JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

An Equity Analysis of California's Assisted Living Waiver

Webinar Transcript

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Natalie Kean: Hello and welcome. Thank you for joining Justice in Aging for this training on, An Equity Framework for Medicaid, Home and Community-Based Services, or HCBS. I am Natalie Kean, Director of Federal Health Advocacy, and I'm joined by my colleague Hagar Dickman, a Senior Attorney focusing on California's HCBS programs. Next slide.

So Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable healthcare, economic security, and the courts for older adults with limited resources in California and nationwide. We've been around for about 50 years and focus our advocacy on people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ+ individuals and people with limited English proficiency. To receive trainings like this and other timely resources in your inbox, we invite you to join our network by going to justiceinaging.org and hitting sign up or sending an email to info@justiceinaging.org.

We are committed to achieving justice in aging by advancing equity for low-income older adults in economic security, healthcare, housing, and elder justice initiatives. We work to address the enduring harms and inequities caused by systemic racism and other forms of discrimination that uniquely impact low-income older adults in marginalized communities, and we're committed to recruiting, supporting, and retaining a diverse staff and board.

So today we're going to talk about the drivers of inequities in HCBS or Home and Community-B-ased Services. I'll provide a overview of Justice in Aging's equity framework for HCBS and then Hagar will take a look at applying this framework to California's Assisted Living Waiver program. This work is part of Justice in Aging's California Long-Term Care Equity series supported by the California Healthcare Foundation.

So to start off, when we think about centering equity in HCBS design, it's important to think first about what are the drivers of inequity. HCBS programs are susceptible to racist, ageist, ableist, and other discriminatory policies. These can be embedded in the law itself. For example, the bias in federal Medicaid law towards institutional care compared to home care, or redlining in the housing sector or the policy of Medicaid estate recovery, which disproportionately harms low-income families of color and exacerbates the racial wealth gap. But beyond those biases in the laws themselves, even seemingly neutral HCBS policies and program rules can perpetuate existing inequities or result in unanticipated inequities and disparate impact due to the longstanding discrimination in healthcare and society more broadly. And ultimately, these biases lead to disparities in health outcomes and the quality of life for older adults and people with disabilities.

So Justice in Aging has designed an equity framework to examine how discrimination and biases show up in HCBS. This HCBS equity framework is intended for policy makers, providers, advocates, and other interested parties to ensure equity is a primary focus at every stage of HCBS program designed as well as implementation. There are five domains to this framework, beginning with program design. Then the second is provider availability. Third is program awareness and enrollment. Fourth are assessments and authorization of services. And fifth, on the right side of this chart, it's provision of HCBS. To identify and remedy these inequities, data collection and reporting is necessary at every stage as is indicated by the line across the bottom of this graph.

To really ensure that equity is a focus across all stages of program design and delivery, policy makers, providers, advocates, and all of us should be evaluating the impact of a policy or program, what the impact would be or on a specific and population or particularly populations with intersectional identities such as older adults who are LGBTQ individuals, immigrants and people with limited English proficiency, people with disabilities, people living in rural, urban, suburban, and tribal regions.

Inequities can occur in each or all of the five domains. The first domain starts at the high level looking really at the structure of a program, how the program is designed. And specifically, here, we're looking at decisions that are made regarding the framing of the HCBS as program around who is eligible, where and how the program operates and what services will be provided. The second domain provider availability is also system-wide and focuses on measuring disparities in access to providers and on the policy decisions that would influence that access, including reimbursement rates and investments or disinvestments that could drive inequities.

The next three domains focus more on the enrollee. The third domain, awareness and enrollment, looks at the state's communication efforts that would raise awareness of HCBS programs and how to access them. The fourth, assessments and authorization, looks at the presence of disparate impact and

implicit bias in state tools and processes for consumer eligibility. And finally, the provision of services domain looks at access to person-centered quality care, examining language access, cultural competency requirements and training, and the need for quality measures that identify disparities in quality to actual care.

