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Understanding Barriers to Accessing Personal Care Services in California

Webinar Transcript

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Tiffany Huyenh-Cho: Hello everybody and welcome to today's webinar presentation, Breaking Down Barriers to Personal Care: Unlocking Vital Services for Those Who Need Them Most. My name is Tiffany Huyenh-Cho and I am the director of California Medicare and Medicaid advocacy on the health team at Justice in Aging. Today I am joined by Hagar Dickman and Carol Wilkins who are leading the webinar. Hagar is the director of California Long-Term Services and Supports Advocacy in Justice in Aging's health team. And Carol is an independent consultant with a deep background in homelessness advocacy.

Before we all begin, I would like to go over a few webinar logistics. Again, welcome to everyone. You are all on mute, but we welcome your participation in today's presentation through the Q&A function in the Zoom control panel. Also available in the control panel is the closed caption button, CC button, which enables closed captioning.

I'll be watching the participant questions as they come in throughout the webinar, and we'll uplift high-level themes during the Q&A segment at the end of today's presentation. Any unanswered questions in today's webinar will be addressed via email following the conclusion of the presentation. You can also use the Q&A function to request technical assistance with Zoom, and our staff will do our best to assist you. The webinar is being recorded, and after the conclusion of the webinar, the slides and recording will be available on our website and emailed to all registrants. Also, there will be a survey that pops up at the end of the webinar. Please stay on to complete the survey for our funders. We appreciate it. Next slide please.

So just a little bit on Justice in Aging. We are 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. Since 1972, we focused our efforts primarily on fighting for people

who have been marginalized and excluded from justice such as women, people of color, LGBTQ+ individuals, and people with limited English proficiency.

Justice in Aging is committed to advancing equity for low-income, older adults in the areas of economic security, healthcare, housing, and elder justice initiatives. We strive 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. Next slide, please.

Justice in Aging produces a wealth of information like the webinar you are viewing today, along with fact sheets, issue briefs, alerts, and other material to keep you updated on important developments. If you're not already a member of our Justice in Aging network, we encourage you to join by going to our website and signing up or simply emailing info@justiceinaging.org. Slide please.

So, about our guest presenter, Carol Wilkins is an independent consultant with decades of experience working on behalf of people with complex health needs, experiencing homelessness. In her career, she has supported a range of entities including state and local governments and community organizations to improve the alignment of housing and supportive services, including those delivered through Medicaid. All right, well thank you for sticking with us through the housekeeping section. I'm going to turn it over to our presenters to get us started.

Hagar Dickman: Thanks, Tiffany. Good morning. My name is Hagar Dickman. I'm the director of California LTSS Advocacy, and I'm going to just walk us through the agenda and get us started. Today we're going to be providing an overview of California's Medi-Cal personal care services programs. We're going to also present findings from stakeholder interviews that Carol and I held in the spring about individuals who are facing barriers to California's personal care services, what are those barriers, and what are the consequences of going without care? And then we're going to review some policy changes that can address these barriers that are experienced by different populations. And in the end, we'll have an opportunity for questions and comments.

So, we are going to be focusing on Medi-Cal personal care services today. Medi-Cal is the main payer of long-term services and supports, including personal care services. And personal care services are really fundamental services that individuals who have functional impairments or functional needs for completing activities of daily living that maybe needed to remain in the community. So services like grocery shopping, toileting, showering, dressing, feeding, and food preparation and transportation are included in personal care services.

And often Medi-Cal is really the only option for low-income older adults and people with disabilities to receive those services. And so we're going to really be focused on the Medi-Cal program, with the recognition that without access to

Medi-Cal personal care services low-income, older adults and individuals with disabilities must rely on unpaid family caregiving or go without care.

So as a background, the personal care services that are available through Medi-Cal are delivered through essentially three avenues. The In-Home Supportive Services program, which many of you might know about, is a service that is included in California's Medi-Cal state plan. It is a state plan benefit, and as such is available statewide and carries no wait lists and no capacity limitations. Any individual receiving Medi-Cal that is eligible for the service should be able to receive it.

California's Home and Community-Based waivers offer a personal care services plus additional services in a service package that support individuals who are living in the community. Three main Home and Community-Based service waivers are available in California to provide personal care services, including the Assisted Living Waiver, which is delivered in licensed residential care facilities for the elderly or adult residential facilities. And in LA County and a limited number of public subsidized housing.

The Home and Community-Based Alternative Waiver also provides personal care services plus additional intensive services including 24-hour care in an individual's homes and as well as nursing services. And the multi-purpose Senior services program couples personal care services together with intensive case management, transportation, and adult day center programming in addition to some other services as well.

