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ISSUE BRIEF

Breaking Down Barriers to Personal Care: Unlocking Vital Services for Those Who Need Them Most

OCTOBER 2024

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INTRODUCTION

Personal care services are essential for older adults and people with disabilities who need assistance with daily activities like dressing, eating, and cleaning to live independently and age in their communities rather than in institutional settings such as nursing facilities.

In California, Medi-Cal pays for personal care services through several Home and Community-Based Services (HCBS) programs including In-Home Supportive Services (IHSS), HCBS waiver programs, and through Medi-Cal Managed Care Plans. IHSS is by far California's largest HCBS program, offering personal care to over 700,000 disabled people of all ages. IHSS primarily uses a consumer-directed model, where participants must manage their own care, including hiring and supervising providers and directing when and how their care is delivered. Meanwhile, HCBS waiver and managed care programs couple personal care services with additional supports, but comparatively serve far fewer people than the IHSS program.

To understand how well the IHSS program and other HCBS programs offering personal care services are working for people with the greatest health and social needs, Justice in Aging conducted extensive interviews with over 80 personal care consumers and providers, consumer advocates, state and national policymakers, and other stakeholders (see Appendix). This paper synthesizes the findings from these interviews with accompanying direct quotes from participants.

KEY FINDINGS

Interviews revealed that personal care services are largely inaccessible to people who are not able to self-direct their care, particularly if they do not have family or community support. This leaves many at risk of injury, prolonged homelessness, hospitalization, and unnecessary institutionalization. And these gaps in care disproportionately harm people who are Black, have limited English proficiency, or are LGBTQ+.

1. Certain groups of **people with disabilities disproportionately face difficulty in accessing personal care services** through the IHSS Program.
2. The IHSS Program design and rules create **significant barriers to self-direction** and **hinder access to personal care services** for certain high-need populations.
3. People **experiencing homelessness face unique programmatic barriers** in accessing personal care services through IHSS.
4. HCBS Waiver Programs and Medi-Cal managed care **do not currently fill the gaps in access** to personal care services.
5. Those who cannot access personal care services **face serious harm to their health and well-being.**

RECOMMENDATIONS

Interviews revealed that people face diverse challenges and barriers in self-directing their own care, pointing to a need for programs and policies that provide a continuum of care and support. Solutions must remove barriers to services and increase supports that foster independence, self-determination, and community living for individuals along this continuum.

1. **Expand the availability of personal care services** delivered through agencies as an alternative to the consumer-directed model for people who face barriers self-directing their care.
2. **Expand access to HCBS waiver programs** for people with the highest care needs by removing enrollment caps and making them more widely available across the state.
3. **Review and improve IHSS and other HCBS program rules** to reduce the barriers to enrolling in these programs and accessing personal care services.`
4. **Improve the availability** of personal care services through Medi-Cal managed care including Community Supports.
5. **Adopt innovative practices** like training, case management, and peer support to facilitate access to consumer-driven personal services.

Funding for this project was provided by the California Health Care Foundation. This paper was informed by interviews with state and national policymakers, consumer advocates, community-based organizations, supportive housing organizations, county IHSS personnel, IHSS Public Authorities, labor organizations, and IHSS consumers and providers. Quotes used in this report are taken from these interviews. Justice in Aging would like to thank the more than 80 individuals who shared their experiences and insights with us.

BACKGROUND: MEDI-CAL PERSONAL CARE PROGRAMS

Medi-Cal, California's Medicaid program, is responsible for providing people with the services and supports they need to remain living at home and in their communities, known broadly as home and community-based services (HCBS). California delivers HCBS through a number of different programs and delivery systems, several of which include the provision of personal care services. These include the In-Home Supportive Services (IHSS) program, HCBS waiver programs, and personal care services that are offered by Medi-Cal managed care plans through Community Supports.

In-Home Supportive Services

IHSS is California's largest personal care services program. It plays a central role in California's compliance with the Supreme Court ruling, *Olmstead v. L.C.*, which requires that all individuals have the right to self-determination and are entitled to receive the supports they need to live in their homes and communities. Rooted in this core principle and championed by the independent living and disability rights movements,[1] the program relies on a consumer-driven model where the consumer is responsible for directing their own care.[2]

Today, California law recognizes three types of IHSS delivery:[3]

- **Independent Provider Mode**: Consumers directly employ a provider of their choice, including a family caregiver like a parent or spouse, a friend, or other certified provider. Nearly all IHSS participants receive IHSS through this mode, with 72% receiving care from family providers.[4] Those without family caregivers must turn to Public Authorities (see text box) or other local nonprofit consortiums for a registry of enrolled providers, or identify and hire an eligible provider from their community.[5]
- **Contract Mode**: To serve those who cannot access IHSS through the Independent Provider Mode, counties may also contract with a home care agency to act as the employer of IHSS providers, rather than the consumer. At this time only San Francisco County uses Contract Mode, providing IHSS services to 1,100 out of the county's 27,500 IHSS recipients.[6]
- **Homemaker Mode**: The County acts as the home care agency. This model is currently unused.[7]

IHSS Public Authorities

Under Independent Provider Mode, IHSS consumers hire their care providers directly, but share employment responsibilities with their county's Public Authority. The Public Authority serves as the employer of record for over 600,000 unionized IHSS providers, including family providers, in collective bargaining about terms of employment, such as wages and benefits.[8] Public Authorities are also responsible for recruitment, orientation, background checks, and maintenance of provider registries.

