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An Equity Framework for Home and Community-Based Services: Evaluating In-Home Supportive Services

Webinar Transcript

June 2, 2023

Presenters:

Amber Christ
Managing Director,
Justice in Aging

Hagar Dickman
Senior Attorney,
Justice in Aging

Amber Christ:

Hi, and thank you for tuning into this webinar, An Equity Framework for Home and Community-Based Services: Evaluating In-Home Supportive Services, or IHSS. IHSS is California's personal care program. My name is Amber Christ. I use she/her pronouns, and I am the Managing Director of Health Advocacy here at Justice in Aging. I'm joined by my colleague Hagar Dickman, who is a Senior Attorney with us at Justice in Aging. This webinar is being pre-recorded. Next slide. Just a little bit about Justice in Aging, we are a national organization that uses the power of law to fight senior poverty.

We were founded in 1972, about 51 years ago, here in California, and we focus our advocacy on securing access to affordable healthcare and economic security for those populations who have been denied and excluded from justice, including older women, people of color, LGBTQ+ individuals, people with limited English proficiency, and immigrants. Next slide. We believe that in order to achieve Justice in Aging, we must be committed to advancing equity in all of our advocacy to address the enduring and ongoing harms of systemic racism and other forms of discrimination that uniquely impact low income older adults.

We work to recruit, support, and retain a diverse staff and board to carry out our work. All right, next slide. Moving to today's webinar, for today, we're going to take a look at the drivers of inequities and Medicaid home and community-based services. We're going to review Justice in Aging's HCBS equity framework that we developed to help evaluate and center equity at every stage of HCBS program design, all the way through the provision of services. And then we're going to apply that framework to the IHSS program and identify areas in which IHSS is doing a really great job at providing equitable access to the program and then where there are opportunities for improvement. Next slide.

To begin with, like in healthcare broadly, the systemic drivers of health inequities, racism, ageism, ableism, fascism, sexism, xenophobia, and homophobia, all intersecting are embedded in the laws, in the policy, in governance, and in culture that all shape HCBS programs. In fact, HCBS

programs are particularly prone to inequities. That's because from the outset, HCBS availability or the lack thereof of availability has really been shaped by discriminatory views of people with disabilities of all ages, seeing them as less valuable to society, and that has been born out with attempting to segregate and isolate people with disabilities into confined settings.

And really policymakers enshrined these discriminatory views into federal Medicaid law, which requires states to pay for care that's provided in an institutional setting like a nursing facility or mental health facility, but it makes it optional for states to cover and offer home and community-based services. We really see that inequity baked right in from the outset where home and community-based services are optional and care provided in institutional settings are mandatory. Disabled advocates have really led the effort to address this institutional bias, and that's particularly true here in California.

The In-Home Supportive Services program, IHSS, is 50 years old and it is a testament to disabled advocates' success in obtaining services to remain living at home and in the community. Yet, a lot of work remains. The structural and historical barriers and HCBS programs run deep. We see that what seem to be neutral policies actually maintain a discriminatory status quo, and that status quo remains to be completely inequitable. We see neutral policies that result in racial or other forms of discrimination, a disparate impact on people. Even though maybe the policy wasn't intended to have that impact, it is actually having that impact because has it really been evaluated?

Similarly, implicit bias, biases that occur automatically that affect our judgment, our decisions, and our behavior perpetuate those inequities and retain that status quo. It is absolutely essential that we are intentional and evaluate affirmatively HCBS program policies and rules to ensure that they're not preserving existing inequities and then they're not causing unintended inequities. Next slide. To that end, Justice in Aging has developed an HCBS Equity Framework, and it is really designed to support policymakers, payers, providers, advocates, and HCBS users to make equity a primary focus at every stage of program design and implementation.

I will just note that the evaluation, the tool is not intended to be exhaustive. Instead, we're trying or attempting to provide a starting point and thinking about how we can build and implement HCBS programs and specifically for the purposes of this webinar in the case of In-Home Supportive Services, so that that program is equitably accessible and not leaving people behind, especially not leaving behind those that have been most marginalized due to racism and other forms of discrimination that are so deeply embedded in our healthcare systems and society more broadly. Next slide. The inequities really play out as we look at them in the Equity Framework and five domains.

