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Free Webinar: Using an Equity Framework to Evaluate & Improve Medicaid Home and Community-Based Services (HCBS)

Webinar Transcript

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Amber Christ:

Give it a second for folks to log on. All right. Hi, everyone, and welcome to today's webinar, Using an Equity Framework to Evaluate & Improve Medicaid Home and Community-Based Services. 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 colleagues today, Gelila Selassie, senior attorney, and Natalie Kean, our director of federal health advocacy.

Before we jump into the contents of the webinar, I want to cover a few housekeeping items, if we move to the next slide. All participants will be on mute today. If you have any questions, please use the question function for substantive and technical concerns. If you have for some reason been kicked off of the webinar or are having issues with getting back on, you can send an email to trainings@justiceinaging.org. Following this webinar, you will find a recording and the slides from this webinar as well as past trainings on our website and our resource library, and we also have a Vimeo page where those recordings are located.

Just a little bit about Justice in Aging on the next slide. We are a national organization that uses the power of law to fight senior poverty by securing affordable healthcare and economic security for low-income older adults. We focus on fighting for people who have been marginalized and excluded from justice, including older women, people of color, older LGBTQ+ individuals, and older immigrants and people with limited English proficiency.

In order to achieve justice in aging, we are committed to advancing equity for low-income older adults by addressing the enduring harms and inequities caused by systemic racism and other forms of discrimination. We do this both in

how we approach our advocacy and through our organization's efforts to recruit, support, and retain a diverse staff and board.

Turning to today's webinar, we are going to start off with a quick overview of Medicaid home and community-based services. I'm then going to turn it over to Gelila to discuss the inequities in accessing HCBS, and she's going to provide an overview of Justice in Aging's HCBS equity framework. And then Natalie's going to walk through the framework's five domains with examples of how to center equity from the initial design of an HCBS program to the provision of services. And then we're going to leave some time, we hope, for some questions-and-answer time and discussion.

So starting off with an overview of HCBS. So first, what are home and community-based services? HCBS is an umbrella term that encompasses long-term healthcare services and supports provided to people in their own home or in an integrated community-based setting. The list of HCBS are long. And this isn't exhaustive, because the types of services people need are a lot.

So some common examples of HCBS-covered services are things like home health, personal care to assist with activities of daily living, so things like getting dressed or bathing, transportation, homemaker and chore services, things like helping cook with meals or clean, case management, financial and legal services, home repairs and modifications, things like grab bars or ramps, adult daycare group or center-based day supports, assisted living. The list goes on and on.

If we turn to the ways in which home and community-based services are authorized through Medicaid, first it's really important to know that with the exception of Medicaid Home Health, HCBS are optional for states to provide in their Medicaid programs. In other words, states do not have to provide any HCBS to those enrolled in Medicaid other than the home health benefit. Of course, states are offering HCBS, but they are optional. This is different than nursing facility care, which is a mandatory benefit under Medicaid. So states have to provide care in nursing facilities. But again, with the exception of home health in Medicaid, states do not have to offer HCBS.

Gelila and Natalie will discuss this more, but the fact that these benefits are optional give rise to a lot of inequities we see in access to these services, both within a state and to certain populations and people with certain disabilities and also the variation we see across the country from state to state. It also means that the way that HCBS are authorized under Medicaid law is incredibly complex. There are a lot of different ways in which states can authorize HCBS. So we're going to walk through those very briefly. I will point you to the fact that Justice in Aging has an HCBS primer that goes into a lot more detail about HCBS. Again, it's a very complex set of authorities for states to use to authorize HCBS with a lot of complexity about how those services are delivered.

But the first broad way that states can authorize HCBS is through the state's Medicaid state plan. A state plan and Medicaid is the agreement between the state and the federal government, because Medicaid is the shared partnership. And in that agreement, the state agrees to abide by federal rules. The state plan sets out which groups of people are going to be covered under Medicaid in the state. It sets out what services are going to be provided. It sets out how providers are going to be reimbursed for providing those services and other administrative activities.

So under federal law, the only benefit, like I've mentioned before, that is required under the state plan that's HCBS is the Medicaid Home Health benefit. That is mandatory. Other HCBS we often see in a state's Medicaid state plan is personal care service. So those are the two big ones that we typically see in the state plan.

