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## The New Medicaid Access Rule: Primer and Advocacy Strategies

Webinar Transcript

December 17, 2024

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Hannah Diamond:

Hello everyone, and welcome to today's webinar entitled The New Medicaid Access Rule: Primer and Advocacy Strategies. My name is Hannah Diamond. I'm a Policy Advocate at Justice in Aging. I'm a white woman in my 30s with brown, curly hair and glasses, and I'm wearing an orange sweater. My colleague, Eric Carlson, Director of Long-Term Services and Supports Advocacy at Justice in Aging, unfortunately could not be here with us today, but he contributed extensively to the developments of these slides and materials, and as a leader in advocating on behalf of the access rule at Justice in Aging, I will do my best to fill in for him today. And I am pleased to be joined by our friends at the Community Living Policy Center at the Lurie Institute for Disability Policy at Brandeis University, specifically Syd Pickern, Project Manager of the Community Living Policy Center, and Joe Caldwell, Director and Principal Investigator of the Community Living Policy Center.

A few webinar logistics before we begin. Again, welcome to everyone who's participating in today's webinar. You are all on mute, but we welcome and encourage your participation in today's presentation through the Q&A function in the Zoom control panel. Also available in the Zoom control panel is the CC button, which enables closed captioning. We will be able to monitor participant questions as they come in through the webinar, and we will uplift those questions during the Q&A segment at the end of the presentation. Any questions that are unanswered when we conclude 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.

Now, we always get this question, this webinar is being recorded, and after the conclusion of today's webinar, we will share the slides and the recording of today's presentation on our website, and they will also be emailed to all webinar registrants. We would also appreciate your participation in a post-

webinar survey that will pop up on your screen following the close of the webinar. We are also providing American Sign Language interpretation on this webinar. The ASL interpreter will stay on video throughout the training to provide this service. You do have the option to pin the interpreter's video box to maximize your view of the interpreter. To do this, click their video window, then select the pin icon. And reach out in the Q&A if you need support with this.

So a little bit about 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. We've been doing this work for over 50 years, and our efforts focus on populations that have been historically marginalized and excluded from justice, such as women, such as people of color, LGBTQ+ individuals, and people with limited English proficiency.

The Community Living Policy Center at the Lurie Institute for Disability Policy at Brandeis University conducts research on the provision and quality of home and community-based services, HCBS is the acronym, programs for people with disabilities in the United States. Their research seeks to answer questions regarding the state of HCBS services for people with disabilities in the United States, the policies that help people with disabilities live and participate in the community or prevent them from being fully integrated, and what policies are most effective to ensure that people with disabilities can live and participate in their communities.

I want to share Justice in Aging's commitment to advancing equity. To achieve justice in aging, we must advance equity for low-income older adults in economic security, healthcare, housing, and elder justice initiatives, we must address the enduring harms and inequities caused by systemic racism and other forms of discrimination, and we must recruit, support, and retain a diverse staff and board.

Finally, just for our beginning materials, I would encourage you all, if you're not already a member of the Justice in Aging Network, to join us. We produce a wealth of information, like the webinar you are viewing today, along with fact sheets, issue briefs, alerts, and other materials, to keep you up to date with important developments in this space. If you're not already a member of our network, we encourage you to do so by going to our website, [justiceinaging.org](http://justiceinaging.org), and clicking on sign up, or simply by sending an email to [info@justiceinaging.org](mailto:info@justiceinaging.org). Okay, thank you for bearing with me through that background information, and now let's get started.

So we are going to be exploring the access rule, the requirements that are outlined in the access rule specific to the grievance system, the critical incident system, and various reporting requirements, and then you're going to hear from Joe and Syd later in this presentation about the HCBS quality measures and interested parties work group component of the access rule. So within my

portion, I'm going to be talking about the requirements in the rule, opportunities to improve upon the floor that's established by the access rule, and then also leveraging lessons learned from a previous rules implementation process, called the HCBS Settings Rule, all so that we can improve the quality of care and services that are delivered via HCBS services. And for all of our segments that we're going to be talking about today, the access rule applies federal oversight for Medicaid home and community-based services provided in people's homes and in licensed facilities, like an assisted living facility or a group home.

So a little bit of background, there was a rule that came about in 2014 called the HCBS Settings Rule, and this rule established basic parameters to differentiate HCBS settings and services from institutionalized care. Unfortunately, despite nearly a decade-long implementation process, many states remain out of compliance with the settings rule, and the result is that HCBS residents and recipients often lack basic protections. Two prominent examples that Justice in Aging advocates on are undermined eviction protections and insufficient person-centered planning processes. The access rule builds on the settings rule to provide a foundation of protections for HCBS recipients, aimed at improving the quality of care that is received. The access rule became finalized in July of 2024. And so, to actualize the promise of the access rule, it's important for advocates, for government employees and policymakers, to know what's in the rule, to identify opportunities to expand upon the existing floor established in the rule, and then to leverage lessons learned from the settings rule implementation process. So that lesson is to get involved early and be persistent in your advocacy.