We try to think about this from the inception of a program, the idea, all the way down to when people are actually receiving services. In program design,

inequities can arise in who is eligible for that program, where programs are made available, what counties are they made available, what services are offered. Inequities can arise in provider availability. Is there an adequate network of providers? Are reimbursement rates adequate enough to have an adequate provider network? Are there investments in training and support and particularly training and support tailored to the needs of the HCBS users themselves?

Inequities can arise in awareness and enrollment. How do people learn about these programs? How do they get enrolled in these programs? What do the application processes look like? How are they assessed for those programs? What do those assessment tools look like? What kind of training did the person who's conducting that assessment receive? Oh, I combined those two a little bit. Assessment and authorization includes... I'm sorry. Domain three is awareness and enrollment about actually enrolling in the programs and how people are enrolled. And then assessment and authorization is about the biases that can arise when people are being actually assessed for services.

And then finally, in domain five, we talk about provision of services, and that those services are person-centered and accessible, and that there are actually quality measures to determine whether those provision of services are meeting the health outcomes that those services are - intended to provide. We're going to move a little bit now into talking about, next slide, applying that framework to the In-Home Supportive Services program. I'm going to hand it over to Hagar to provide an overview of the IHSS program and the basics of the IHSS program.

Hagar Dickman:

Thanks, Amber. As a state plan program, there are no geographic limitations or enrollment caps or wait lists that you see in other home and community-based services for IHSS. Anyone who meets the eligibility criteria for IHSS is going to be able to access the services. Among those criteria are that the individual has to be Medi-Cal eligible, be 65 years old, blind or disabled, live in their own home, and be unable to perform some activity of daily living independently, and then without in-home support due to that inability will be at risk of out-of-home placement.

Personal care services and housework and grocery shopping and accompaniment to medical appointments are some of the services that are provided for individuals in the IHSS program. Recently, the definition of what one's home is has been expanded to include alternative homes, such as temporary shelters, such as homeless shelters or homes of friends and family members, as well as RVs. Before the expanded definition, individuals experiencing homelessness were unable to receive IHSS services, which disproportionately affected Black individuals who make up 25% of the state's homeless population.

The expanded definition allows individuals staying in homeless shelters to receive services, but unfortunately does not include those who are unsheltered.

When it comes to data, the IHSS program has the most robust public data available. It's published on the Department of Social Services website on a monthly basis. And while the program data has been available for some time, CDSS has also included additional equity data on the dashboard. One of the limitations that the data dashboard has is the fact that it only reflects who is authorized for IHSS services and what number of hours individuals are authorized for.

The data does not include how many hours are actually used or how many individuals actually receive services. The data that we do have shows that as a state plan program, IHSS exhibits few disparities when we're looking only at authorized users. This means that the population authorized to receive IHSS is demographically proportional to the overall Medi-Cal population. For example, Black Medi-Cal enrollees 65 years or older or disabled represent 9.3% of the total Medi-Cal population, but are actually slightly overrepresented at 14% of authorized IHSS users.

Hispanic Medi-Cal and release make up 31% of the total eligible population in the Medi-Cal enrollees, and 31% as well of those authorized to receive IHSS. But differences do appear when you look at specific service types, specifically protective supervision is a higher level of IHSS in which an individual demonstrates the need for 24 hours a day supervision to remain living in the home.

Black IHSS users make up 14% of authorized users, but only 10% authorized for protective supervision, while white users make up 29% of total IHSS users, but 34% of those authorized for protective supervision. I'm going to go back to Amber now to walk us through application of a couple of the domains into the IHSS program.

Amber Christ:

Thanks, Hagar. The first domain is that program design element, and that's where we're looking at the design of HCBS programs. Just broadly speaking, that could include county selection or regional selection of where an HCBS program might exist. Obviously there are notable differences in county demographics, population density, and economic differences when we make choices about where an HCBS program is available. For programs that have slot allocation, how many slots are allocated in relationship to a county? Demographics can create inequities. And then wait list administration, how a wait list for those available slots and how people advance on that wait list can lead to inequities.