Home and Community-Based Waivers

People with complex needs who require more support in addition to standard personal care services can turn to California's Medicaid HCBS waiver programs. Waiver programs can provide personal care services through an agency, can supplement IHSS when the maximum allowable 283 hours are not enough to meet a consumer's needs, and include additional intensive supports when people need them to remain living in a community setting. But unlike IHSS, these waiver programs are geographically limited and have enrollment caps, leading to long waitlists.[9]

There are three primary HCBS waiver programs that provide personal care assistance (plus additional services) to older and disabled adults that were discussed by interviewees.[10]

- **Assisted Living Waiver (ALW):** Provides up to 24-hours of care and supervision a day to older adults and adults with disabilities in Residential Care Facilities for the Elderly (RCFEs) or Adult Residential Facilities (ARFs), and in a limited number of publicly subsidized housing units in Los Angeles County.[11] The ALW is available in 15 of California's 58 counties, is expected to reach its maximum capacity of 14,544 individuals by the publication of this paper, and carries a waitlist of approximately 3,200 people.[12]
- **Home and Community-Based Alternatives (HCBA) Waiver**: Offers up to 24 hours per day of personal care services (plus a variety of intensive services such as in-home nursing care) to medically fragile individuals of all ages, in their homes, through both independent and agency providers. The HCBA waiver is available statewide and currently serves 9,031 people, and has a waitlist of over 5,300 individuals.[13]
- **Multi-Purpose Senior Services Program (MSSP)**: Provides supplemental personal care services and comprehensive supports including care coordination and management and adult day services to individuals over age 60.[14] As of the publication of this paper, 9,653 people are enrolled in the program, [15] and it will soon be available in all 58 counties.[16]

Medi-Cal Managed Care

Medi-Cal managed care plans also have the option, but are not required, to offer one or more of fourteen services, known as Community Supports.[17] Community Supports are offered to address health-related social needs by filling care gaps that impact access to stable housing, food security, and community living.

Personal care services are primarily offered through three Community Supports:[18]

- **Personal Care and Homemaker Services:** Delivers additional or temporary personal care to eligible individuals in three situations:
  - » Provides additional personal care hours beyond those approved under IHSS
  - » Provides temporary personal care services while an IHSS application is pending; and,
  - » For a maximum of 60 days, provides personal care for those not eligible to receive IHSS to avoid a short-term stay in a nursing facility.[19]

  While nearly all managed care plans offer the Personal Care Community Support as of July 2024, utilization remains low. During 2023, 1,780 people received this support, and one plan accounted for 1,465—or 82%—of all those who received this support.[20]
- **Nursing Facility Transition/Diversion to Assisted Living Facilities:** Gives members the option to transition out of or avoid the need to stay in a nursing facility by moving into a licensed residential care (assisted living) facility and to receive assistance with activities of daily living in that setting.[21] As of July 2024, all but two managed care plans included this Community Support as a covered service. However, only 552 individuals received this service during 2023, a majority of which were provided by only two managed care plans. [22]
- **Recuperative Care (Medical Respite):** Offers up to 90 days of care, including limited assistance with activities of daily living, in unlicensed interim housing settings for people experiencing homelessness who are discharged from the hospital and need additional time to recover before returning to unstable living situations like shelters or encampments.[23] Nearly all plans offer this Community Support, and 4,518 members used this service at some time during 2023.[24]

FINDINGS

Interviews revealed that California's personal care services programs as designed are inaccessible to people who, due to impaired capacity, structural barriers, discrimination, and bias, are unable to direct their care. These individuals encounter significant challenges in navigating complex program applications and administrative processes, hiring and managing care providers, and ensuring the quality of services they receive.

FINDING 1

Certain Groups of People with Disabilities Disproportionately Face Difficulty in Accessing IHSS

Interviewees identified five groups of people with disabilities who are more likely to face difficulty self-directing or managing their own care as required by the predominant model of IHSS (Independent Provider). This list is not exhaustive but illustrates the types of health conditions or situational circumstances that can hinder self-direction as required by the IHSS program.

- **Individuals with Cognitive and Decision-Making Impairments**: People with conditions like Alzheimer's, dementia, or behavioral health conditions may experience memory loss, confusion, or other symptoms that limit their ability to communicate or problem-solve as needed to consistently direct their own care, particularly as these conditions progress.
- **Individuals Experiencing Homelessness or At Risk of Homelessness**: People without stable housing often cannot establish consistent routines to become eligible for personal care services programs or to hire providers and effectively manage their own care.
- **Individuals Leaving Incarceration**: People leaving incarceration are faced with social stigma, limited family or social support networks, high rates of housing instability, economic barriers, and challenges in accessing or recovering documentation, such as identification needed to access social services programs. These challenges can make it difficult to apply for IHSS and obtain and retain a care provider.
- **Individuals Facing Discrimination**: Communities of color and LGBTQ+ individuals may experience discrimination and stigma from their providers, hindering their ability to find and retain a provider and address quality deficiencies or discriminatory treatment. People who have faced discrimination are also more likely to face isolation.
- **Individuals with Limited English Proficiency (LEP):** Language barriers may create obstacles to effectively communicating with a provider and complying with program rules.
- **Individuals Living in Rural Communities**: Physical and social isolation people living in rural areas experience, as well as reduced choice in available providers due to worker shortages, may cause dependence on a single caregiver and result in unequal power dynamics that make care direction challenging.

"I pray every day that I can kind of remember, because once you get on these services you have to reapply and recertify…I gotta do my recertification every year for that. I have to stay on top of my Medicaid and any other subsidy I get. I have to literally apply every year. Make sure I have all my information, my bank information, and it's a lot. It is really a lot." (IHSS Consumer)

"For some individuals [who have Alzheimer's and no family support], when we ask [application] questions, like what [health] plan do you have, or about their finances, they just have a hard time answering some of those questions, so it becomes kind of tricky… The thing is, how are they going to be able to follow through? Sometimes I involve APS [Adult Protective Services]…but I don't know what happens after I make the referral—then it's out of my hands." (Advocate)

"If you have to have multiple providers, it's really like running a small business. You have to hire, train, figure out schedules and sign time cards. It means that you have precluded individuals that have significant psychiatric illness, substance use disorder, or otherwise, high levels of disorganization…It's just not feasible for a lot of folks." (Service Provider)

"Incarcerated individuals don't even know about [IHSS], and it's really hard to get in to do education—the sheriff's department and CDCR [California Department of Corrections and Rehabilitation] make it really difficult." (Consumer Advocate)

Compounding Inequities

Barriers to accessing services are not experienced equally by everyone. Stakeholders reported that barriers to self-direction are compounded when individuals fall into multiple groups, particularly for people who live in rural areas or lack a family caregiver altogether. Further, discrimination in our healthcare system and society contributes to higher rates of Alzheimer's, dementia, homelessness, and incarceration among Black and Latino individuals.[25] As a result, obstacles to accessing IHSS and other personal care services disproportionately affect Black and Latino communities. Policies aimed at removing these barriers can help improve equitable access to essential support services and to community living for historically underserved populations.

