(b)(5)

- 27 California Welfare Directors Association, [“IHSS and Homeless: Building a Bridge.”](#) Oct. 2017. See also, Ramsey, Claire & Kushel, Margot, [“California Offers In-Home Support, and Homeless Older Adults Should Have Access Too.”](#) California Health Report, (Oct. 24, 2017).
- 28 California Health and Human Services, [“Master Plan for Aging Long-Term Services and Supports Subcommittee Stakeholder Report.”](#) (May. 2020.)
- 29 California State Auditor, [Report 2020-109](#), (February 2021).
- 30 Newcomer, Robert J., and Kang, Taewoon, [“Allowing Spouses to Be Paid Personal Care Providers: Spouse Availability and Effects on Medicaid-Funded Service Use and Expenditures,”](#) Gerontologist, (Aug 2012) at 517-530; [CDSS, IHSS State Plan Option](#), (last visited 05/22/2023); MPP 30-763.44-.45; MPP 30-763.413-.416; CDSS, [ACL 21-91](#) (Sep 29, 2021); (An able and available spouse may be paid for personal care services and paramedical services; when the spouse is unavailable due to employment, health or “other unavoidable reasons,” another provider may be paid for meal preparation, transportation and protective supervision services during the spouses absence. Spouses may not be paid for domestic, hazard abatement, teaching and demonstration and heavy cleaning services.)
- 31 Section 1915(j); 1915(k); Newcomer, Robert J., and Kang, Taewoon, [“Allowing Spouses to Be Paid Personal Care Providers: Spouse Availability and Effects on Medicaid-Funded Service Use and Expenditures,”](#) Gerontologist, (Aug 2012) at 517-530.
- 32 Little Hoover Commission, Report 113, [“Unsafe in their Own Home: State Program Fails to Protect Elderly from Indignity, Abuse and Neglect,”](#)(Nov. 1991) at 12; CA Senate Office of Oversight and Outcomes, [“In-Home Supportive Services Examination of the Impact of SB 1104: The 2004 Quality Assurance Initiative,”](#) (March 24, 2009); CDSS, [IHSS Program Data](#), (Feb. 2023). Of the 70% that make up family caregivers, 19.3% are parents and 4% are spouses.
- 33 Jia, Haomiao and Lubetkin, Erica, [“Life Expectancy and Active Life Expectancy By Marital Status Among Older U.S. Adults: Results from the U.S. Medicare Health Outcomes Survey \(HOS\)”](#) (Aug 15, 2020) (finding that “both married and unmarried men were more likely to spend a higher proportion of their future life years married as compared to married and unmarried women, respectively. This would mean that a married woman would be far more likely to become a widow, as opposed to a married man becoming a widower”)
- 34 Wu, Fei, [“Provider Retention and Turnover in the In-Home Supportive Services Program: Statistical and Geo-Spatial Analyses”](#) Report to County of Los Angeles, Department of Public Social Services (March 2016).
- 35 California State Auditor, [Report 2020-109](#), (February 2021).
- 36 CalSWEC, [“New Report Highlights Findings from the Adult Services Workforce Survey,”](#) (Feb. 22, 2022).
- 37 CDSS, [ACL 22-65](#), (Aug. 2, 2022); Cal. Welf. & Inst. Code §12300.6, stating that “a county or a public authority, as established pursuant to Section 12301.6, in collaboration with the applicable county, shall administer a backup provider system for in-home supportive services and waiver personal care services providers in compliance with the requirements of this section and Section 12300.5.”
- 38 Legislative Analyst’s Office, [Budget and Policy Post: IHSS](#) (March 2, 2023).
- 39 Chong, Natalie, Akobirshoev, Ilhom, Caldwell, Joseph, Kaye, Stephen H., Mitra, Monika, “The Relationship Between Unmet Need for Home and Community-Based Services and Health and Community Living Outcomes,” Disability & Health Journal, (April 15, 2022), “Many direct care workers experience poor job quality, including low wages, limited benefits, and insufficient training, leading to high employee turnover and job vacancies. These workforce issues may impact the quality of HCBS and lead to unmet need and other adverse outcomes.”
- 40 Howes, Candace and Greenwich, Howard, C Berkeley Labor Center, [“Struggling to Provide: A Portrait of Alameda County Homecare Workers,”](#) (May 1, 2002).
- 41 See Auditor of the State of California, Report 2020-109, [“In-Home Supportive Services Program: It is Not Providing Needed Services to All Californians Approved for the Program, Is Unprepared for Future Challenges, and Offers Low Pay to Caregivers,”](#) (Feb. 2021), finding that “wages in many counties are so low that caregivers without other sources of income would be eligible for public assistance, such as CalFresh, California’s food assistance program.”
- 42 *Id.* citing MPP § 30-766.
- 43 Wu, Fei, [“Provider Retention and Turnover in the In-Home Supportive Services Program: Statistical and Geo-Spatial Analyses”](#) Report to County of Los Angeles, Department of Public Social Services (March 2016), (in a geo-spatial study in LA County, finding that 40-50% of provider-user relationships were terminated for reasons other than the user’s eligibility, and that over an eight month period, 5% of users per month did not have providers. At the end of the 8-month study, 17% of those users still did not have a provider.)