And finally, people can now receive some personal care services through CalAIM managed care. So managed care plans are now delivering Medi-Cal services and include 14 community supports which are optional Home and Community-Based like services that are delivered by managed care plans. Three of these services really focus on the delivery of personal care services, including the personal care homemaker service, which is an IHSS stopgap program, the nursing facility diversion to assisted living, which is a program that's really mirroring the Assisted Living Waiver, except that it is an unavailable in public subsidized housing. And a Recuperative Care service, which is a temporary service for individuals experiencing homelessness who are discharged from hospital care but are not yet able to be discharged into unstable housing situations, including shelters or the street.

Personal care services can also be received through a couple of other programs that are out of the scope of this program, but worth mentioning. The Adult Day Health Center program through Community-Based Adult Services or CBAS is available in 22 counties, and older adults over age 55 can choose to receive their healthcare including personal care through a pace or Program of All-Inclusive Care for the Elderly program, which is available in 26 counties.

So, we'll start with IHSS because it's really the main deliverer of personal care services in the state. IHSS can be delivered at the choice of counties through three different modalities. The independent provider mode is a consumer-directed model where the consumer is the employer and decides when, how, and where to receive care.

Contract mode is a model of IHSS delivery where the county contracts with a home health agency to act as the employer and deliverer of care. And homemaker mode allows the county to be actually the healthcare agency essentially and hire providers directly, and then assign those providers to IHSS consumers. And the homemaker model currently is not regularly used by any counties and the contract mode agency-directed model is used only in San Francisco.

So IHSS is the largest consumer-directed program in the nation. And this is not surprising because California has really been a leader in disability rights and independent living movement. And the consumer-directed model really reflects these values, the values of those movements, including the rights of individuals with disabilities to self-determination, dignity, and independence, community living in a setting of one's choice, and the right to control when and how to receive care. And this program really works well for maybe 70% of individuals who receive care from their family members and those individuals who can direct their care.

But what about people who don't have family members and who are not able to direct their care? How do people who can't direct their care access personal care services in a consumer-directed system?

So, we've looked at all of the different ways in which personal care services can be delivered to explore the answer to that question of what's really currently available and how are people accessing these services when they can't direct their care?

And so as we mentioned, using contract mode to deliver IHSS can really be a good option to address the needs of those who can't access the program under the independent provider mode. But only one of 58 counties are currently using this mode of delivery. Homebridge is a nonprofit agency in San Francisco that's serving around 1100 individuals in San Francisco County and is the only home health agency that is participating in IHSS.

And Homebridge uses a continuum of choice model where working together with the San Francisco Public Authority, Homebridge can deliver agency-delivered care. The public authority administers the independent model. And then in between where individuals maybe need additional supports to participate in the independent provider mode, they can receive those supports from Homebridge. And then as people require more care or more support,

Homebridge is there to provide that care, including additional training, peer support, and supervision that may be needed.

It's worth mentioning that LA County has also been working on creating a contract mode model for the last two years and looking to expand its current local program for individuals experiencing homelessness. Senior staff from Department of Health Services and Social Services as well as the CO's office have been actively engaged in this effort working through many questions about program design and implementation, with the hopes that a program could be launched by fiscal year '25 or "26.

But at this time, LA County is facing substantial competing demands for funding related to strengthening and expanding its countywide homeless response system. And then coupled with uncertainty about available resources, there is really a question about how this project is going to go forward and whether LA County will be able to stand up a contract mode model by its '25 '26 goal.

So given that San Francisco is the only county in the state that's providing contract mode and LA County has been looking to add this mode but has been struggling to get going to get this going, there's really been a low uptake of contract mode, and it's really attributed to the high startup costs in starting a contract mode for a county, together with concerns about the impact on county budgets, because adding a contract mode model will permanently increase IHSS costs, cost sharing obligations called maintenance of effort. And then there's also very steep learning curve with little public information available about all the administrative steps that counties must take to create a contract mode.

So, without an alternative to independent provider mode through IHSS, consumers who need more than IHSS has to offer who are not able to access the program, need to look to California's Home and Community-Based Services Waivers, which deliver personal care services as part of a benefit package that include additional services that may be able to support individuals living in the community.

Waivers are limited to people with high needs who need nursing home facility level of care to remain in the community, and are limited in capacity, have long wait lists, and are not all available statewide.

So, for those who are not able to access these waivers services, they must now have the opportunity to look to their managed care plan that may be able to deliver some community supports for them.