In addition to the Medicaid state plan itself, there are a number of specific HCBS state plan authorities that states can use to provide HCBS statewide. Those are the 1915(i), 1915(j), and 1915(k) options. Those are the statutory provisions in which these authorities live. So these HCBS-specific authorities allow states flexibility in who they can offer HCBS to under the statewide, so what populations, and also flexibility in what HCBS benefits are offered. But regardless, they have to be offered statewide under the state plan options.

Meanwhile, if we go to the next slide, HCBS can also be authorized under what are called Medicaid waivers or HCBS waivers, and the most common are the 1915(c) waiver and the 1115 waiver. And when we use the term waiver, the reason we're using that word and why Medicaid uses that word is because states can waive pretty much any part of the Medicaid federal law in developing these programs.

So for example, under an HCBS program under a 1915(c) or 1115 waiver, you can cap the number of people who are enrolled in the program. That's why we see long wait lists for HCBS programs, because states can cap how many people can get them. You can't see that. That's not available in the state plan. If you're eligible for a service under the state plan, then you're eligible for the service. There are no wait lists for services. But under a 1915(c) or 1115 waiver, these programs can be capped.

They can also be limited geographically. For example, they can be available in certain counties or regions in the state or even certain zip codes. So you'll see variation of whether these programs are available in certain parts of the state. And also these waivers can be tailored to specific populations. So we see people with intellectual and developmental disabilities having one waiver. You might have a waiver that's for people who are 65 or over. You might have a waiver for traumatic brain injury. So the waivers can be tailored to certain populations.

And of course all of those things can be true at the same time. So you can have a waiver that is for a certain population and capped at 2,000 people. Or most recently we saw a waiver that Wyoming's proposing that would have a cap of 350 people. So lots of ways that these waivers can allow the states to change eligibility and enrollment in the programs. Additionally, the waivers can have higher financial eligibility, and this is called the special income rule. So you see people being eligible up to three times the rate of the supplemental security income benefit, so three times SSI. So lots of different ways that states can structure these HCBS waivers.

If we go to the next slide, we can take a look at the utilization of these different authorities. The most common HCBS authority is definitely the 1915(c). Well, of course home health because it's mandatory. It's in all of the states and territory. Or no. States here. 51 states and Washington DC. But then we also have the 1915(c), which is serving almost two million people. And then next to that we have personal care services under Medicaid state plans, and that's about 1.2 million people.

But you can see here there's about 47 states that are offering at least one 1915(c) waiver. You have 37 states offering personal care under their state plan. And these aren't mutually exclusive. A state can have multiple 1915(c) waivers and also have an 1115 waiver and also have a personal care benefit under the state plan. And these aren't unique users. Some of these users, as long as services aren't being duplicated, can be receiving services under multiple HCBS authorities or programs under multiple HCBS authorities.

So lots of variation in what states can do and what authority states can use. But that's really complicated. So just the way in which states can choose how to offer their HCBS through just the decision of what federal Medicaid authorities are going to use is ripe for inequities.

So I'm going to turn it over to Gelila now, who's going to summarize some of those gaps and inequities in access to HCBS and then provide an overview of the HCBS equity framework that ... Its goal is to help policymakers, advocates, and HCBS providers address some of those gaps and inequities.

Gelila Selassie:

Great. Thank you, Amber. So as Amber mentioned that we'll be discussing some of the inequities that are present in our HCBS system. And I'll start with an overview of the framework before Natalie dives into each of the domains. And so next slide.

And as Amber mentioned, HCBS is an optional benefit, which because of that leads to many significant gaps in how people are able to access care. For mandatory Medicaid benefits, states are required to cover all people who are eligible, regardless of the cost to the state. However, because HCBS is optional, states can limit the number of people who are able to enroll, even if they are

eligible, which is why we see such a huge waiting list for a lot of these programs, which is currently at about 656,000 people nationwide.

And as concerning as this number is, there are a lot of other factors to consider that isn't captured by the waiting list. There's a lot of people, for example, who may not be aware that HCBS exists, and so they're not even applying, but they still have unmet needs that should be provided for. Or there are people who may have started applying or may have looked into applying but were deterred because of this massive waiting list where it would take months or years to even begin rendering services, so they may not even bother. And none of this is really captured well in the existing data that's looking at unmet needs.

And so this process is referred to as that institutional bias, where because it's so much harder to get guaranteed Medicaid services through HCBS, as opposed to an institution, people are often forced into the institution to receive Medicaid-funded long-term services and supports.