In program design, really we're thinking about when we're approaching an HCBS program, there are just a hundred decision points that bear out how the program is going to serve people from what benefits are available to where it's located, to who is eligible. Each one of those assistance points is an opportunity for an inequity to rise if we're not affirmatively evaluating it with equity at the center. If we're looking at In-Home Supportive Services specifically, if we move to the next slide, a lot of the inequities that we see in HCBS programs broadly

that are limited or a waiver benefit that include regional differences or cap enrollment, we don't see in IHSS because IHSS is a state plan benefit.

IHSS has no enrollment caps or wait lists. It's available statewide to anyone who is eligible Hagar, if you could just move to the next slide for just a second. If we compare that to, for example, the Assisted Living Waiver, you can see the inequities borne out by the decision to make the Assisted Living Waiver a waiver benefit that limits where it's located, where you can get assisted living, how many people can get it, and then the administration of that wait list. For example, the Assisted Living Waiver was 5,744 slots. It added 7,000 spots. Basically around 12,000 people, almost 13,000 people could possibly be eligible for the program.

Current enrollment today is just 8,785. There are 3,626 people on the wait list, so still trying to make it through. Even though there are available slots, actually getting to that available slot has been a real barrier on the wait list. And then geographically, this Assisted Living Waiver is only available in 15 of the 58 counties. And then where are those Assisted Living Waiver providers exist within those counties, there are also differences. We see real limitations in creating an HCBS program and real inequities arising out of creating an HCBS program that is limited to the number of people it's serving and where it's serving people.

IHSS doesn't do that. One way the state could address some of the inequities we're seeing in our HCBS infrastructure overall would be to make all HCBS programs a state plan benefit. Of course, there's a lot of resources and discussion that would need to be had about that and workforce considerations to take into account, but that would address some of those inequities we see in other HCBS programs from arising. Back to IHSS and program design, IHSS has actually taken some... The program itself has done some work to address some of the inequities that we're seeing.

As Hagar noted previously, the definition of what is considered to be one's own home has been expanded to include individuals who are living in RVs or in temporary shelters or in the residence of another family member. But those who remain unsheltered, who actually represent 70% of those experiencing homelessness in California and are increasingly older adults and people with disabilities, could really benefit from IHSS, yet there's no route for them to receive the benefit at this point. Yet, there are models there. We could see something like Alameda County's bridge pilot be implemented statewide.

This would provide IHSS services to those who are unsheltered experiencing homelessness, making that benefit more widely and equitably available. You could see a real benefit in doing that and making the program far more equitable. Another major area in program design in which inequities are arising is in the availability of IHSS to adequately serve individuals who face barriers to directing their own care. A real hallmark of California's IHSS program is its

commitment to consumer direction. IHSS recipients hire, fire, and supervise their IHSS providers.

That gives great autonomy and independence to people with disabilities of all ages and often the type of autonomy that is stripped away in the healthcare system. IHSS, it's a consumer-driven model at so many critical.... And how you receive your services and in a lot of ways, how the program was even designed. This is absolutely essential and has to be maintained. But where we see inequities arise is when people face barriers to directing their own care. This particularly impacts people with cognitive disabilities, including people with Alzheimer's and dementia. And also, it's compounded by when you don't have a family caregiver.

Right now we know that our HCBS infrastructure does not adequately support people with Alzheimer's and dementia. National data shows that at age 80, 75% of people with Alzheimer's are living in a nursing facility. Compare that to 4% of the population, generally at age 80. 75% of people with Alzheimer's are having to live in a nursing facility. That just demonstrates that our at home system, our home and community-based services are not adequately supporting that population. And that is really critical because this has a disproportionate impact on Black and Hispanic older adults and older women who are experiencing dementia and Alzheimer's at much higher rates.

California to trust this could consider creating targeted alternative models that still provide consumer direction, but also better serve those people who face barriers to consumer direction overall. This has been explored in San Francisco County through the contract mode, so that's one such alternative. That could be piloted in other counties or explored further, or other alternative models could be explored. But regardless of model, the consumer direction piece is absolutely essential and should be maintained at the highest level within any alternative model.