Unfortunately, for reasons that we're going to discuss later, there's been significantly low utilization and uneven accessibility of those services as well. So we're going to just take a quick look. Here we have this utilization chart. The first three programs up top are the California's waiver programs, and you'll note that the current enrollment is quite high. The Assisted Living Waiver and the

HCBA waiver have reached capacity and have ballooning wait lists, as does the multipurpose senior services program. And the Assisted Living Waiver program is available in only 15 counties.

And then if you look at the data for utilization for community supports, that data is current as of the end of 2023. So we don't have 2024 numbers yet. But as of 2023, you can see that the Personal Care Homemaker support only was accessed by 1,700 people, most of which were delivered by only one plan.

And then I think the other noteworthy thing is that the Nursing home diversion to assist living program has 552 individuals enrolled as of the end of 2023, whereas you have 3,200 individuals on the Assisted Living Waiver that could really benefit from that community support. So that disparity indicates a pretty significant low utilization.

And finally, the Recuperative Care program, which has a little bit of a higher utilization, is really limited and Carol is going to discuss why, to individuals who are able to complete their ADL. So really people who don't have a need for personal care services or who can complete ADL needs on their own.

So, with that, I'm going to pass the baton on to Carol who's going to talk about our project around exploring barriers to personal care services.

Carol Wilkins: Great, thank you Hagar. And I want to start by expressing my gratitude both to Justice in Aging for inviting me to partner with this project and bring the perspective that I have from several decades of work trying to align services and housing assistance for people experiencing homelessness. It's been really great to be able to connect with Justice in Aging's broader mission, and focus, and deep expertise on the needs of older adults who live in poverty and people with disabilities. And I also want to express my appreciation to the California Health Care Foundation for supporting this project.

We launched this project because we understand the California's IHSS program, as Hagar has explained, requires self-direction and it heavily relies on people who have family caregivers. While other states have different ways of making personal care services available to Medicaid beneficiaries. We knew that we'd been hearing about the kind of problems and barriers that people are experiencing if they don't have family caregivers.

And so while we recognize that for many people being able to self-direct their care is empowering, and that that's a cornerstone, a foundation for California's approach to IHSS, we know that this doesn't work for everyone. And we wanted to hear from those people and from others who recognize the challenges they face and the impact of their unmet needs.

And in addition to the challenges related to IHSS and the individual provider mode, we wanted to figure out and learn more about the other barriers that limit access to personal care services.

The next slide's going to describe the people that we talk to, but I want to mention that there are people who are missing from our interviews. First of all, it's not too surprising that people with unmet needs for personal care services who don't have support from a case manager or a family member, were really hard for us to reach. We primarily talked to people who could give us a kind of secondhand perspective on the experiences of those individuals, the case managers and the service providers who work with them, and describe their frustration and their concerns about their limited capacity to assist them.

And we also recognize that for people with advanced Alzheimer's who if they don't have family support, we were also unable to reach those individuals. We do want to recognize that Kaiser Health News recently published a report about those individuals. It was published and picked up in a number of newspapers. The headline was Millions of Aging Americans Are Facing Dementia by Themselves. So, we know this is a growing problem and we know that these are people who are left out of the state's largest program that's intended to support people to age in place in their own homes.

So, we talked to more than 80 people in this project. Lots of people wanted to talk to us about these issues. We set out to talk to a smaller number of folks and we kept hearing from people who wanted to join this conversation.

Here's a list of the kinds of people we talked to. We talked to people directly impacted, consumers and providers of IHSS services. We talked to state and national policy experts and advocates. We talked a lot to people in organizations that serve people who have complex needs, and they often advocate for their clients to get the services that they need. Whether those were people working in community clinics or homeless service providers, people who are case managers trying to help people navigate the system and experience big problems.

And we talked to state and national policy leaders who understand how Medicaid works in other places where there are other models, as well as representatives from the public agencies and the other organizations that are involved in implementing IHSS, the public authorities, the county social services personnel, and the folks who work in Medi-Cal managed care plans. We're really grateful to the people who shared their stories and their expertise with us in this project. So let me talk a little bit about what we heard and what our findings are.

And one of the things that I want to emphasize is that there was a really strong consensus about the core finding of this issue brief in this project. We heard lots of details, lots of unique stories of individuals. We have lots of quotes that didn't

fit into our report. I think the first draft that Hagar and I worked on was about three times as long as the issue brief that you have access to today. So we want to recognize that there was an enormous wealth of information that people shared with us. Over and over again, we heard something along the lines of IHSS works as it was designed. It works for people with family members who can deliver their care, but it doesn't work for people who can't self-direct their care. The services are inaccessible to people who don't have family or community support.