And the fractured nature of HCBS waivers and state plans, as Amber mentioned, also leads to a lot of variation across states. Even with required Medicaid benefits, there's still already a fair degree of variability, because there's a federalized standard, and then states can go beyond that standard. But with HCBS, there isn't really a great federal standard. There's very minimal. And so you see those variations much wider across states and even within a state across populations, and that leads to a lot of confusion as well for beneficiaries.

And then lastly, there are a lot of delays in services for HCBS because it isn't a mandatory benefit. Nursing home coverage or institutional Medicaid is required to have prompt and retroactive coverage. So for example, if someone's in the hospital and has a stroke or a fall and they're determined to need a nursing home-level of care, they can apply for Medicaid and then be immediately sent into a nursing home, and the nursing home will accept them because they know that Medicaid will cover any retroactive period that they're eligible for.

However, if that person with that exact same situation decided, "Hey. I'd rather receive my long-term care at home or in the community," they would have to apply, and they very likely would not be able to get services right away, because there's no retroactive coverage, and very few HCBS providers are able or willing to render services until Medicaid is approved, because they would have to absorb those costs. And so that is another huge challenge, and we have a wonderful brief with a link here that delves into that a bit more.

Next slide. And so now we'll look at how some of these gaps can perpetuate a lot of these inequities based on all sorts of demographics, like age, disability type, race, geography, and other factors. So one example is that two out of every five adults in California report having little or no support at home, with black older adults reporting the highest level of unmet needs. And because of these unmet needs are unavailable because of a lot of the complexities of our

long-term care infrastructure, most people end up relying on informal or unpaid caregivers such as family members or friends.

Only 13% of people who need HCBS receive paid support, and 92% receive unpaid support. And so this 92% number is really high, because even among that 13% who have the paid caregivers, those paid caregivers aren't sufficient enough to meet all their unmet needs. So you see that there's a lot of informal support being provided, particularly when people have no paid support, but even when they do, the amount of support they're getting from Medicaid is still usually not enough.

Next slide. And so we can see that there are further inequities that exist among black and Hispanic or Latinx families because of the financial strain of caregiving. Without adequate support from Medicaid through HCBS, families are required to spend more of their income on long-term care expenses. And black and Latino families spend between about one third to nearly half of their income on out-of-pocket expenses, while all individuals typically spend about a quarter of their income towards long-term care.

And because of some systemic inequities and systemic racism, we know that a lot of these families from black and Hispanic backgrounds often have lower incomes, and so that just further perpetuates inequities when it's compounded in long-term care, because what little income that's received ... A greater proportion of it is having to be spent on long-term care.

And then lastly, as we discussed in the previous slide, is that family caregivers are playing such a vital role to meet some of the needs and some of the gaps that exist in our formal paid caregiving system. And this is particularly problematic because older LGBTQ adults and older black women are more likely to live alone and are less likely to even rely on those family or informal supports. And so again, that widens the gap of unmet needs for some of our most marginalized groups.

Next slide. And so we're going to break down a bit more into how inequities can occur based on the specific populations that are impacted. For example, advocates have frequently noted that spending on LTSS has been, quote unquote, rebalanced in favor of HCBS over institutions, and that means that more Medicaid dollars are going to HCBS as opposed to institutions.

And while that's great overall for the entire Medicaid enrolling population, the case is not quite the same for older adults. In fact, about half of states spent twice as much on institutional care for older adults than they do on HCBS. And all states spend an average of 35% of the LTSS dollars towards HCBS, as opposed to 56% for all Medicaid populations. So you can see that older adults are receiving significantly less dollars towards HCBS, which is a huge inequity for a population that desperately wants to age in place and receive services in the community.

Relatedly, the variability in Medicaid waivers can worsen inequities, depending on the state. Only eight states spend more than 50% of LTSS dollars on HCBS for older adults, with the lowest spending occurring in Iowa, where only 10% of Medicaid LTSS dollars goes towards HCBS for older adults. In the highest three states of Washington, Oregon, and Minnesota, we spent 70%. And while that 70% number is high, you can see how when states like Iowa are contributing as little as 10%, that really drags down the average to well below 50%.

And next slide. And then finally, there are many inequities in HCBS access that impact older adults of color. Demographics and particularly race and ethnicity data are really hard to find and are very limited and hard to measure, again, because HCBS is so fragmented and there's not really a clear standard across states.