FINDING 2

IHSS Program Design and Rules Create Significant Barriers to Self-Direction and Hinder Access to Personal Care Services for Certain Groups

Accessing personal care services through IHSS is complicated for many care recipients, especially for those who lack a family caregiver, and can be insurmountable for older adults and people with disabilities with certain medical conditions or social circumstances.

Program Navigation Barriers

- **Application Process and Program Navigation**. Navigating the IHSS application process involves multiple steps, such as filling out and submitting forms, obtaining doctor certification, scheduling and attending functional needs assessments, and, if necessary, filing appeals and grievances.
- **Program Knowledge and Rules**: Understanding the complexities of IHSS rules and consumer responsibilities as an employer, including reporting and timekeeping requirements, is crucial. However, many people are often unaware of program rules, and performing required administrative tasks like monitoring and signing timesheets, particularly when managing multiple providers, can be even more challenging for people with cognitive impairments or organizational and memory difficulties, or for people who are transitioning from one setting to another.[26]

"We have people that have been in our registry actively looking for providers that might go eight months or a year and run through 600 referrals and not hire anybody… [when we] try looking at people who are experiencing homelessness and connecting them with a providers, it's a nonstarter." (Public Authority)

"The [IHSS] wages and benefits are a problem [for retention], but also it's the level of care. People don't mind coming in doing light housework, or ...doing your grocery shopping. But it's that personal care that we worry about the most – that's where the biggest problem is, you just can't get a provider to do that. Not for $15 or $20 an hour." (Stakeholder)

"People [with Alzheimer's and dementia] can change from day to day, so if [there is a provider] just twice a week, or there could be two different providers, it's hard to have consistency, predictability, and a routine with somebody who is coming intermittently." (Policymaker)

"I have a neighbor that was just diagnosed with dementia last year, and lives in her apartment, alone. Sometime when I try to help her, and I can see that it's cognitively just really hard for her to remember the information. She's already getting IHSS, and she has a provider who is a family member, and the family member is not able to commit. So now she has to find someone new, and she's afraid of someone coming to her home to give care…." (IHSS Consumer and Advocate)

"It's very hard for [Black older adults] to reach out and get [IHSS] services because of trust, and because of the prejudice they deal with in [these rural areas]." (Service Provider)

Provider Management and Retention

- **Identifying and Hiring Providers**. IHSS consumers who do not have a trusted family member or friend who is willing to be their caregiver often rely on Public Authority registry lists or word-of-mouth to find providers to deliver services. These registries are often very difficult to navigate, requiring consumers to sort through and interview potential providers from a list of hundreds to find a suitable match in terms of skill set, geographic accessibility, and availability. Providers consider factors such as personality or perceived safety concerns when deciding whether to work for a consumer, and many prefer to work for those requiring a lower level of care. Provider concerns and preferences limit options for individuals with complex physical, mental health, or social needs.

- **Retaining Providers.** Consumers who have complex care or mental health needs requiring intensive or 24-hour care are often unable to retain IHSS providers who are willing to provide the necessary hands-on care or able to work when they need assistance.

- **Quality of Care Management**. Although the Public Authority is the employer of record, the entity's role is largely focused on ensuring providers meet program requirements, and not on ensuring provider quality. Managing how and when an IHSS provider delivers care and the quality of that care falls to the consumer, which is more challenging when a person relies on a single provider for care, communication, and community access because of physical isolation or dependency. This puts the provider in a position of power over the care recipient. When consumers struggle to identify and hire a provider due to personal obstacles or provider shortages, power dynamics between consumers and providers are impacted. This can prevent consumers from addressing job performance and quality issues, leading to unmet or neglected needs and sometimes resulting in abuse or serious conflicts between consumers and providers.

- **Compounding Factors:** A person's disability and lived experience can further exacerbate barriers to navigating IHSS program rules and managing and retaining a provider. For example, people with cognitive impairments or some behavioral health conditions may experience symptoms of paranoia or distrust, making it difficult for them to permit caregivers into their homes. Populations experiencing bias due to race, sexuality or gender identity,

"I live in a place that is pretty polarized politically, so it's not safe for communities that are not hetero white male Caucasian. We've seen an increase in our trans population feeling targeted…I've talked to many people in our community who are more scared now than before to access [IHSS] and get their needs met. It comes with the systemic trauma they have endured." (Service Organization)

"When someone's in a shelter and needs IHSS, it's not that it's impossible, but it's really tough to find IHSS workers that are willing to support folks in a shelter setting." (Provider)

"IHSS for sheltered versus unsheltered individuals is an area of real emerging need. And it's been emerging for a number of years as older homelessness has grown. But you need to be stable, and you cannot get in to a shelter until you're stable… IHSS is not a crisis intervention model so some county's concerns are legitimate about what we could do in a shelter. Like, if they make everybody leave [the shelter] all day long, what does IHSS look like? How are we finding the person? And there are functional things where the counties get nervous that they can't conceptualize how to operationalize it in shelters, but, on the other hand, they are supposed to do it." (Policymaker)

or trauma based on a history of victimization may also feel unsafe and be reluctant to engage a caregiver. The frequency of provider turnover for personal care services can act to intensify this distrust.