We wanted to hear about which kinds of circumstances, and experiences, and conditions people had that limited their access to IHSS in particular as well as other models of personal care services. And over and over again, we heard about the challenges facing people who have cognitive decline or cognitive impairments, who have difficulties making decisions or navigating the requirements of the program.

People with mental health and substance use disorders, people with histories of victimization, experiences of racism and trauma that exacerbate or that increase feelings of distrust, and the difficulties that people felt in both trusting the public systems that were intended to provide benefits to them and trusting workers who they would need to hire and invite into their homes.

We heard about obstacles faced by people who experience homelessness, people trying to transition from homelessness into housing, people returning from incarceration, people facing discrimination based on race, or ethnicity, or limited English proficiency, as well as LGBTQ people, particularly in rural communities. So, these are the folks who particularly find it difficult to access the assistance that should be available to them through IHSS.

And I want to mention that many of these challenges disproportionately impact people who are Black and other people of color, and this contributes to and is exacerbated by the kind of racial disparities we see. Let's go to the next slide.

So, what we heard is that the design and the program rules of IHSS create significant barriers to self-direction and make it very difficult for some groups of people to access personal care services. Program design elements like program navigation. It's really hard to know how to apply for the benefits, what forms to fill out, what documentation is required, how to complete reassessments. We often heard that people had been told that people, for example, who experienced homelessness aren't eligible for IHSS. This is not true. But with this widely shared misunderstanding makes it nearly impossible for people to know how to navigate past those kinds of barriers.

We heard that the IHSS application process can take six weeks or more, or that IHSS workers won't come to conduct an assessment for a person who's experiencing homelessness. And we heard that people who need these services often give up, and they're unable to stay in contact and follow through with

applications, or they're unable to stay in contact with and follow through on the responsibilities of hiring and supervising IHSS workers.

It can be very difficult also for people who experience these kinds of obstacles or experience isolation and rely on a single provider to navigate these kinds of power dynamics when they're vulnerable and have their needs met by a single worker.

So, what we see is that all of these circumstances contribute to the obstacles to accessing the program. And when people face more than one of these barriers, more than one of these challenges in their lives, that makes it even more difficult. Let's move on to the next slide.

We heard in particular that individuals experiencing homelessness face unique barriers. First of all, people who are unsheltered often have no care options. So we see people who need significant help with activities of daily living are living in cars, in tents, and on the streets. The counties often refuse to send staff to go to shelters to establish eligibility for benefits. The state provided guidance in an all county welfare director letter in 2020 to clarify the definition of a person's own home and to encourage and allow the assessment and the delivery of IHSS services to people living in shelters. But that is not widely recognized, and therefore many people are told that they're not eligible for IHSS when they're in shelters.

Even if people can navigate the application process, it's difficult to find care providers who are willing to serve people experiencing homelessness or people who have significant behavioral health problems. And it can be difficult to make contact with or deliver services to people who are living in shelter needs if they have to go out during the day to try to navigate access to benefits or if shelters have program rules that make it difficult for outside caregivers to come in.

We also heard that waiver programs and other approaches to using Medi-Cal for personal care services are not filling the gaps for the people who we've found who face these challenges. As Hagar explained, the waiver programs offer really important additional services that could support access to personal care services. The waiver programs may offer 24-hour care and, intensive case management and care coordination, and agency-provided personal care, but they may not be accessible because of eligibility criteria.

People can't access waiver programs unless they meet nursing home level of care need. There are administrative burdens in applying for the programs. For example, in Los Angeles, there are at least 15 different organizations involved in care coordination who are involved in the process of helping people establish eligibility for waiver programs. It's really hard to know which of those 15 agencies you're supposed to contact.

Thousands of people are already on waiting lists, and the people who have priority are people coming from institutional settings and young people, kids. In the cases of the HCBA waiver program, that makes it really difficult for people who are living in community settings to even get onto the wait list or see any hope of coming off that wait list. As well as geographic limitations. Waiver services aren't available in all communities.

When we looked at community supports, we saw that the availability of community supports fall short. Hagar shared with you the numbers. So we see relatively low numbers of Medi-Cal beneficiaries are receiving personal care services through the community supports.

The personal care homemaker community support option has the potential of filling gaps in access to IHSS and making services available through agencies, but it's very time limited. What we found is that there is still very weak coordination between counties and health plans for this service, and very inconsistent implementation.

Often, we heard from health plans or from people who were trying to navigate access to this service through their health plan on behalf of clients that the health plans would deny this service for somebody who they believed was ineligible for IHSS. So, creating this kind of catch-22. The service that was intended to fill gaps was denied to people because they were unable to access the IHSS program. And we believe that's a misinterpretation of the state's policy guidance, but there's really an opportunity to address that.