However, one of these measures that we are able to find these correlations with that determines some of these inequities exists when we look at the trends in nursing homes. And so over the past couple decades, nursing homes have ... Older white adults are entering nursing homes much less in favor of less institutionalized care. However, older adults of color are really growing in nursing homes. There's much more older adults of color proportionately than there are white older adults, which suggests that these populations, older adults of color, are not receiving adequate supports for non-institutionalized long-term care.

Relatedly is that we're seeing that a huge majority of adults with dementia or Alzheimer's are residing in a facility by the age of 80. About 75% of people with dementia are in a facility by the age of 80, compared to just 4% of the population reside in a facility by age 80. And the reason why this might have some racial implications is because Alzheimer's and dementia are much higher and much more prevalent for black and Hispanic older adults. Black older adults are twice as likely to get dementia and Alzheimer's, and Hispanic older adults are one and a half times more likely to be diagnosed with Alzheimer's dementia, compared to white older adults.

And so again you can see that based on these factors, the growth in nursing homes and the fact that certain conditions like dementia are much more prevalent based on race, that that is also leading to a lot of inequities when a lot of these individuals could be receiving that dementia care and related services in the community.

Next slide. And we're just going to dive into just some of the basics of the framework before I turn it over to Natalie. Next slide. And so as we mentioned, we have this wonderful framework that looks at centering equity in the design of HCBS programs by looking at the drivers of inequity like racism, ageism, sexism, homophobia, xenophobia, ableism, and classism. And we're looking at how these inequities are embedded either in the law itself, like what's written

down in the statutes or in the regulations, as well as the program policy and design or even the implementation of HCBS.

So some of these inequities can occur based on how the law is written, sort of like the institutional bias. They can exist in how the program or policy is actually designed at the state level. Or it can come off appearing very equitable, but when these policies are put into practice, you see a lot of these inequities. And HCBS programs are susceptible to racist, ageist, ableist, and other forms of discriminative policies that could be embedded in the law itself. And that's, as I mentioned, is where the inequities in the law occur. And these neutral HCBS policies can often be based off of structural or historical barriers, disparate impact, or implicit biases. And so we're keeping these factors in mind when we go through the HCBS equity framework.

Next slide. So the HCBS equity framework is intended as a tool to center equity in HCBS programs, design, or policy and the impact it'll have on specific groups. And so to ensure equity is a focus across all stages of HCBS program design and delivery, policymakers, providers, advocates, and really all other interested parties should evaluate the impact that the policy or program has or would have on specific marginalized communities, including communities that live at the intersection of these multiple identities, so older adults, people with disabilities, communities of color, women, LGBTQ+ individuals, immigrants, individuals with limited English proficiency, and then individuals across all living settings, so urban communities, rural, suburban, and indigenous and tribal regions as well. And this is just a starting point and we have sort of a visual description, a visualization of what these programs look like. But I will break it down a bit further if we can go into the next slide.

And so as I mentioned, the framework is broken down into five domains where inequities arise and should be addressed. The first is program design, which looks at who is eligible, where the programs are available, and the types of services that are offered.

The second is the provider availability, which is focused on the inequities and access for providers, so things like network adequacy, reimbursements rates, and the types of training and support providers receive in order to be able to be retained in the profession and provide the best care to older adults of all backgrounds. And this is particularly important in the last couple years because we've seen a really high rate of turnover for the direct care workers that's providing the bulk of HCBS for older adults and people with disabilities.

And then it's a bit of a twofer because a lot of people who are providing the support are people who are from our historically marginalized identity. So a lot of women, a lot of black women, immigrant women, women of color are really the backbone of the HCBS services, and so making sure that the provider availability is crucial and that there's adequate support for providers is

necessary not just for the providers, but also for the beneficiaries who are relying on these providers to provide quality care.

The third is program awareness and enrollment, and this looks at the type of education and communication that is available to members of the community so that people actually know that these programs exist and are able to apply.

The fourth is the assessments and authorizations of services, and that's how we determine if and how biases impact the number of hours or types of services that are approved. In many instances, this could be implicit bias. This could be cultural biases, for example, for people who live in multi-generational households and whether the reliance on informal caregivers may impact how many hours they're given. And so that's another really crucial aspect of the framework.

And then we also are looking at the provision of HCBS in terms of how it appears for person-centeredness and services, accessibility, and quality measures. And so this isn't just looking at who is receiving services or how many hours are they getting or the types of services, but also are they receiving quality services. Is older adults being centered? That's a big aspect of HCBS is person-centered care and not making it super clinical or institutionalized the way someone receiving institutional care would be. And so that's a really important aspect too is that they're receiving high quality care.