FINDING 3

People Experiencing Homelessness Face Unique Programmatic Barriers to Accessing IHSS

People who do not have stable housing often experience unique challenges in accessing IHSS and directing their care. Completing the IHSS application, for example, can be challenging for people who are staying in shelters or need to move frequently.[27] Compounding this issue, some counties improperly refuse to accept IHSS applications or perform functional assessments in shelters. This is contrary to Department of Social Services guidance allowing eligibility determinations for people at risk of homelessness or those living in a shelter or other locations.[28] For those who are assessed, they often find it very difficult to identify a provider who is willing to work in a shelter setting because of safety concerns or because shelter operators may be unwilling to provide accommodations such as flexibility in visitor policies to facilitate access for providers.

FINDING 4

HCBS Waiver Programs and Other Approaches to using Medi-Cal for Personal Care Services Do Not Fill the Gaps

Personal care services delivered through the HCBS waiver programs and Medi-Cal managed care plans could potentially address gaps in the IHSS program by providing the services that higher-needs individuals may require to live in the community, such as agency-provided personal care services, intensive case management, and 24-hour supervision. But these programs are not accessible to a majority of those who need them due to administrative, geographic, and capacity limitations.

HCBS Waivers

California's HCBS waiver programs play an important role in supporting community living for people who have the highest care needs and face obstacles in directing their care under the IHSS program. However, these programs fall short for many older adults and people with disabilities due to several key challenges:

"I haven't heard from [anyone] telling me they've been successful in getting [into ALW] and by the time like they get a response either the person has passed away or placed [in a nursing facility]." (Consumer Advocate)

- **Administrative Burdens**. Like IHSS, waiver programs are complicated to enroll in and are siloed, with each program administered and overseen by different government and waiver agencies with different enrollment steps and assessments.
- **Long Waitlists**. Waiver programs have long waitlists, and these waitlists are even more difficult to navigate by people who cannot direct their care or who have no family support.[29]
- **Geographic Limitations.** Some waiver programs, like the ALW are unavailable in most California counties.[30] In many areas in the state a shortage of provider agencies or workers impede expansion of HCBS waiver services.[31]

Medi-Cal Community Supports

Community Supports offered by Medi-Cal managed care plans have the potential to provide a more robust continuum of support and fill in the gaps where IHSS and HCBS waiver programs fall short—particularly if coordinated with Enhanced Care Management through CalAIM.[32] However, to date, data demonstrates that Community Supports are not adequately filling those gaps due to low utilization and lack of integration with other HCBS programs.

"We can't exchange data [with the counties], so we have no means of knowing when folks are actually getting [IHSS]…we need to exchange personal data about folks' healthcare information, so we have to have [an agreement] with counties that says that we are partners, to protect the plans. But government entities don't like these [agreements], so we don't have one with the social services agencies, and they can't give us that information and we can't share with them our information." (Medi-Cal managed health plan)

- **Personal Care and Homemaker Services**. This Community Support has the potential to serve as a bridge for people who need IHSS but who are not yet eligible or who are not in a position to self-direct their care. For example, people experiencing homelessness who have functional limitations that prevent them from accessing stable housing may be more likely to move into (and at less risk of losing) housing if they could use this Community Support prior to establishing IHSS services. This Community Support could also provide personal care services while people navigate the IHSS application process, identify permanent providers, or acquire skills in managing their own care.

  As discussed above, however, this Community Support is currently significantly underutilized.[33] Stakeholders reported that the low utilization stems mainly from managed care plans not reliably identifying potentially eligible members, and because plans and counties are not coordinating sufficiently to ensure the Community Support is effectively serving as a bridge to IHSS as intended. In addition, people may be excluded when plans require them to submit an IHSS application as a precondition to receiving the Community Support, particularly when a county does not accept IHSS applications from people who are experiencing homelessness.

  Setting aside these utilization barriers, the temporary nature of this benefit as currently structured cannot bridge the gap in access to personal care services for those people unable to use the IHSS program due to medical conditions or disabilities that prevent them from self-directing their care.

"Recuperative care programs require folks to be independent with activities of daily living, and that includes bathing, dressing, toileting, managing finances, managing medications, shopping, cleaning all of that…that's a general requirement to get into recuperative care. The staff [in recuperative care] don't do hands on assistance…so oftentimes, folks that have any personal care requirements are denied, or the referrals aren't accepted." (Health Services Specialist)

- **Nursing Facility Transition/Diversion to Assisted Living Facilities**. This Community Support could help to address the ALW waitlist and expand access statewide to people who need personal care and other services that are comparable to ALW. However, lack of awareness and low provider and managed care plan participation keep utilization low (see above). Further, unlike the ALW, this Community Support is unavailable in public subsidized housing, limiting where people can receive assisted living services due to a limited supply of licensed residential care facilities that are available for Medi-Cal recipients.
- **Recuperative Care (Medical Respite).** This Community Support can provide limited personal care services to individuals experiencing homelessness who are transitioning from hospital care.[34] But because recuperative care organizations do not generally offer personal care services due to insufficient staffing, inadequate funding, and concerns about the scope of services that can be delivered by operators of unlicensed settings, this Community Support is largely unavailable to those who need assistance with daily living activities.[35]

FINDING 5

Those Who Cannot Access Personal Care Services Face Serious Harm

"I work with a lot of [individuals with Alzheimer's who have no family support] and these are the most challenging cases. I honestly don't know how to tackle these cases… when [consumers] are in the middle or middle to late stage [of Alzheimer's], they don't have capacity, then we call APS...I work with APS and other organizations but [when] I request assistance from APS, I get bounced around on this kind of loop and we don't know how to help…" (Consumer Advocate)

Older adults and disabled people who need assistance with activities of daily living can experience significant harm when going without personal care, including poor health and psychological harm, increased risk of falls and injury, hospitalization, neglect and abuse, institutionalization, homelessness, and death.[36] People with impaired cognitive capacity are frequently referred to Adult Protective Services (APS), which has few tools to assist people beyond seeking conservatorship and placing people in nursing facilities or other institutions.