Similarly, the health plans can offer the nursing facility diversion or transition to assisted living community support. There's very limited participation in this program. It's reached a very small number of Medi-Cal plan members. And currently, unlike the Assisted Living Waiver program, it's only available to people who want to move into licensed residential care facilities.

And finally, with Recuperative Care, we know that Recuperative Care programs provide a really important opportunity for people to stabilize after they have been discharged from a hospital. And the idea is that these programs provide a bridge that facilitates a transition from the hospital into housing or interim housing shelter settings. But most Recuperative Care programs have very little or no capacity to offer support for activities of daily living.

Many Recuperative Care programs would like to be able to align the community support for personal care and homemaker services with the Recuperative Care benefits. But currently there are significant obstacles to doing that. And as a result, some people return to unsheltered homelessness because they can't get the care they need in a Recuperative Care setting, or they may remain in nursing homes or end up in institutional care.

So, the outcomes that we found were that people who cannot access personal care services face very serious harms. They often have significant unmet needs for assistance with their activities of daily living and poor health or psychological harm and despair. They may have increased risks for falls or injuries, repeated hospitalizations that are avoidable, or they may be vulnerable to abuse and neglect by others or self-neglect.

Often that may lead to a call for services from Adult Protective Services, but APS doesn't have the tools and resources to address this problem, even though they're often called in to assist in these circumstances.

For people who experience or at risk of homelessness, what we see is the lack of In-Home Supportive Services can lead to people losing their housing or having unstable housing. And when people don't have access to assistance with their activities of daily living, it can be a huge barrier for people experiencing homelessness to access either interim or permanent housing.

What we see is that many interim housing or permanent housing settings require that people be independent in their activities of daily living or have already caregiving supports available to them. And so, they're unable to accept residents, potential residents who lack that support. And this can lead to avoidable institutionalizations or to people dying.

So those are in a nutshell, the dire harms that are experienced by people who are unable to get the care that they need. I'm going to let Hagar talk about our recommendations.

Hagar Dickman: Hey Carol. So, this process of talking to stakeholders, and providers, and consumers has really given us an opportunity to think through some recommendations for removing barriers in access in a variety of areas. Looking both at how people are receiving their care, and then at what services they are able to receive has been the driver, the thought process behind our recommendations.

And we've put our recommendations into two buckets. One bucket is looking at really big system level changes. These are long-term changes that we recommend, which will require pretty significant financial and infrastructural investment both on the state level and at a county level.

And then additional smaller changes that are focused on program integration and coordination that can be pursued in the short term and by smaller groups of stakeholders and policymakers.

And this might not be a surprise based on the presentation you've just heard, but expanding contract mode can really make personal care services accessible to individuals who are not able to access IHSS under the independent provider mode. So, this recommendation is really focused on making IHSS specifically

more accessible and making IHSS as the main driver and service for personal care service accessible to all individuals who might need it, when they don't need those additional services that waivers might offer.

The contract mode can be more accessible, because agencies can offer the type of support that's missing from the independent provider mode. And that includes provider trainings and oversight, intensive case management, employee support, and care coordination. And when provided as part of a continuum of care model, based on what I've talked about before about what Homebridge has, with the independent provider mode on one end, for individuals who are self-directing and the agency provided care on the other end of the spectrum for individuals who are unable to direct their own care. This can really be a system that both respects, and empowers, and bolsters, increases access to the independent provider mode by using a continuum and providing additional supports for that self-directed care, or also providing an alternative for individuals who are not able to use that program. And in that sense, an expanded contract mode system can really address the needs of all individuals along a continuum of need.

A contract mode expansion would generally we believe require also a differentiated pay scale to help support and incentivize providers to participate and provide care for individuals with higher, more complex needs. And then we also recommend that the state in order to expand the contract mode provide both the technical assistance that counties may need to take this program up and also provide financial incentives and assistance for counties or financial relief in order to enable counties to take on the financial investments that are necessary.

Another opportunity is to provide pay parity for the homemaker mode, pay parity with contract mode. So using the same rate that is provided to contract mode agencies in the homemaker mode in order to incentivize counties to hire their own providers for a specific set of consumers. And that can also go a long way in closing some gaps.

It's important to note, again, that because contract mode can be expensive, historically counties were very reluctant to take on a contract mode model because the reimbursement rates did not reflect health healthcare agency costs. But then even though the contract rates for contract mode were increased in 2022, this wasn't sufficient to incentivize counties to take on contract mode. And so that really calls to attention the fact that additional both financial and administrative supports are needed to help counties to incorporate this model.