- 44 Fabius, Chanee D., Wolff, Jennifer L., Willink, Amber, Skehan, Maureen E., Mulcahy, John, Kasper, Judith, Commonwealth Fund, [“Community-Based Long Term Services and Supports: Are the Needs of Older Adults and Their Caregivers Being Met?”](#) (Oct 27, 2021)
- 45 DHCS, [Semi-Annual Report on HCBS Spending Plan for FFY 2022-23, Q3](#).
- 46 Center on Budget and Policy Priorities, [“States can Reduce Medicaid’s Administrative Burdens to Advance Health and Racial Equity.”](#) (Jul. 19, 2022), citing Office of Management and Budget, [“Study to Identify Methods to Assess Equity: Report to the President.”](#) (Jul. 2021); White House, [“Executive Order on Transforming Federal Customer Experience and Service Delivery to Rebuilt Trust in Government.”](#) (Dec. 13, 2021).
- 47 CDSS, [In-Home Supportive Services Program](#), (last visited 05/22/2023).
- 48 San Mateo County Health, [In-Home Supportive Services](#) (last visited 05/22/2023); Kern County, [In-Home Supportive Services](#), (last visited 05/22/2023); Sacramento County, [In-Home Supportive Services](#), (last visited 05/22/2023).
- 49 Auditor of the State of California, Report 2020-109, [“In-Home Supportive Services Program: It is Not Providing Needed Services to All Californians Approved for the Program, Is Unprepared for Future Challenges, and Offers Low Pay to Caregivers,”](#) (Feb. 2021) at 17.
- 50 CDSS, [Forms & Brochures](#), (last visited 05/22/2023).
- 51 CHCF, [“In-Home Supportive Services \(IHSS\) 101: Opportunities and Challenges Under CalAIM.”](#) (May 2023).
- 52 Cal. Welf. & Inst. Code 12300(a)
- 53 Cal. Welf. & Inst. Code, §§ 12305.7(e)(1), 12309; MPP § 30-761.
- 54 MPP § 30-757.1(a)
- 55 Cal. Welf. & Inst. Code 12304; unlike the other IHSS programs, the Personal Care Service Program has a maximum of 283 hours for all recipients. See [ACL 93-21](#) (March 16, 1993).
- 56 MPP § 30-756.372
- 57 Solis-Moreira, Jocelyn, Health, “Black Patients Are Less Likely to Receive a Timely Dementia Diagnosis Despite Having the Highest Risk,” (Aug. 8, 2022); National Institute on Aging, [“Data shows racial disparities in Alzheimer’s disease diagnosis between Black and white research study participants.”](#) (Dec. 16 2021); see also Hoffman, Kelly, Trawalter, Sophie, Axt, Jordan and Oliver Norman M., [“Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites,”](#) PNAS, (April 4, 2016).
- 58 See Table 1, citing to CDSS, [IHSS Program Data](#), (Feb. 2023).
- 59 MPP § 30-757.173
- 60 Disability Rights California, [In-Home Supportive Services Protective Supervision](#), (April 1, 2023).
- 61 CDSS, [“In-Home Supportive Services \(IHSS\) Social Worker Assessment Field Handbook.”](#) (Nov. 2020).
- 62 See for example, National Institute of Health, [Implicit Bias Training Course](#) (last visited 05/22/2023).
- 63 Auditor of the State of California, Report 2020-109, [“In-Home Supportive Services Program: It is Not Providing Needed Services to All Californians Approved for the Program, Is Unprepared for Future Challenges, and Offers Low Pay to Caregivers,”](#) (Feb. 2021).
- 64 See NYU News, [“Home Care Patients with Language Barriers at Higher Risk for Rehospitalization.”](#) (Oct. 27, 2021), citing Squires, Allison, Ma, Chenjuan, Miner, Sarah, Feldman, Penny, Jacobs, Elizabeth, Jones, Simon, “Assessing The Influence Of Patient Language Preference On 30 Day Hospital Readmission Risk From Home Health Care: A Retrospective Analysis,” International Journal of Nursing Studies, vol. 125 (2022) (Finding that language asymmetry between patients receiving home health care and caregivers was associated with higher hospital readmission rates.)
- 65 DHCS, Aged, Blind and Disabled Medi-Cal Enrolled in 2022 Data (provided by DHCS); IHSS averages calculated using equity data published by CDSS, [Program Data](#) (July 2022-Dec. 2022.)
- 66 KQED, [“Lack of Oversight for In-Home Caregivers Can Lead to Neglect and Death.”](#) (Jan. 1, 2015).
- 67 See for example, CA Senate Office of Oversight and Outcomes, [“Examination of the Impact of SB 1104: The 2004 Quality Assurance Initiative.”](#) (March 24, 2009), discussing the intent of the legislature to standardize hourly task guidelines in order to reduce over-allocation of service hours, identify overpayments and fraud.

- 68 [Section 12600\(a\) of the Cures Act, Public Law 114-255](#); CMS, PowerPoint Presentation, [“Section 12600 of the Cures Act Electronic Visit Verification System”](#) (Dec 2017).
- 69 CDSS, [2009 Uniform Statewide Protocols](#), (2013) (implementing Welf. & Inst. Code 12305.82(b) IHSS fraud prevention measures through unannounced home visits ensuring that services authorized consistent with program users’ needs at a level which allows them to remain in the home, as well as a monitoring tool to for user safety and program integrity.)
- 70 See for example, CDSS, [2022 All County Information Notices](#) (last visited 05/22/2023); CDSS, [IHSS Quality Assurance \(QA\)](#) (last visited 05/22/2023); for more on the IHSS Quality Assurance program, see Welf. & Inst. Code 12305.7, 12305.71; MPP 30-702; see SOC 824, [“In-Home Supportive Services Quarterly Report On Quality Assurance/Quality Improvement \(QA/QI\) For Personal Care Services Program \(PCSP\), IHSS Plus Option \(IPO\) And IHSS Residual \(IHSS-R\) Programs.”](#)
- 71 CMS, [HCBS Quality Measure Set](#), (July 21, 2022).
- 72 DHCS, Aged, Blind and Disabled Medi-Cal Enrolled in 2022 Data (provided by DHCS); IHSS averages calculated using equity data published by CDSS, [Program Data](#) (July 2022-Dec. 2022).