Data further underscores the severe consequences faced by populations unable to access HCBS and personal care services through existing programs. For example, in 2022, over half of those residing in nursing facilities in California —approximately 43,000 people—had diagnoses of Alzheimer's or dementia because these individuals and their families are not adequately receiving the support they need through existing programs.[37] Similarly, people with behavioral health diagnoses account for one third of all inpatient hospitalizations and one fifth of emergency room visits, again demonstrating how existing programs are not adequately supporting the people with the highest needs.[38]

RECOMMENDATIONS

Interviewees highlighted several potential policy opportunities for designing personal care services programs that both preserve self-direction and effectively serve people across a continuum of ability to self-direct. Although no single solution would resolve all barriers, comprehensive system-wide reforms, coupled with targeted policies to promote self-direction, could gradually expand access to personal care services for those who need them most.

RECOMMENDATION 1

Expand Contract Mode IHSS

Nearly all interviewees identified the need to expand Contract Mode IHSS to better serve people who face challenges directing their own care. While San Francisco County has been able to make Contract Mode financially viable by adding local and private funding streams to state and federal IHSS funding (see textbox below), counties that previously implemented it have since abandoned it, citing concerns about cost. [39] This is because counties are required to contribute a set dollar amount, called the Maintenance of Effort, every year to the IHSS program, and adding a Contract Mode option would permanently increase that amount.

Of California's remaining 57 counties, only Los Angeles County is currently working on adding this option. The County is planning a contract mode program to improve access to personal care services for people experiencing or transitioning from homelessness who have higher-acuity in medical, mental health, or cognitive impairments. The County is finalizing outstanding administrative, programmatic, and operational details, with implementation expected to begin in the 2025/2026 fiscal year. The model is using local funding through the Housing for Health program to contract with agencies delivering home caregiving support to people experiencing homelessness who cannot access care through IHSS. Providing an IHSS contract mode option for people experiencing or transitioning from homelessness will create a pathway to IHSS services that are often needed to support stable housing. It will also allow the county to leverage matching state and federal funding and expand the program's capacity to serve more people who are unhoused or living in supportive housing. Yet, as interviewees reported, county concerns regarding financial impact on the county's maintenance of effort have led to a more limited program design.

LA County is also facing steep administrative challenges in its attempt to create a contract mode program. "There's not a blueprint for how to stand this up. Though the state has been very supportive in helping the County navigate various requirements and decision points as we develop our implementation plan…we've had to kind of build the airplane a little bit." (LA County Representative)

California could support efforts to expand Contract Mode to more counties by:

- Removing administrative burdens and providing technical assistance to counties wanting to add a Contract Mode option.
- Removing financial disincentives by reducing the maintenance of effort impact on county budgets.
- Providing additional financial assistance for counties to establish a Contract Mode option.
- Supporting the establishment of collective bargaining agreements with agencies that have contracts to provide IHSS services, and ensuring parity in labor conditions and benefits for workers who provide caregiving services across different modalities.[40]
- Incentivizing counties to employ and manage providers for people with high needs through Homemaker IHSS mode by creating pay parity with Contract Mode.

Interviewees strongly emphasized the importance of ensuring that any expansion of Contract Mode does not erode

the current consumer-driven model and fundamental right to manage one's care. Rather, Contract Mode should serve to empower people to direct their own care to the greatest extent possible. Targeted training should be required for agency providers to ensure culturally competent care that is responsive to the needs and concerns of communities of color and LGBTQ+ consumers, as well as people experiencing homelessness and others who have experienced trauma, victimization, or racism.

Homebridge: A Successful Contract Mode Model Promoting Self-Direction

Homebridge was established almost three decades ago with the goal of improving services to IHSS care recipients who were without networks of support.[41] Working in collaboration with Homebridge, San Francisco's Department of Aging and Adult Services' IHSS program refers eligible people to the agency. Homebridge is financed through a combination of IHSS reimbursement, private funding, and local financing.[42] Agency services are limited to people who have no family caregivers and are unable to direct their care. Many of these care recipients live in permanent supportive housing sites and single-occupancy units that are served by on-site Homebridge staff, who provide personal care services, case management, caregiver training, and mentorship support, as well as training for consumers.[43]

Recognizing that a recipient's needs may shift or change over time, the San Francisco program uses a "continuum of choice" model that allows people to transition between lower and higher tier agency services, and move between Independent Provider Mode and Contract Mode when appropriate.[44]

"Having options is really important. That's where we see Homebridge fitting in, is this continuum of choice and support. We try to have a continuum of services for it to meet different needs. For us, it's really about having options." (County Representative)

RECOMMENDATION 2
Make HCBS Waiver Services Available Statewide Through the State Plan

Today, California's HCBS waiver programs provide the most extensive support to those with the highest needs. Yet these programs are not available statewide and have long waitlists. California could transition these HCBS waiver programs into the Medicaid state plan through a State Plan Amendment, potentially using 1915(i) federal authority. This would make waiver benefits a statewide entitlement and eliminate HCBS waiver waitlists. Eligible Medi-Cal enrollees could receive personal care services through IHSS's consumer-directed model if they prefer, or through the types of agencies currently providing HCBS waiver services. Such an expansion would allow those who face challenges directing their care and have high health care needs to access personal services coupled with more intensive supports to help them remain at home.