Our next recommendation goes beyond contract mode and really looking at the additional services and supports that are included in California's waiver services. Expansion of Home and Community-Based service waiver programs through either amending California's Medi-Cal State plan, or through pursuing a 1915(i)

state plan benefit can really improve access to personal care services because providing these additional services can really help individuals remain in the community, including we've mentioned a couple of times now, intensive case management, agency-delivered care, nursing services, and 24 hours care. These can really support community living for individuals with complex needs.

I'm not going to go too much into what a 1915(i) state plan benefit is except to say it is a federal pathway to provide Home and Community-Based Services that don't have capacity limitations and don't have geographic limitations. So, they're essentially on the same footing as IHSS where they will have no wait lists and will be provided to all individuals who meet the eligibility requirements of the program.

Expansion through either 1915(i) or through adding waiver benefits to the state plan will therefore eliminate slot capacity limits that drive long wait lists and remove geographic limitations. But it's noteworthy that expanding Home and Community-Based Services statewide in either one of these mechanisms is not going to solve the infrastructure and provider capacity issues that all of us are well aware of in the state. These recommendations may remove administrative barriers to access for these high-level services, but will also require additional investments to ensure that services and providers are present in areas where they're not available right now in the state.

And an example of this is the Assisted Living Waiver, which is right now available in 15 counties. Expanding Assisted Living Waiver services statewide is not going to make sure that there's actually providers statewide. And so additional intentional sort of infrastructure investments will be needed.

Going to move us through a little bit quicker, now just looking at what state agencies and counties can do to work together in making some targeted changes that can improve access to services. For example, removing access to barriers for individuals experiencing homelessness can be facilitated by doing additional assessments in shelters, and really requiring and supporting counties in efforts to provide those assessments in sheltered settings. And then expanding those assessments to unsheltered settings as well to make sure that individuals experiencing homelessness are not stuck in a catch-22 where they need the personal care service to get stabilized housing, but they can't get stabilized housing without the personal care service. So really looking at removing those barriers, the first step would be to make the assessments for services available in all settings.

Improving county capacity to provide intensive case management for targeted group of IHSS recipients can be really helpful in assisting individuals who might have difficulty either completing forms and applications or complying with program rules and administrative requirements. And then investing in models that braid housing with intensive supports can improve access to stable

community housing and ensure individuals with complex health and other needs can have their needs met in community settings.

And then finally, one of the recommendations we have here that is actually a fairly low-hanging fruit that can go a long way in supporting individuals with either stable or progressive cognitive impairment, offering advanced healthcare planning as a covered service. So for example, legal assistance for nominating a power of attorney can really reduce administrative barriers and reliance on adult protective services for individuals that might have future decision-making difficulties and will need some support and assistance in the long-term for their care.

Improvements to CalAIM community supports, ensuring that these services can actually play a gap stop function is going to be also helpful in creating a more seamless Home and Community-Based Services system in California. Part of the recommendations around CalAIM really focus on refining definitions and the alignment of community supports. For example, making sure that the personal care service is linked with and coordinated with the Recuperative Care community support including, for example, matching the reauthorization timelines between these two services or requiring that people who assessed for and identified as needing Recuperative Care are also assessed for personal care services. This can improve access to both services with individuals with ADL needs.

Expanding the use of the personal care community support as an agency model rather than just the short-term replacement or addition to IHSS can also play an important factor in making sure that individuals who can't self-direct have additional options. Supporting communication between managed care and Assisted Living Waiver agencies can help ensure that people on the ALW wait list can access comparable service through their managed care plans, and reduce also the wait times of people on those wait lists.

And then policies that improve awareness of and access to available services can also be a good place to start when trying to improve utilization. For example, making sure that community supports are mandatory benefits for all plans instead of optional. And then standardizing member referrals and self-identification to make sure the community-based organizations and members can know how to access services regardless of what plan they're enrolled in.

And finally, we've identified some innovative practices that counties can also tap into and replicate in order to enhance pre-existing services to support individuals with higher needs. Some of those are fairly straightforward, like providing differential pay for higher levels of care, providing additional trainings for providers, or investing in peer support and educational opportunities. Or using targeted policies that address the needs of specific populations, expediting applications or providing additional supports for those experiencing homelessness or those who have adult protective supervision involvement, or

leveraging the public authorities as a resource by increasing their capacity to provide peer support, employment mentorship, or enhanced capability to match providers with recipients.

So that was a lot, I'm sure. And so it might not be surprising that there's even more. So if you wanted to learn more about both our findings and our recommendations, please feel free to read our brief with all of our findings there. You can go to Justice in Aging's resource page. We've also included a couple of other resources that you can take a look at in this PowerPoint to learn more about contract mode and about the IHSS program. And we're going to move to questions and I'm going to hand it back to Tiffany who's going to moderate.