At the same time, any alternative model cannot erode the current robustness of the consumer-directed model as it stands today, but a real area in which we're seeing inequities arise and the availability and adequacy of the IHSS program to serve people who cannot fully direct their own care. Another area within program design if we look at it through the equity framework that could be improved is in the types of benefits that IHSS provides. And that really requires talking to and consulting with a diverse group of people who are using IHSS services. As an example, today under the program, IHSS does not cover reading of mail and other paperwork.

That is not a covered service. This particularly impacts people who have low vision or who are blind, who can't read their own mail, and especially as compounded if they don't have someone else that they're living with, a caregiver or a relative or a roommate, who could do that for them, and then that has compounding impacts. Not being able to read your mail or see that

some change in your healthcare is coming or a utility bill has come that needs to be paid is really problematic for people's overall well-being. Adding that benefit, which advocates have been pushing for, is a demonstration of where the program could more equitably serve the diverse needs of the IHSS population. All right, next slide. Two slides.

If we move to domain two, which is provider availability, what we're looking at here when we're thinking about evaluating through the Equity Framework is things like network adequacy standards. These are typically absent from HCBS programs, but could be used to assess and address disparities and unmet needs. We're looking at infrastructure and workforce investments. Anything from a burdensome process to becoming a provider disproportionately impacts smaller provider types, which are generally serving communities of color or smaller based communities. That can be really problematic.

There's also just thinking about rate reimbursements and where people live and whether those rates are adequate to actually maintain that line of business if it's an organization providing those services or to live. And then caregiver supports for unpaid caregivers. Are there supports for unpaid caregivers? If we look, the next slide, at IHSS specifically, IHSS has always faced issues with having an adequate workforce. However, there's been a lot done to address that. In particular, policy changes made in the early two thousands that allowed relatives and parents and spouses to become IHSS providers really changed the game.

As a result, today 70% of IHSS recipients now have a relative as an IHSS provider compared to 43% just back in 2000. The challenges really though and workforce persist for the 30% of IHSS recipients who do not have a relative IHSS provider. These people have to find the provider using the means that are available. They're relying on public authorities at the county level, their provider registries or the backup registries that are now required to access and find a provider. Going through that process is really cumbersome. This is, again, going to disproportionately impact those without relatives living with them.

Women who live longer, LGBTQ+ individuals, and undocumented immigrants who now under expansion of Medi-Cal can use IHSS, but whose undocumented relatives cannot act as a provider because they can't be an employee basically. They're having to navigate those backup provider registries or provider registries through the public authority. Just that process alone is difficult, particularly for people with complex needs or cognitive impairments, but there's also not enough providers. We're seeing real workforce shortages overall.

I think the data that demonstrates those workforce shortages probably the most clearly is looking at that data that while Hagar noted that's in the data snapshot about IHSS, there's really robust data about who is authorized for IHSS and how many hours they're receiving. What we don't know a lot about how many hours those people are actually using, and the aggregate we know that the number of

hours that are authorized each month that people are not using has increased from 33,000 hours in 2019, so 33,000 hours per month that were authorized in 2019 went unused. That's increased to 40,000 hours a month in 2023. 40,000 hours that are authorized are not being used.

And probably a very large driver of that is the fact that people don't have a provider to provide those services. That is really key data and as Hagar noted where we need more data to actually figure out what's going on there, who are those people whose hours they're not able to use? Like we have on authorized users, what's race, ethnicity, primary language, all of those things that we want to know about, both authorized and utilization of those actual hours so that we can see if there are disparities happening there, and then put in strategies to address them. We also know that turnover rates are high.

It's estimated at 33% annually, and that was in 2019, which was pre-pandemic, which has only then exacerbated the issues. There are some strategies we think that can be used in order to improve equitable access in the provider availability space. Putting in some network adequacy standards. Right now there aren't any in IHSS, so even setting up baseline and then using the data and demographics of the counties to determine what would an adequate network look like, and then what can we do to ensure that adequate network. Putting in place infrastructure investments.