And then data is sort of underlying in all of these things. So data is on that previous slide where we had the arrow data sort of covering all of these domains, because it is key not only to letting us know where these inequities exist, but also in making sure that there's transparency and oversight. Data just for the sake of having numbers doesn't really do a lot for us, but if we're able to incorporate data in all of these domains and all of these metrics, it helps us determine what kind of oversight and policy initiatives are needed so that policymakers can specifically address inequities at each of these levels.

And so with that, I will turn it over to Natalie to dive into each domain.

Natalie Kean:

Thank you so much, Gelila. Hi, everyone. I am Natalie Kean, she/her. I'm the director of federal health advocacy at Justice in Aging. And we're going to walk through each of the domains, and I'll give an example for each of how we use the equity framework to really identify some inequities and potential solutions.

So the first domain is program design, and this is really looking at the threshold decisions that states make when setting up an HCBS program and how and if those are producing inequities. So for example, does the state choose to use state plan authority and make these HCBS services available statewide, or are they choosing to use waivers? If they're using a waiver, as Amber talked about, states can elect to limit where HCBS is provided to certain regions or certain

counties, and this can exclude populations across various demographics and economic backgrounds.

States can also cap enrollment under waivers. So when there are these limited slots, how are states allocating those slots? Are they looking at population centers and demographics to determine how many slots are available in a particular county, for example? And then we look at if the state is providing programs to serve all populations, or are there more programs proportionally that serve people with intellectual and developmental disabilities or older adults and not people with mental health conditions, for example?

The next consideration here is whether people with lived experience are consulted and engaged in designing and refining these programs, and are their needs really being responded to in the way these programs are set up?

We also look at the types of benefits that are covered in the program. So for example, respite care is really essential for people with dementia who may need 24-hour services and often rely on family caregivers. Is that a benefit in an HCBS program?

And then waiver wait list administration. So when there are more applicants than spots available in a program, how does the state choose to administer its wait list? Is it a first come first serve basis, or are people prioritized based on risk of institutionalization or other factors? And if there isn't a wait list, which is often the case for waivers serving older adults, is the state filling all of the authorized slots, and is the need being met?

So we'll look at Michigan's MI Choice Waiver for an example of equity evaluation of program design. So this is a 1915(c) waiver, and it is offered statewide, but the distribution of waiver slots has resulted in inequitable access for people of color.

So Michigan has 50% of their population living in 10 counties, and in one of those counties, Wayne County, 40% of the older adults there are people of color. But when we look at the distribution of waiver slots, we see some disparities. So there's only one waiver slot per 58 eligible people in the most populous counties where more people of color reside, compared to one slot per 20 eligible people in the rest of the state.

Looking at provider availability, disparities and access arise when there are not enough service providers. And as Gelila talked about, there are a variety of reasons for this and a real crisis in the direct care workforce right now. But still there are decisions that states can and should be making to try to consider equity in provider availability. So network adequacy standards that evaluate the sufficiency of provider availability in managed care, for example, are largely absent from HCBS. And states may be developing standards for existing waivers

now, and so it's really important that those standards don't perpetuate inequities that already exist.

States also need to be examining their reimbursement rates. Are they sufficient to maintain an adequate workforce? Do they account for the cost of living, the rural location, for example? Inequities can arise if the process for applying to be a provider is overly burdensome for small community-based organizations who are best suited to serve diverse communities, and this could be a particular issue for adult day and assisted living services where an already established provider might be in a better position to secure the contracts. So looking at whether new providers are able to join. Are underserved areas shrinking or growing? Are geographic disparities in access growing?

And then finally, also looking at caregiver supports. As Gelila mentioned, caregivers play an enormous role in providing HCBS to their loved ones. So if there are caregiver supports, which caregivers know that these supports exist, and are these supports meeting the diverse needs of unpaid caregivers?

So we'll look at New Jersey's Assisted Living Residence program as an example of evaluating the equity of provider availability. So New Jersey, like Michigan, has an uneven distribution of population and people of color among its counties. So there are three counties with the highest older adult populations that are also the most racially diverse. But there are only 24 ALR facilities located in these three counties, compared to 51 facilities in three other counties that are less racially diverse.