Tiffany Huyenh-Cho: Thank you Hagar and Carol for your excellent presentation. We did get some questions in the Q&A function. One that I wanted to uplift., can you explain how the design of the waiver service programs prevent people leaving incarceration from accessing them? And which if any of your recommendations in the paper would be helpful particularly to the reentry population.

Hagar Dickman: It's a great question. I think there's two things here. One is the reality of individuals living in incarceration is that they're really... Individuals in carceral settings are really isolated and don't have access to prior to release to the kind of programs and services that are available through Medi-Cal.

And so there is an opportunity through the Justice-Involved PATH initiative that California has been pursuing through CalAIM to really provide the information and linkage for individuals who are leaving and reentering from incarceration into the community. A lot of opportunities there. Our paper does touch on that.

The reentry process and the CalAIM engagement through Inreach and re-entry and Enhanced Care Management should really be playing an integral role in making those connections, filling out forms, connecting individuals with waiver agencies. There are for waiver programs, a requirement for health certification and nursing facility level of care determinations. All of those things, person-centered care planning. All of these things can be done during the 90-day pre-release period.

Once individuals leave incarceration, those periods of re-entry can be quite chaotic. And so in addition to all of the administrative barriers and the confusion around what programs are available, how to apply for them, which agencies to work with for each program, that chaotic period of finding housing, and dealing with parole requirements, and additional leftover requirements that are leftover from the incarceration period can be very difficult. It can be very difficult for individuals to also follow up on all of these other administrative requirements.

So I think the PATH program, the Justice-Involved Initiative really presents an opportunity but has so far fallen short of truly incorporating and contemplating HCBS programs. And so I think there's a real opportunity there that we hope the state decides to take on and pursue. Carol, did you want to add to that?

Carol Wilkins: I think there's a lot there in what you've said, Hagar. I think the only thing I would add to that is that we know that many people who experience homelessness have histories of incarceration, and that many people get caught in a revolving door of incarceration and homelessness because of the obstacles that you just described.

And so I think all of our recommendations about expanding the feasibility and the opportunities for counties to implement contract mode IHSS would also be very helpful because individuals who have experienced incarceration and/or homelessness and face stigma for a variety of reasons often find it very difficult to secure, even if they can navigate the access to IHSS eligibility. When they're handed up a list of hundreds of potential IHSS individual providers, it's very difficult to navigate that list and find a provider who's willing to serve them. And so I think the contract mode IHSS could be very, very helpful in conjunction with other services and supports to facilitate successful re-entry.

Tiffany Huyenh-Cho: Thank you both for answering that question. It was a great question. Hagar and Carol, you both mentioned the low utilization of several community supports such as personal care services and the nursing facility transition and diversion. Can you expand more on the barriers contributing to this low utilization that you learned throughout this process?

Carol Wilkins: I'll start with that and I think Hagar can help. One of the things that we heard is that first of all, many of the organizations that work with the very same populations, the same groups of people who face barriers to making IHSS work in the individual provider mode. Those are organizations that deliver services to people experiencing homelessness, people with behavioral health disorders. Many of those organizations that know the consumers or the potential beneficiaries, are themselves struggling with the challenges of establishing contracts with the Medi-Cal managed care plans for the housing-related supports or other supportive services. They're wrestling with what it takes to establish a contract and then get paid to deliver Enhanced Care Management or housing navigation services and those kinds of things.

And so to some extent, it's that the provider capacity and the managed care plan readiness to partner with community-based organizations is really lagging behind when it comes to some of these additional community supports. The managed care plan may be contracting with or partnering with far fewer organizations to deliver these other community supports. And the referral pathways and the referral criteria for these services and supports are really not well understood, not well communicated. And so it's just a very narrow and hard-defined pathway, and a very narrow door that people have to get through

to access these services, either as a consumer or as a potential provider. I think that's the number one thing we heard.

Tiffany Huyenh-Cho: Thanks Carol. We have another question. You both covered some barriers to IHSS that must be resolved. But in the meantime, do you have any recommendations for health advocates to help IHSS recipients get connected to providers and support in the meantime?

Hagar Dickman: That's a really good question. I think the reality of the current system is that individuals who don't have family caregivers rely on the public authority, the local public authority to receive these registry lists of people who have been approved to provide IHSS services.

I think just without any other changes to the system, the one thing that I think individuals could, as a very preliminary matter, receive help with is actually using those register lists that they get from public authority to follow up, interview people, and help really access those registry lists in a real way. So that involves making, specifically for people with maybe organizational difficulties or cognitive impairments, using those registry lists can be very difficult.