The big thing that California has done using American Rescue Plan dollars is to invest in the program called Career Pathways, and that was aimed at growing the caregiver workforce and improve and just improve provider retention. Yet that funding's about to end. We have heard that the state doesn't intend to continue on Career Pathways because that funding is ending. We really think that that's a really missed opportunity because there's a just such great need for that training and even to expand on that training and supports and benefits that providers are getting through Career Pathways.

And then there's wages. I'm not going to pretend to be a wage expert and understand the complexity of that, but there are real inequities in where wages are too low to attract participating providers. Thinking about what does a competitive wage look like and looking at that through an Equity Framework would help to improve provider availability in the IHSS program. Now, I'm going to turn it back over to Hagar to cover the rest of the domains.

Hagar Dickman:

Domain three really deals with how people find out about a particular program and actually go through the process of enrolling. Only those who are aware of an HCBS program can apply. Disparities in awareness and enrollment are very closely linked. Centralized language accessible and searchable information that's disseminated through diverse hubs where people receive their information, including county services, offices, Area Agencies on Aging and senior centers, local health clinics are all key to ensuring that different communities are reached. Then those who hear about our program can also experience barriers

when application forms are overly burdensome or inaccessible or difficult to find.

Application processes that are overly burdensome or complex disproportionately impact people of color. Really evaluating an HCBS program to see where there are barriers in both finding out about a program and then how to enroll is key to addressing inequities. In IHSS, unlike other HCBS programs, there is wide public awareness of the program, possibly explaining the minimal disparities that appear at least among those authorized to receive program services.

High public awareness may be in part due to the longevity of the program, which has existed in its current form since the '70s, but other factors also may have contributed to public awareness and can be used as a model for other HCBS programs. For example, information about IHSS is both centralized with comprehensive program information and forms that are available on a dedicated section of the Department of Social Services website, as well as disseminated through various channels, including social services offices, Aging and Disability Resource Centers, Area Agencies on Aging, and local departments of aging.

There are some problems though. The information is widely available, but it's not easily accessible for all. For example, application processes vary by county, with some counties allowing direct submission of applications and others requiring a more burdensome referral process. Standardizing application submission processes to reduce burdens and increasing ease for applicants can further reduce disparities between counties and who is applying for the program. And then even though forms are widely available on the CDSS website, information is mostly available in English and only a fraction of the forms are available and a fraction of the 19 Medi-Cal threshold languages in the state.

To ensure that everyone can access IHSS information and programs and different services, all forms should be available on all threshold languages to ensure that individuals with limited English proficiency, as well as individuals with visual impairment can access the forms. Forms would also be available in braille in a large print format. And finally, the state can maximize ease of submission for forms and applications in order to minimize hurdles for the program applicant.

One of the options is, for example, to allow online submissions and online signatures so that people can easily submit their forms, as well as sometimes some counties allow a Dropbox in order for individuals to just leave their forms there at their convenience. Domain four deals really with the implicit bias section of the Equity Framework, implicit bias both in assessment tools and in assessor and in evaluations related to, for example, perceptions of gender in evaluations are related to perceptions of gender, race, ethnicity, or sexual

orientation and is a recognized driver of inequity in healthcare and health outcomes.

Implicit bias can influence level of care determinations that must be met for program availability or eligibility, and such bias can affect whether the assessor finds that the applicant needs and symptoms rise to the level that's required by a program. Needs assessments determine the type and quantity of services that people receive through HCBS programs and can have biases that are built into algorithms on which the tools are based, but also bias in assessor themselves can drive disparities in service allocation. And finally, diagnosis requirements in HCBS programs are vulnerable to the same biases that drive disparities in healthcare.

Like for example, significant delays of dementia diagnosis among Black and Hispanic and Native patients can actually lead to disparities and delays in eligibility for programs that serve individuals with those disabilities or conditions. While we see less disparities in authorized IHSS users, these disparities increase when we examine service allocation, as we mentioned before, specifically for protective supervision, which is the highest level of service you can get in IHSS. One reason may be the implicit bias that might be present in the assessor, which is a social worker and assessment process.