Expansion of these HCBS programs would particularly benefit people with cognitive impairments like dementia and behavioral health impairments, the populations with very high needs and the highest rates of institutionalization. And eliminating waitlists can reduce inequities that occur when individuals with less resources must move into institutional care or go without care due to long wait times.[45]

Any expansion of these programs would require investments in the infrastructure to build service capacity statewide, particularly in rural areas, and to address provider shortages.[46] For example, California could work with stakeholders including community-based organizations, consumers, counties, and managed care plans to identify strategies for increasing service availability in underserved areas and reducing provider turnover, including through rate increases and other investments such as those pursued under the Community Care Expansion Program.[47]

RECOMMENDATION 3

Reduce Barriers to Program Enrollment

California could take a number of steps to mitigate the administrative barriers to applying for IHSS and other programs that include personal care services, such as:

- Requiring counties to assess unhoused individuals for IHSS eligibility in both unsheltered settings and sheltered settings such as interim housing, recuperative care, and other temporary settings.
- Increasing Medi-Cal managed care plan capacity to assist with IHSS referrals and applications through training, technical assistance, and supports for data sharing between plans and counties.
- Assigning social workers or providing case management for individuals who need assistance with filling out program forms, obtaining required documentation, and fulfilling required program administrative tasks.
- Providing financial and administrative support for broader implementation and sustainability of wraparound models that integrate affordable housing, intensive case management, and personal care and homemaker services. (See textbox: Cardea Health Model)
- Using Older Americans Act funding to expand access to legal services that assist with advance health planning and designating a power of attorneys to avoid APS involvement and promote supported decision-making.

Cardea Health Model

Using the Home and Community-Based Alternative waiver (HCBA), IHSS, and other funding streams, Cardea Health provides supportive services in a range of settings, including permanent supportive housing sites for people coming out of homelessness who have high care needs. Service recipients include formerly incarcerated people, and those who have significant mental health needs and substance use disorders.

"I was in prison for 38 years, and got out in 2019. I worked in picking up trash, carrying heavy hoses, washing the streets. I did that for six months, but I got sick. When I got out, I didn't have Medi-Cal so I didn't go to the doctor. By the time I went to the hospital, I was losing a lot of weight and didn't know why. I found out that I had stage four lung cancer. Because of the treatment, I was really weak. I couldn't get up to use the restroom. I had a lot of falls. I got hit on the head, I'm afraid of falling so I have a walker now. Cardea saved me. They coordinated my care, toileting, taking me to appointments. Here, the nurse comes and checks on me regularly. The caregiver came to help wash, dress, take me to treatments. As I'm getting stronger, I need less help. I'm trying to get stronger." (Consumer)

RECOMMENDATION 4

Improve Availability and Use of Community Supports in Managed Care

California could improve the availability and use of Community Supports that provide personal care services statewide to help fill in care gaps by:

- Mandating the provision of all Community Supports by all Medi-Cal managed care plans statewide rather than making them optional services, and bolstering network adequacy requirements to push Medi-Cal plans to strengthen incentives for personal care services providers to participate in their networks.

"It's more difficult to provide any type of services when somebody is socially unstable, has psychiatric illness and or substance use disorder… housing, medical stuff, personal care, everything is harder… if there's no rate supplement associated with provision of services to this population that has higher needs… in effect, there is a penalty paid by that organization for investing those supplemental resources to provide the very same service that you might (provide) more easily to someone else." (Service Provider)

- Mandating standardized provider and self-referral processes, as the state has done with the CalAIM Enhanced Care Management (ECM) benefit, and using tools to screen and identify members who should receive Community Supports across plans.
- Improving coordination of ECM with Community Supports to assist with identifying and managing providers, coordinating services across Community Supports, and improving utilization and access.
- Requiring managed care plans to offer the Personal Care Community Support to eligible members immediately upon assessed need, rather than only after referral to the county for an IHSS assessment.
- Requiring plans to facilitate the alignment of this Community Support service with other Community Supports such as Recuperative Care and Housing-related Community Supports as needed to facilitate care transitions and improve access to interim and permanent housing in community settings.
- Allowing individuals who are unable to direct their care to access the Personal Care Community Support instead of IHSS.
- Ensuring people leaving incarceration receiving Medi-Cal services prior to release are screened for IHSS, Community Supports, and HCBS waivers and provided with program application assistance and access support where appropriate.

RECOMMENDATION 5
Expand Innovative Practices

California can facilitate the broader replication of promising practices that have been implemented in some counties to improve access to personal care supports for people who need them, including:

- Offering differential pay and additional supports such as training, peer supports, and education opportunities for providers who support people with higher or complex needs.
- Employing county-designated IHSS social workers to support applicants and beneficiaries who are referred from Adult Protective Services (APS), providers of homeless services, or permanent supportive housing providers.
- Expediting or prioritizing referrals to HCBS waiver programs, Personal Care Community Supports, and other programs for people who are experiencing housing instability or having difficulties directing their own care.
- Offering mentorship, training, and support to IHSS consumers on directing care and program navigation by funding Public Authority peer support programs.
- Funding Public Authority peer support programs or standalone county

programs that support self-direction through mentorship and training IHSS consumers on provider supervision, care management, financial management, and navigating services.

- Funding training and incentives for providers on supporting people with complex needs.

CONCLUSION

California's IHSS program plays an essential role in delivering personal care services to older adults and people with disabilities who are capable of directing their own care or have a support network to assist them. However, for those without these supports—particularly individuals facing complex health or social circumstances—the system remains out of reach. Alternative programs, such as HCBS waivers and Community Supports through Medi-Cal managed care have the potential to bridge some gaps, but are currently limited by capacity, geographic availability, and administrative barriers.

California's long-standing commitment to community living and self-determination provides a strong foundation for the continued development of solutions that empower individuals to live independently with dignity, regardless of their ability to direct their own care. But ensuring that all Californians have access to the personal care services they need requires a system that is adaptive, inclusive, and responsive to the diverse needs of those who rely on it. A continuum of care that offers both self-directed and agency-delivered models, coupled with streamlined access and stronger support mechanisms, can make a profound difference in the lives of individuals who face barriers to managing their own care.

By addressing these gaps in service availability, reducing administrative hurdles, and expanding innovative models of care, California can take significant steps toward building a more equitable and accessible system. The opportunity to reimagine personal care services offers the potential for improved outcomes for those with the highest needs and least resources.

APPENDIX

Report Scope and Methodology

Given the limitations in both capacity and scope of HCBS waivers and managed care organizations to provide personal care services, IHSS is often the only personal care service available for low-income older adults who need the support to remain in their home. However, IHSS requires consumers to self-direct their care, presenting challenges for those unable to do so.