So receiving them, knowing to ask for them, knowing to call and how to vet or interview people, and identify people that might be a good match. And then because those lists can be very long and have maybe more inactive than active providers, but kind of persisting through it.

I think organizations that can provide any kind of peer support program or employer trainings that can support individuals in managing their care can also be really helpful. And then also filling out applications. Application support and then following up on those applications and obtaining documentation. So really, the administrative barrier part can also be an opportunity to assist. But these are very preliminary issues I think before people actually receive the care. Once care is in place, I think the kind of barriers that people are facing require maybe more intensive case management type support.

Carol Wilkins: The other thing I would add is that one of the things that's really challenging is that unlike other Medi-Cal benefits, IHSS is administered through county welfare departments, county social services departments, and through the public authorities. So for folks who may turn to other healthcare or behavioral health providers to get access to other services, those providers often aren't super familiar with how to navigate the IHSS system, because it lives in a different bureaucracy even though it's funded by Medi-Cal.

We did identify a handful of places, counties that were implementing some really promising practices that we would hope to see more broadly replicated. So for example, if a county in the eligibility, in their IHSS program has specialized social workers who work with people experiencing homelessness, or with people who are returning from incarceration, or for people with particularly

complex needs. If they've got dedicated social workers who can help them through the eligibility determination and troubleshoot the barriers to care, that can be really helpful. One county is funding peers who themselves are IHSS service coordinators to offer coaching support to individuals who find it difficult to navigate the process.

Those were little bright lights that we encountered in our work. And often if we had those conversations with people from multiple counties, folks would say, "Gosh, I wish we had something like that where we live or where we work." So we wanted to lift up some of those practices that are promising, because our system's fragmented and it's not very easy for people to navigate. So the people who need the support the most are those who find it most confusing and find doors closed that should be open.

Tiffany Huyenh-Cho: Thank you both. And maybe on that note, we have one time, a few minutes left for a broad question. Is there anything either of you would like to share about the process you underwent to write this paper and its recommendations? We know a large number of interviews were conducted, and if there's any surprising insights or challenges that you had while writing this paper.

Hagar Dickman: I can start us off if you don't mind Carol. And I think I speak for both of us, but Carol can always correct me. But I think I'm surprised by the wide consensus across essentially all stakeholders. And we've talked to policymakers at the government level, county level, community-based organizations, healthcare providers, legal advocates, consumer advocates, and consumers and providers themselves. And across the board, there was consensus that there's just a group of people that do not have care, that are just not able to access everywhere they look, any direction they look, they just cannot get care.

And I think especially the thing that was most painful is talking about individuals with Alzheimer's and dementia. I think there's a recognition that IHSS is not going to be... That people with Alzheimer's and dementia are not going to be able to access those services long-term unless there's a family member. And even with family member support at a certain point, there's just not enough support that's needed for individuals with Alzheimer's and dementia.

And again, it's not because people with Alzheimer's and dementia shouldn't be in the community living in community settings. It's just that there's not the support, the intentional focused support to provide the care that they need. And so the only option that people have is to go into nursing home care. And for individuals without family caregivers, the road from the diagnosis with Alzheimer's and dementia, having that early diagnosis to the nursing home can be quite painful and have a lot of complex health and other poor outcomes.

So I think those were two of my big takeaways, both the consensus on the harm side and the consensus on the understanding of the deficiencies. And then really a desire. And I'm really grateful to everyone who contributed because I feel like

there is a consensus that there's a desire to fix this problem. And it's just so overwhelming because the program is what the program is. And we have a complex system, and understanding where to plug the holes and where the opportunities are can be kind of overwhelming. So I'll stop there.

Carol Wilkins: Hagar has answered really well. I think the only thing that I would add is that when we've talked to people in other states, other states are surprised to hear some of our reflections about the challenges that we observed and reported on in this issue brief. So, while when we talked to people in California, folks were like, "This is the way it is and this is the way the program is designed, and we are unanimously frustrated and concerned about the people who aren't reached." When we talked to people in other states, they talked about the value of consumer choice, and that consumers should have the ability to choose whether they are self-directing their care in hiring and supervising their own workers, or whether they are receiving care that's organized and delivered through an agency. And we talked to people from outside of California. They were surprised that California doesn't offer consumers that range of choices and options.

Tiffany Huyenh-Cho: Thank you both so much for presenting today and thank you all for joining us for the webinar. As a reminder, any unanswered questions will be followed up via email, and feel free to reach out with any additional questions that come later. There's a survey that pops up at the end, and please complete it if you have time for our funders. And again, thank you everyone and have a great rest of the day.