So these are some of the inequities that we have identified in California's HCBS programs, just to illustrate. Overall, across California's HCBS programs, we see that two in five older Californians who report needing help at home are either receiving no help at all or not enough help. And black older adults report the highest levels of unmet need. More specifically in certain programs, we see that 30 of California's 58 counties have no community-based adult services, or CBAS providers, and most of these counties without CBAS are rural. So another example, Hispanic individuals make up a disproportionately low share of assisted living waiver users, about 11% of people in the assisted living waiver compared to their share of the Medi-Cal population at 30%. And today Hagar is going to walk us through an analysis of California's Assisted Living Waiver using the equity framework. Hagar.

Hagar Dickman: Thanks Natalie. So I'm going to give a little bit of background about California's Assisted Living Waiver and then delve into the equity framework and give some examples of how to use the framework and specifically how to apply it to the assisted living waiver, as a case study.

California's Assisted Living Waiver provides a variety of personal care and other services to individuals 21 years or older who require a nursing facility level care and have full scope Medi-Cal without a share of costs. Some of those services are personal care, chore and companion services, medication oversight, therapeutic services, and 24 hour onsite direct care staff. To receive waiver services, participants must move into a residential care facility for the elderly, or RCFE, or adult residential facility, where they can receive 24 hour care from the facility itself or publicly subsidized housing, or they can receive care from a registered home health agency. Only eight publicly subsidized housing settings are enrolled in the waiver and all are located in LA County and served by one home health agency. The assisted living waiver is limited to 15 of the state's 58 counties and is capped at 5,744 spots. In 2022, an additional 7,000 spots were added to clear the waiver's long waitlist. As of January, 2023, 8,785 individuals are enrolled in the program and 3,626 remain on its waitlist.

In 2022, California's Department of Healthcare Services started the work of integrating the Assisted Living Waiver into the Home and Community-Based Alternatives waiver. The department stated that there will not be a waiver within a waiver, meaning that all assisted living waiver services will be provided through the HCBA waiver. Because the HCBA waiver is statewide, the result of the integration will be to expand all assisted living waiver services statewide as well. The aim of both our paper that is the background to this webinar on equity analysis for assisted living waiver and for this particular webinar is to use the equity framework to identify sources of inequities within the current assisted

living waiver and to recommend areas in which these can be addressed through the integration. In the rest of the webinar, I'll walk you through the five equity framework domains, identify the ways these domains appear in the assisted living waiver and discuss some opportunities for improvement in the integration.

The first domain in the equity framework that we identified as a place where disparities can arise in HCBS is program design. Unlike benefits offered under the state plan, waiver programs do not have to provide services statewide, which requires states to make decisions about which counties to include in the waiver or when there are limited slots, how many to allocate to each county, and when there are more applicants than slots, how to administer a waitlist. These decision points can give rise to inequities. For example, demographics, population density and economic differences between counties can translate into disparities when wealthier white counties get more spots per capita than dense low-income counties or counties with high proportion of persons of color.

The decision to have capped enrollment and geographic limitations in assisted living waiver contributes to disparities in the waiver by limiting both how many people can access the program and where they must live. Currently, around 8,000 individuals are enrolled with 3,600 on the waitlist. The impact of limited enrollment and long waitlist is greater on those who do not have the means or support to continue living in the community while they wait for a slot. For example, LGBTQ plus older adults are more likely to live alone, be socially isolated, and have less family support disproportionately leading to a reliance on long-term care and can be more adversely effective by policies that require help at home while waiting for additional care or support.

Disparities can be reduced by removing or increasing these caps to meet the needs and demands of the statewide population. Geographic restrictions further reduce access to the Assisted Living Waiver program, which is currently available in only 15 of the states counties. Nearly 20% of California's Medi-Cal eligible older adult and people with disabilities population live outside of these 15 counties, meaning that they have no access to it, which can lead to disparities in who can and cannot access the program. With the integration of the two waivers, the Assisted Living Waiver services will be available statewide. But as we'll discuss shortly, disparities can persist with statewide expansion if investments necessary to expand services do not ensure that the expansion reduces disparities rather than exacerbate them.

Next element or domain in the framework is provider availability. Decisions that affect provider availability may also lead to inequities in HCBS in access, because disparities in access arise when there are not enough service providers. Network adequacy standards that evaluate the sufficiency of provider availability in managed care, for example, are largely absent from HCBS programs. Adequacy standards can help determine whether there are disparities in provider

availability, particularly as a source of unmet need. Investment that is directed to only some communities and leave out others lead to disparities as well.