To explore this issue, Justice in Aging conducted interviews with 80 stakeholders including personal care consumers and providers; community-based organizations; county IHSS agencies; IHSS Public Authorities; Medi-Cal managed care plans; IHSS union leadership; and Medicaid HCBS experts (See below for full list of interviewees).

Interviews focused on factors impeding self-direction, barriers in accessing care, and potential policy solutions.

Limitation: While the interviews included people recently transitioning from homelessness, incarceration, and those with substance use disorder, we were unable to interview a key group—people with Alzheimer's and dementia who lack family caregivers. Justice in Aging was unable to identify community-dwelling people who were able to participate in an interview due to the high rates of institutionalization and social isolation among this population.

Justice in Aging is grateful to the following organizations for participating in this project and for taking the time to share their experiences and insights with us:

- Hand in Hand Domestic
- Employers Network
- LeadingAge California Santa Cruz County (IHSS)
- United Domestic Workers
- Legal Aid Society of San Diego
- Alzheimer's Association of Greater LA
- Solano County Health Services (IHSS)
- Service Employees International Union Local 2015
- Bet Tzedek Legal Services
- Disability Action Center
- County Welfare Directors Association of California
- National Association of State Directors of Developmental Disabilities Services
- Disability Rights California
- Health Trust
- Public Authority (LA County)
- Washington State Aging and Long-Term Support Administration
- S California Advocates for Nursing Home Reform
- Peachtree Health Care Services Public Authority (Santa Clara County)
- California Department of Social Services
- Legal Services of Northern California
- Home Health Care Management
- Public Authority (San Francisco County)
- California Department of Aging
- Senior Advocacy Network
- Shasta Community Health Center
- Public Authority (Imperial County)
- Department of Health Care Services

- California IHSS Consumer Alliance
- Housing Works Public Authority (Yolo County)
- LA County Department of Health Services
- Institute on Aging
- Population Health, LTSS & SDOH Consultant
- CA Association of Health Plans
- LA County Department of Health Services
- Cardea Health
- National Health Care for the Homeless Council
- Anthem Blue Cross
- East Bay Innovations
- San Francisco Human Services Agency
- LA Care Health Plan
- Partners in Care San Francisco IHSS
- CalOptima Health
- Libertana
- Riverside Department of Social Services (IHSS)
- Health Plan of San Juaquin
- Lifelong Medical Care
- Sacramento Adult Services (IHSS)
- Health Plan of San Mateo

ENDNOTES

1 CICA, IHSS Background (last visited 07/1/2024); Nilchian, Mina, "In-Home Supportive Services, the Olmstead Decision and Possible Future Directions," (March 2018)

2 KFF, "Key State Policy Choices About Medicaid Home and Community-Based Services," (February 2020), (Appendix Table 3, page 35), (of the 34 states that offer personal care services, 29 use Contract Mode, also known as Agency Mode, and 16 use the independent Provider mode).

3 Welf. & Inst. Code §12302; CDSS, MPP Div. 30, Ch. 300-767.11-.12, (last updated Jul. 1, 2019).

4 CDSS, "IHSS Program Data," (June 2024).

5 Dickman, Hagar, Justice in Aging, "California's In-Home Supportive Services Program: An Equity Analysis," (June 2023).

6 Data was provided by Homebridge and the San Francisco Public Authority.

7 Confirmed by email communication with Leora Filosena, Department of Social Services, on Aug. 7, 2024.

8 Welf. & Inst. Code §12301.6; Department of Social Services, IHSS Program Data, (May 2024); Hunter, Savannah, UC Berkeley Labor Center, "Snapshot of California's Union Membership: It's not your grandfather's union anymore," (Aug. 29, 2023); see also Dickman, Hagar, Justice in Aging, "California's In-Home Supportive Services Program: An Equity Analysis," (June 2023).

9 Christ, Amber and Dickman, Hagar, Justice in Aging, "An Equity Framework for Evaluating California's Medi-Cal Home and Community-Based Services for Older Adults & People with Disabilities," (Dec. 2022).

10 Individuals over age 55 can receive personal care services by participating in a Program for All Inclusive Care for the (PACE). There are currently over 20,000 people enrolled in PACE in 26 counties in California. DHCS, Program of All-Inclusive Care for the Elderly, (last visited Oct. 1, 2024).

11 DHCS, Assisted Living Waiver, (last visited Oct. 1, 2024)

12 DHCS, "ALW Enrollment and Waitlist-January 2019-July 2024" (July, 2024); DHCS, Memorandum: Important Information Regarding Prospective ALW Enrollments," (Sep. 4, 2024).

13 DHCS, "HCBA Monthly Dashboard" (July, 2024).

14 CMS, MSSP 2024 Approval Letter and Application, (Sept. 26, 2024).

15 Based on site self-reporting, provided by email communication with Denise Likar, California Department of Aging (Oct 1, 2024).

16 DHCS, MSSP Program (as of the publication of this paper, the renewed MSSP application was not yet publicly available.)

17 DHCS, "Transformation of Medi-Cal: Community Supports"; for more information see DHCS, Medi-Cal Community Supports In Lieu of Services (ILOS), Policy Guide, (July 2023).

18 While not discussed with interviewees, Medi-Cal managed care plans are also responsible for administering California's adult day health benefit, Community-Based Adult Services (CBAS) which provides personal care assistance on site at adult day centers. CBAS is available in 28 counties and serves 39,826 individuals. California Department on Aging, "List of CBAS Providers," (Last visited Oct. 1, 2024); California Department of Aging, Center Overview, (June 2024).

19 Id.

20 DHCS, Quarterly Implementation Report: Total Number of Members Who Utilized Community Supports by MCP and County By Service By Quarter," (last updated August 12, 2024); DHCS, CalAIM Community Supports - Managed Care Plan Elections (July 2024).