So what this amounts to is that there's only 19% of people enrolled in the ALR program living in the three most diverse and populous counties compared to 32% in the less diverse counties. These data really demonstrate that provider availability is inadequate in the state's most populous and racially diverse counties. And it's consistent with research more broadly, finding that assisted living facilities tend to be located disproportionately in higher income and less racially diverse communities.

The third domain is program awareness and enrollment. So here we look first at HCBS program information. Most HCBS programs, which often have their own names or sometimes they're just called the waiver, say nothing about HCBS or Medicaid. So they can be really hard to find or to understand, even if you heard the name, what it does and even harder to navigate. Program information is rarely centralized or searchable. There's no equivalent [healthcare.gov](https://www.healthcare.gov) for HCBS programs, no place where people can go and look for the programs that might meet their needs. And inequities then can arise in who is able to learn about and enroll in these programs, and it tends to favor people with more resources, including more connections.

We also want to look at the education by enrollment entities. So inequities can arise when the agencies or organizations that are responsible for processing

enrollment do not consistently describe the program or promote the program awareness or application processes, possibly due to implicit biases or also just to a lack of understanding about the programs and who might be eligible.

HCBS application forms also are not easily found and usually not available online. They are typically complex and long, and inequities can arise when people who need services cannot find the application, or when the applications themselves are inaccessible, for example, if they're not in language or large print or if that application process, as is often the case, is overly burdensome. And here we want to also be looking at what support is available to help people apply, and is that support equitably and readily available?

So for an example with this domain, we'll look at California's Assisted Living Waiver. So the ALW operates in 15 counties and has more than 4,700 people on its wait list, but we know that the need for these services is much greater. Unfortunately, many people do not know that the ALW program exists, especially in underserved communities. There's very little consumer-facing information available about the ALW, and the information that is available is inaccessible to non-English speakers, and so most applicants are finding out about the program through word of mouth or from agencies who steer them towards that program. So the communities that are already connected to the services are more likely to find out about the program to begin with, and people in underserved communities are less likely to be made aware that it even exists.

Implicit bias can also play a role here in who hears about the program and who doesn't. So a particular waiver agency may make a decision to provide information to a particular potential applicants. Or if an individual calls an agency to inquire about getting assistance with care needs, the agency may identify the color as a poor fit for the Assisted Living Waiver because of limited English proficiency, cultural preferences, or racial bias and refrain from informing them about the waiver as an option.

And making these problems worse, the ALW currently has no application forms. So individuals cannot initiate their own applications. Instead, they have to rely on these agencies to collect and submit their information and documents to the state. And people who do apply often have to wait two years or more to get services.

Moving on to the fourth domain, assessments and authorization of services. The assessment tools used to determine HCBS eligibility and services can be biased. Most rely on algorithms or other automated decision-making, and they're subject to the same types of racial and gender biases that these tools are subject to in other areas of healthcare. Further, the people who are conducting assessments may also have their own biases, both implicit or explicit, that affect the process and outcome.

So there are really two main places in the HCBS enrollment process where these tools are used. The first is the HCBS level-of-care evaluation, so eligibility for HCBS in addition to financial eligibility. You have to meet a certain level of care, and for most programs, that's a nursing facility level of care. So an inequity can arise in determining whether applicants meet those level-of-care requirements, particularly for people with mental health disabilities, developmental disabilities, or dementia, which, again, as Gelila mentioned, disproportionately impact black and Latino older adults.

And the second place these tools and assessments are done is in the needs assessment. So after being found eligible for an HCBS program, individuals are assessed for the types and level of services they will receive. Here, inequities can arise in the tool assessing an individual's needs or ability to participate in a program, or when the person doing the assessment has a subjective bias. So they may be looking at things like presence of family caregivers and what is culturally appropriate or missing what is culturally appropriate. They may not be considering that more time should be allowed for language assistance for a recipient, for example.

So the example we'll use here is the Medicaid Money Follows the Person program, or MFP. This is a program that helps older adults and people with disabilities of all ages move out of institutions and into the community. And it's been a really successful program. Over 45 states and territories have had these programs, and many still have them. Some states are even starting new programs. But what we see is that even though it's been successful, people age 65 and older are accessing this program at a disproportionately lower rate than younger people.

So 64% of people in nursing facilities and other institutions are over age 65, but they account for only 36% of MFP participants. And this disparity could be, in part, a result of age bias intersecting with disability bias in assessing who is identified and deemed appropriate to participate in the program. Unfortunately, race, ethnicity, and other demographic data is not available to assess whether there are other compounding disparities in access to the Money Follows the Person program for older adults of color or for people whose primary language is not English, for example.