Inequities could arise if the process for applying and being awarded funds is overly burdensome for small community-based organizations best suited to serve diverse communities. Inequities can also arise based on the location of approved and funded providers. For example, residential care facilities for the elderly are disproportionately located in more affluent and white communities. If only existing RCFEs are awarded funding or receive a disproportionate amount of funding inequities persist. Finally, unpaid caregivers make up a central role in supporting older adults and adults with disabilities. HCBS programs often provide support for unpaid caregivers and disparities can arise in who hears these supports and who's able to access them.

So looking at just a couple of these, like most of HCBS programs, the assisted living waiver does not have a provider network adequacy standard, which could be used to identify one community's experience, know or reduced availability of waiver services, inequities and the type of services available and the distance participants must travel to access programs. The waiver integration is an opportunity to build data collection and publication into the waiver application, which can help the state assess whether sufficient waiver bets are available equitably across communities and demographic groups on an ongoing basis. This kind of data can also help inform future infrastructure investments to ensure that such investments are reduced rather than worsen inequities.

Administrative burdens in assisted living waiver make it difficult for community-based organizations to become enrolled providers, which can also impact availability of services. This is because these smaller organizations also have small staff size, narrow skill sets, limited resources or financial instability, which make it difficult to navigate processes for becoming a waiver provider. And they're not helped by out-of-date and difficult to access state manuals and support materials. The integration is an opportunity for the state to update provider manuals and enrollment materials, providing robust technical assistance and clear state guidance both in the application process and for ongoing compliance with changing regulations could help these small or lesser resourced organizations provide necessary high-quality resources in underserved communities

Because only those who are aware of an HCBS program can apply, disparities in awareness and enrollment are closely linked. Centralized language accessible and searchable information that is also disseminated to diverse hubs where people receive their information, including county services offices, agencies on aging, senior centers and local health clinics are all likely to ensure different communities are reached. Also,

Another element is application forms. Those who hear about a program can also experience barriers when application forms are overly burdensome, inaccessible

or difficult to find, and application processes that are overly burdensome or complex disproportionately impact people of color. And finally, information about waitlist policies and placement can also drive disparities. And when applicants depend on waiver agencies for communication and waitlist placement, there can be inequities in the information and services received from one agency to another.

Communication is particularly problematic for the assisted living waiver. Very little consumer facing information is available from the state and the information that is available is inaccessible to non-English speakers and individuals with limited English proficiency. Most applicants find out about the waiver through word of mouth or from agencies who steer individuals towards the program. Those communities that are already connected to services are more likely to find out about this program, and communities that are underserved are less likely to be made aware that it exists. The lack of centralized information and the reliance on word of mouth increases the role of agency discretion, and as a result, the risk of implicit bias influencing who finds out about the program. For example, a person or family member may call an agency for assistance and the agency may identify the caller as a good candidate for the assisted living waiver and inform them about it. Implicit bias can heavily influence who is told about the waiver and who is not.

Intentional community outreach can be an opportunity to increase awareness among potential applicants. A state-initiated community facing website and equity centered communication strategy informing potentially eligible individuals about the program and how to apply, which includes high quality consumer friendly materials translated into Medi-Cal's threshold languages, and a comprehensive and accessible website and in-person non-web outreach efforts through community-based channels can all improve awareness among communities that may otherwise lack awareness. Requiring agency or outreach plans that are monitored together with close disparities monitoring of submitted applications can help ensure equity is front and center in agency outreach efforts and that potential disparities in who applies are tracked and addressed.

Finally, the assisted living waiver currently has no application forms and applicants are not able to initiate their own waiver application. Instead, they must rely on agencies to collect and submit their application materials and documents to the state. Creating a universal home and community-based services application can empower consumers to initiate their own application and help identify potential eligible consumers from a larger, more inclusive pool of individuals.

Implicit bias, both in assessment tools and an assessor as well as in evaluations related to, for example, perceptions of gender, race, ethnicity, or sexual orientation is a recognized driver of inequity in healthcare and health outcomes. Implicit bias can influence level of care determinations that must be met for

home and community-based services eligibility. Such bias can affect whether the assessor finds that an applicant's needs and symptoms rise to the level required by the program. Needs assessments that determine the type and quantity of services people receive through these programs can have bias that may be built into an algorithm-based tool, but also bias in assessor themselves can drive disparities in service allocation. And finally, diagnosis requirements in HCBS programs are vulnerable to the same bias that drives disparities in healthcare, like for example, significant delays in dementia diagnosis among black, Hispanic, and Native patients.