In IHSS, social workers assess what type of service applicants may need and rank that need to direct the number of service hours that are allocated. Although much work has been done to standardize social worker assessments and rankings that influence these hours and types of services, implicit bias can still play a role. Doctor certifications that are required for both IHSS eligibility and to access protective supervision may be affected by the same bias that influence a health access generally.

For example, as we mentioned before, lacks in diagnosing Black and Hispanic people with Alzheimer's and dementia may be reflected and decreased certification for protective supervision, which is a service that's for the most part allocated to individuals with these conditions. Implicit bias can be a set addressed through a holistic strategy that includes oversight through collection and analysis of utilization data that is used to identify actual disparities on where they occur in a particular program or service. Implicit bias training of the assessor, particularly IHSS social workers who are making assessments and evaluating individual need and allocating hours.

And then the inclusion of external applicant provided evidence for eligibility. In the context of protective supervision, for example, many advocates recommend that applicants submit additional documentation such as log of incidents that demonstrate need for the service. The state can actively inform applicants of their ability to submit additional evidence and also give adequate weight to that evidence in order to reduce the effects of implicit bias in third party assessors and help ensure that those who need services may access them.

And finally, the final domain really, oh excuse me, deals with the provision of services, so how are people actually experiencing the services that they're receiving and whether they're actually able to receive the services that they need. Disparities can also arise in the actual provision of services. Many of the services provided through HCBS programs create an intimate relationship between the provider and the recipient. Language access and cultural competency and humility are cornerstones for establishing the trust that's necessary for that type of relationship.

Services that are not provided in recipient's language may be inaccessible, but can also create disparities in the type and the quality of the services provided. Language is fundamental for a person-centered care. Disparities in who is able to receive person-centered care and who's receiving services that may not be appropriate for their needs or preferences can come out of who is able to communicate those preferences and needs and whose needs are respected and observed. In order to identify differences or disparities in the provision of services, we really need to have quality measures in place to assess what are the outcomes for individuals who are not getting those services.

It's very challenging to identify disparities in provision of services for IHSS, because IHSS data, like we discussed, reflects only authorized users and does not identify who among the authorized population is actually accessing services that's allocated to them. The IHSS program also lacks robust service focused quality measures and many of the current quality measures focus instead on the administration of the program and on identifying fraud.

Still, the workforce shortages that are reflected and authorized but unclaimed service hours, long delays between approved and active IHSS claims, and high work turnover can reflect disparities in the provision of services when they're stratified with demographic data, and having that data is really fundamental to be able to assess where those disparities lie. We do know that there are disparities between the number of users who speak a particular language and a number of providers who speak that language, which reflects a gap in service access or possible lower quality of person-centered care.

Assessing those gaps and looking at specifically how many users use a particular language and making sure that there's symmetry between the spoken language of the user and the recipient is an important part of ensuring that people are able to access services. Addressing workforce shortages by increasing wages to a living wage, reducing linguistic and cultural asymmetry between users and providers, and providing ongoing workforce training and development can help support a linguistically and culturally diverse workforce that reflects the diverse population it serves and is able to provide services to users with diverse needs.

The Equity Framework that we just presented is really a way for policymakers and state actors and advocates to center equity throughout program design process. It identifies the five domains that make up the waiver or HCBS program

from the bare bone structure that is created at the onset of program design to elements of provider availability, and then turning to how a consumer is assessed and how potential applicants become aware of the program and enroll, to how they're authorized for services, and finally focuses on the quality sufficiency and accessibility of the services themselves.

In each of these program levels or Equity Framework levels, there really needs to be an ongoing collection of data that's reported and analyzed to be able to allow the advocates and the state to identify and mitigate disparities as they arise. If you'd like to find out more about Justice in Aging's Equity Framework, you can go to our website at justiceinaging.org and look for our briefs titled Equity Framework for California's HCBS Programs. You can also join our network by going to justiceinaging.org and hitting sign up or sending an email to this email address. Thank you very much for joining us today.

Amber Christ:

Thank you.