And reaching the end of our five domains, we want to talk a little bit about the provision of home and community-based services. So home and community-based services are very intimate. This typically involves one or multiple people coming into an individual's home and helping them with their daily activities. So it's really important to understand a participant's experience and address disparities at the individual level. So here we urge stakeholders to be looking at the adequacy and quality of services provided. Are they monitored and measured? Are there grievance processes and other enforcement mechanisms that participants in these programs can easily access and navigate?

HCBS quality measures are relatively new. Do those quality measures include demographic data to measure disparities for marginalized communities?

In terms of language access, we want to be thinking about whether HCBS participants can communicate with their providers. Are language resources, including translated information about the program and the grievance procedures and so on, provided to participants?

And then cultural competence and humility is really a huge factor here. So are providers doing their part to ensure that the direct care workers are receiving cultural competency training? Do states have requirements for providers to deliver services in a culturally appropriate manner?

And we'll look a little more closely about the impact of this on LGBTQ+ older adults. So LGBTQ+ individuals are particularly vulnerable to ongoing discrimination in their daily care. Misgendering and harassment are quite common for individuals, particularly in residential settings. And many LGBTQ+ older adults report hiding their identity out of fear of mistreatment.

Unfortunately, HCBS and LTSS providers more broadly aren't required to train on LGBTQ+ culturally appropriate care, and this can lead to limited provider choice. An individual may not feel safe receiving care from providers who don't have this training. It impacts the service quality and it risks discrimination and harm. A provider or particular worker may not feel comfortable bathing a transgender older adult, for example, and you can imagine how this can really impact the quality of care and cause harm.

So that concludes our overview and walkthrough of our equity framework. We do have resources on the framework, so we have an issue brief that describes each of these domains and gives examples with lots of detail. We also have a fact sheet that's a two-page overview. And we have full equity analyses of several California HCBS programs on our website, and there's a link to those in the issue brief as well. We also have our HCBS primer that Amber talked about and an accompanying HCBS 101 webinar recording that we invite folks to take a look at. And with that, I think we have some time for questions.

Amber Christ:

Yeah. Thanks, Natalie. Thanks, Gelila. I've been taking a look at the questions, and I think what comes to light from these questions is just how complex HCBS is and also how nuanced and difficult it is to sort of evaluate inequities. And just thinking about the HCBS equity framework, we really see the framework as a jumping-off point, a start of the discussion, a way of approaching these issues in a way that has not previously been centering equity. So it's a starting point and certainly not the end point.

And I think a lot of questions and comments we got throughout the presentation just demonstrate the complexity, particularly in HCBS because there is such wide variation from state to state and from program to program

within those states. And so I just want to say that we hope that this is sparking ideas for you all and that it's a jumping-off point and that we hope to continue the conversation.

In terms of questions, I'm going to throw one at either Natalie or Gelila, whoever wants to take it, but it's an overarching question about HCBS generally of whether they can be provided ... Do they have to be provided in a home, or can they be provided in some other residential type of setting?

Natalie Kean: Yeah. They do not have to be provided in a home. There are other types of residential settings. Or I should say a private home. There are some group home settings where people can receive Medicaid home and community-based services. There are important protections under the Medicaid HCBS settings rule that really help people enforce their rights to make sure that those settings are truly integrated into the community.

Gelila Selassie: And just quickly to add to that is just that that is also another area of potential inequities is because in states, it can vary where those community settings are. And so one thing that we've been sort of looking into that we don't have a lot of results yet, but looking into assisted living facilities is one of those areas where you're seeing a lot of wealthier older adults, more privileged older adults entering those facilities.

But they very often do not provide a ton of support, a ton of HCBS. It's usually not accepted in a lot of assisted living facilities. And there's also great variability. So some assisted living can be wonderful and fully integrated and almost palatial, and then others can be really, really grim and really low quality. And so things like that are also another complexity that's sort of added to all of this is making sure that some of those community settings don't exacerbate existing inequities as well.

Amber Christ: Thanks, both. We kind of got at this during the framework talking about Michigan's waiver and slot allocation, but we had a question about with the fact that waivers can be limited to certain geographic areas, whether that's regionally or by zip code or by county, could lead to discrimination or inequities. And I just thought maybe if you could reiterate that point maybe, Natalie, since you covered the Michigan example.