21 DHCS, Medi-Cal Community Supports In Lieu of Services (ILOS) Policy Guide, (July 2023).

22 DHCS, CalAIM Community Supports - Managed Care Plan Elections (July 2024).

23 DHCS, Medi-Cal Community Supports In Lieu of Services (ILOS) Policy Guide, (July 2023).

24 DHCS, CalAIM Community Supports - Managed Care Plan Elections, (July 2024).

25 California Department of Public Health, "Alzheimer's Disease and Related Dementias Facts and Figures in California: Current Status and Future Projection," (Jan. 2021); Benioff Homelessness and Housing Initiative, "Toward Equity: Understanding Black Californians' Experiences of Homelessness," (February 2024); California Department of Public Health, "Health Equity: Beyond the Number," (May 2024).

26 People often need multiple providers because they need more care hours than the maximum hours providers are allowed to work per week, or providers who can work the needed hours are unavailable.

27 Kushel, Margot, and Moore, Tiana "Toward a New Understanding: The California Statewide Study of People Experiencing Homelessness," (June 2023), (at page 71), ("The experience of homelessness is highly stressful: participants spent much of their time trying to survive and find shelter, food, safety. They reported that these efforts consumed much of their energy, leaving them less able to seek healthcare including treatment for physical and mental health challenges and substance use and employment.")

28 CDSS, All County Information Notice No. I-19-20, "Clarification Of Definition Of "Own Home" As It Relates To In-Home Supportive Services Eligibility," (Feb. 25, 2020).

29 After reaching capacity in June 2023, the HCBA waiver's waitlist ballooned to over 5,300 individuals, compared with current enrollment of 9,031. In spite of receiving an additional 1800 slots in January 2024, the ALW has over 14,500 participants and carries a waitlist of over 3,200 individuals. DHCS, "ALW Slot Expansion Amendment," (Feb. 6, 2024); DHCS, "Assisted Living Waiver Monthly Dashboard: July 2024," (July 2024).

30 Christ, Amber and Dickman, Hagar, Justice in Aging, "An Equity Framework for Evaluating Home and Community-Based Services for Older Adults & People With Disabilities," (Dec. 2022), (CBAS is limited to 28 counties and the ALW to 15, with a vast majority of Californians without ALW or CBAS providers living in rural counties); see also California Department on Aging, "List of CBAS Providers," (Last visited Oct. 1, 2024).

31 See for example, DHCS, "ALW Assisted Living Facilities Dashboard," (last updated Aug. 15, 2024); the current distribution of ALW providers, concentrated in the Bay Area, Sacramento and Los Angeles County; Department of Social Services, "California Community Care Expansion," (last updated Sep. 27, 2024) was intended to increase capacity in underserved counties, but many rural counties continue to lack providers such as Residential Care Facilities for the Elderly, where ALW services are provided.

32 DHCS, "CalAIM Enhanced Care Management Policy Guide," (Dec. 2023)

33 DHCS, "ECM and Community Support Quarterly Implementation Report: Quarterly Implementation Report: 2023 Q4, Total Number of Members Who Utilized Community Supports by Service in the Last 12 Months of the Reporting Period" (Last updated Aug. 12, 2024); Auditors of the State of California, Report Number 20-109, "In-Home Supportive Services: 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). (Because this reflects the number of people who are approved for IHSS but not receiving the service, leaving out those who are not yet approved for IHSS, the number of people who need the service is likely bigger.)

34 DHCS, Medi-Cal Community Supports In Lieu of Services (ILOS) Policy Guide, (July 2023).

35 Cal. Health & Saf. Code §1503.5.

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37 DHCS, Medi-Cal Long-Term Services and Supports Dashboard, (last visited Oct 1, 2024.)

38 California Department of Health Care Access and Information, "Inpatient Hospitalization and Emergency Department Visits for Patients with a Behavioral Health Diagnosis in California: Patient Demographics," (2021-2022).

39 Hwang, Ann, CHCF, "Targeted Use of Agencies for Personal Care Services: Analysis of a Health Plan's Natural Experiment," (July 2023). (During the California Coordinated Care Initiative, a Medi-Cal demonstration pilot, IHSS was administered by Medi-Cal managed care plans in the seven participating counties, and delivered agency-provided IHSS to up to 5% of their IHSS recipients. All counties except for San Francisco returned to independent provider mode in 2018, at the termination of the demonstration.)

40 See for example, Washington state's personal care services, which are available through independent providers, home care agencies, or qualified residential care providers. A statewide third-party agency serves as the employer of record for all independent providers. State laws require pay and benefit parity for all personal care workers regardless of whether they are an independent provider or an employee of an agency. Washington State Health Care Authority, "Medicaid Personal Care Services," (April 23, 2021). (The majority of beneficiaries choose to self-direct their care, with approximately 15,000 beneficiaries receiving services through home care agencies.)

41 See Homebridge History; Burns, Mark (former director, Homebridge) Letter to California State Master Plan for Aging Taskforce, LTSS Subcommittee, "Memorandum Re: Advocacy for Inclusion of Contract Mode IHSS Access for Counties in Master Plan Recommendations," (December 13, 2019).

42 Steward, Andrew, "San Francisco County's Partnership with the Homebridge Training Program: Training the Fragile Workforce," (2015).

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44 San Francisco IHSS Public Authority, "The IHSS Continuum," (last visited Oct. 1, 2024).

45 For more on the disproportionate impact of waitlists on communities of color and LGBTQ+ individuals, see Christ, Amber and Dickman, Hagar, Justice in Aging, "An Equity Framework for Evaluating Home and Community-Based Services for Older Adults & People With Disabilities," (Dec. 2022).

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47 CDSS, Community Care Expansion Program, (last updated Sep. 27, 2024). See also CHCF, "Addressing Medi-Cal Behavioral Health Workforce Shortages Through Non-financial Incentives," (May 31, 2024); CHCF, "California's Direct Care Workforce: Who They Are, the Work They Do, and Why It Matters," (January, 2023).