Because of the long and complex enrollment process, waiver agencies report using an unofficial screening process that varies by agency and prevents potentially eligible individuals from applying for the assisted living waiver program. Different agencies may create their own discretionary screening processes that may prevent individuals from being formally evaluated for the program through its own formal assessment tools when they're determined to, for example, not be a good fit for the waiver. Each agency may determine whether an application goes forward based on subjective criteria. Because screening occurs prior to the state's application process, it lacks transparency in state oversight. These informal practices are prone to implicit bias. Racial, ethnic, ableist, sexist, or homophobic considerations may all influence this type of discretionary decision-making about who might be well suited for referral and enrollment in an HCBS program and can play a significant role in who is informed about the programs and services that should be available to them.

Instituting a universal HCBS application form can remove this type of discretionary screening by empowering individuals to initiate their own application, which also would create appeal rights that do not otherwise attach at this point of the process. Those individuals who get access to the application process must meet the program's level of care. The waiver requires enrollees to meet the state's nursing facility level of care and bias in the assessor influence whether a person's needs health status or impairments are recognized as rising to that level. State monitoring and oversight, coupled with a robust training program, can help identify and address disparities in who meets this level of care and can access the program.

Finally, 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, and language access and cultural competency and humility are cornerstones for establishing the trust necessary for that relationship. Services that are not provided in the recipient's language may be inaccessible, but also can create disparities in the type and quality of services provided. Language access is a fundamental aspect of person-centered care. Disparities in who is able to receive personal centered care and who is receiving services that would may not be appropriate for their needs and preferences can result from who is actually able to communicate their preferences and needs and whose needs are respected and observed.

Similarly, services that do not take into account cultural preferences, unique needs and experiences of the recipient are not personal centered and can reduce both quality of care and access to services of particular groups. Finally, quality measures that track disparities and the quality of services rendered to marginalized communities must be a part of every home and community-based service system. Quality measures that need to look beyond disparities in utilization and should be aimed at assessing disparities in the type, amount and outcomes of those services.

Unfortunately, the assisted living waiver overall is not accessible to individuals with limited English proficiency. Forms, manuals, applications and assessments are all in English and waiver agencies must engage a translator to meet linguistic needs of those with limited English, which creates an additional hurdle to service access. The lack of state oversight and enforcement means that there is no data to assess whether translators are in fact being provided. In the integration, the state can require agencies and providers to adopt language access plans that explain how language needs of the potential recipient in their service area will be addressed. The state could monitor the implementation of those plans including using, for example, secret shoppers and participant surveys.

Finally, the assisted living wave lacks any meaningful quality measures that reflect the relationship between care delivery and health outcomes. The program also lacks grievance procedures that would allow recipients to address quality failures and to alert the state to quality disparities. To identify disparities in service quality, the state needs a mechanism to receive, record and track user experience through, for example, grievance procedures and user surveys. Disparities in user experience are particularly important to track, given the intimate nature of care services provided under the waiver and the vulnerability this intimacy creates for recipients. LGBTQ+ individuals, for example, are particularly vulnerable to ongoing discrimination in their daily care. Misgendering, including harassing and willful use of incorrect pronouns is a particular issue for individuals relying on care in residential settings. Creating a mechanism to track disparities in hours of care, delivered incidents of hospitalization, program discharge, injury, and death, staff to resident ratios, user experience, and the procedure for grievances and resolutions can help both identify disparities and quality and address them.

As a summary, the equity framework is a way for policy makers, state actors and advocates to center equity throughout program design processes. It identifies five domains that make up a waiver program from the barebone structure that is created at the onset of program design to elements of provider availability, and then turning to the user to assess how potential applicants become aware of the program and enroll, how applicants are assessed and services authorized. And finally, looking at the quality sufficiency and accessibility of services themselves.

If you have any questions, you can email us at hdickman@justiceinaging.org and you can also go onto our website to review the papers that we've drafted in support of this webinar. Thank you.