Natalie Kean: Sure. Yeah. I mean, I think it's tied up both in provider availability and sort of what the state is choosing to do. But we do tend to see opportunities and different programs clustered and there to be disparities geographically. And sometimes that can overlap with disparities in access by populations of color as well. But you really have to look at the proportion of programs available compared to the population and who is living in those areas to identify the disparities. The raw numbers alone won't reveal that information.

Amber Christ:

Yeah. We had a really good comment from someone from Michigan about the fact that these slot allocations have to be looked at in total with what other programs might be available in a specific county, and I think that that's a really good flag too is that there may be other programs filling in the gaps that may not be available in more rural counties, for example. And thinking about those inequities too, that those inequities can arise based on region, based on urban versus rural. And again, looking at the proportion.

I happened to actually know about the Michigan waiver slot allocation history after talking to some advocates about it, and the way that that arose was just when the waiver came about, the counties that were ready to go first happened to be the less populous counties and more resourced counties, and so they were given higher spot allocations at the time, and that's just been perpetuated over time. No one's reexamined it. It's not like some intentional inequity was the intent at the outset, but it just ... Because it hasn't ever centered equity, those inequities have been perpetuated over time.

But again, that could be an inequity, or it could be that we are seeing something that is intentional because there are other things that are filling in the gaps. So it is really state specific and program specific, and it does require looking at the whole picture. So a really good flag there.

Also what came up was a question about data and how do people get data and things like that. So I thought maybe someone could touch on that. And then another really good question maybe to ... We have about four minutes left, but I thought ... A question that we got was, how do people start to advocate about this? How do they engage in their waiver process and waiver renewal process?

Natalie Kean:

I can talk about the second one, and I don't know, Amber or Gelila, if you want to talk about data a little bit more. But yeah. Engaging in this. So when states are applying for a waiver for the first time or renewing that waiver, because they're waivers, they aren't permanent, so the states have to renew them on a periodic basis. There's opportunities for public comment, and the state should be facilitating that. And that's one issue. And something in the equity framework that we highlight is really that engagement with people with lived experience in that process, so making sure that the programs are actually responding to people's lived experience and need.

Gelila Selassie:

I can add just a bit to that and then try to answer the data question a bit. One thing that's really unique about this time period is folks may have heard that we're unwinding after the end of the public health emergency, and a lot of that is looking at Medicaid renewals and states beginning that. But there's another piece of it where a lot of states enacted emergency waivers and flexibilities during the pandemic that have expired or will be expiring soon since the PHE ended.

And that's also a great opportunity, because one of these emergency flexibilities is an Appendix K, which is specific to 1915(c) waivers, and a lot of flexibilities that were enacted during the pandemic ... Paying family caregivers is one. Another one is people being able to receive settings and alternative places, so shelters or faith-based institutions if they're residing there with friends, things like that. And this is a really unique opportunity to make some of those emergency flexibilities permanent in 1915(c)s, now that those emergency flexibilities are ended. So that's another option that folks can kind of capitalize on this moment.

And then data is just really tricky, because I think one challenge is that we can always do Freedom of Information Act request or Public Records Act request to state governments, which is useful. But a lot of times states may not even be collecting that information as well, even if it's ... It's not just that they're not disseminating it. It's that they may not be collecting it. And so I think there's really big efforts to say this really should be a question on an application and just kept in some capacity to be monitored and evaluated.

Amber Christ:

I'll just add that the lack of data is an ongoing issue. I think things are getting better. The states are doing a better job of tracking demographic data along with their HCBS. We did write a paper in California on the rebalancing and limitations of rebalancing data, looking just at the expenditures on long-term services and supports versus institutional care and going beyond just that expenditure data to actual utilization data. So there's a lot of efforts there, but it does take, I think, at the state level, advocacy with your state to start collecting and publicly reporting that data transparently.

And then there's work to be done at the federal level of making sure that CMS is requiring states to report that data. As Natalie noted, for example, we don't have demographic data on Money Follows the Person program, for example. And CMS hasn't been requiring states to report out on demographic data for Money Follows the Person.

I see that we're at time, and I really appreciate everybody's participation. And we will follow up with questions and comments that we received throughout the webinar offline with those that we didn't get to address or were provided in the last couple minutes. So we'll get back to you on those. And again, the recording and slides for this presentation will be available on our website in the resource library and on our Vimeo site. Thanks, everyone.