So first, I'm going to talk about the grievance system contained in the access rule. So a little bit of background about how this came about, as part of the settings rule implementation process, states were required to submit a brief description of how beneficiaries in their state could file a complaint, and then how the state would respond. Unfortunately, this documentation yielded descriptions that lacked even basic details, and demonstrated that states currently provide insufficient grievance systems, and that often, individuals will lack a basic standard of protections to be able to file a complaint. And so, the access rule attempts to provide a basic framework for states to establish a grievance system. It requires states to develop procedures to enable a beneficiary to file a grievance or a complaint against the state or a provider. In other words, it provides a process for HCBS recipients to express dissatisfaction with their services or providers. Now, I want to note the limited scope of this portion of the rule. The grievance system only applies to HCBS services delivered through fee-for-service delivery systems, because Medicaid managed care HCBS already had a pre-existing grievance system requirement in place.

So the grievance system is applicable to a state or provider's performance of a few different things that we're going to talk about. It's applicable to the person-centered planning process, the person-centered service plan, so for example,

whether the plan reflects the individual's needs and goals, whether it's supports community integration, and whether it's agreed upon by the individual, and then also, the HCBS Settings Rule. So as I mentioned before at the top of the hour, that's the rule that differentiates HCBS settings and services from institutionalized care, so it's things like eviction and due process protections, prohibited use of restraints, right to privacy and autonomy. Now, it's important, and you're going to hear me flag throughout my presentation opportunities to really improve upon the floor that's offered in the access rule, and an area to focus on here is ensuring that individuals can grieve quality of care concerns, such as workers consistently missing shifts or frequently arriving late, and I'll talk about that in a little bit.

So this slide outlines the grievance process components that are established in the access rule. So states need to provide individuals with the right to file a grievance, either orally or in writing. States need to acknowledge receipt of the grievance. The grievance decision-makers need to be independent of prior reviews, this is trying to prevent conflict of interest concerns, and they need to have relevant expertise to make such a decision. Beneficiaries have to have an opportunity to submit evidence, whether that be face-to-face or via video or audio or in writing. Beneficiaries have a right to their case file, and states are expected to provide language services to support beneficiaries' use of the grievance system.

So timeframes, beneficiaries can file a grievance at any time. In terms of the state's response, states are required, per the rule, to resolve the grievance, "As expeditiously as the beneficiary's health condition requires," and this process is not to exceed a 90-day period. Now, I'm going to flag, on this slide and the next slide, additional requirements contained within the rule, but I am going to show you that some components of the rule lack detail, and so these areas are in particular need of advocacy attention.

So the access rule establishes various requirements for resolving a grievance. States must establish a method of notifying a beneficiary of the grievance resolution. Unfortunately, the rule contains very limited detail about accessibility requirements for notices, mentioning only broad and basic considerations for individuals who are limited English proficient and beneficiaries with disabilities. States must also maintain records and review those records as part of their ongoing monitoring efforts, and we're going to talk about some opportunities to improve data-gathering efforts to lead to meaningful quality improvement. Additionally, states must provide beneficiaries with reasonable assistance in ensuring grievances are appropriately filed. The rule notes that specifically, states are required to provide language assistance as necessary, including auxiliary aids and interpreter services, states must notify beneficiaries and providers of the grievance system and beneficiary rights, and states must review a resolution when a beneficiary is dissatisfied. So I want to flag again the lack of detail for various components of this slide, for example,

what is a review, how is dissatisfaction defined, what is a resolution, so we're going to talk about that, again, in a little bit.

So the timeline, states have two years since the finalization of this part of the rule to come into compliance, so they have to be implemented by July 9th of 2026. So I've flagged these two areas for you, but it's really important, in terms of timelines, that advocates hold states accountable to addressing grievances as expeditiously as possible. We would suggest that advocates work with their state to establish prompt timelines, based upon grievance type, so that really, the state is prioritizing particular types of grievances. And the rationale here is that in order for a grievance system to work, there needs to be prompt responses so that more critical incidents do not result.

Additionally, it's really important to ensure that the grievance system addresses quality of care concerns. Within the preamble to this rule, it states that most concerns related to HCBS service provision will be covered by the person-centered planning process and the settings rule, but this is a broad assertion and remains to be seen as the rule is implemented. Clarification of the scope of the grievance process applicable to quality-of-care issues is expected in forthcoming CMS guidance, but this can and should be reiterated in state policies.

Additionally, it's really important for the resolution to be meaningful for the beneficiary. Before I even highlight the text on this slide, I think that it's important here to be seeking the expertise from HCBS beneficiaries and seeking their ongoing feedback, whether or not they're satisfied with the resolution, and how to improve the grievance system that the state is developing. So that feedback loop with beneficiaries is really, really important. And then, in order to ensure that you have a grievance system that is working, you need to have a strong enforcement mechanism, so this requires actions and specific resources from the state. So I'm highlighting for you here some best practices used by other states, like random audits, annual site visits, data collection efforts, staff trainings, corrective action plans, all of these things to make sure that the grievance system is working. And then, when it comes to that oversight and that enforcement mechanism, it requires states to allocate sufficient resources, including unique staff and a unit to ensure operation of a robust grievance system.

Additionally, it's important to embed consumer protections within the grievance system. So as I noted, there's a floor that's established by the rule, but then there's some areas that lack detail. So it's important for you all as advocates to be working with the state to describe what is included in a right to review when someone is dissatisfied, how should reasonable assistance be defined to ensure that beneficiaries can get the support and accommodations that they need, and what other accessibility accommodations need to be in place, besides considerations for individuals that are limited English proficient or individuals with disabilities? Additionally, visibility is key here. State staff are going to need

training on this rule, and providers are going to need training on this rule, so that they know the requirements within the grievance system and the critical incidents system and the entire rule that we're going to talk about.

And at the same time, it's extremely important that beneficiaries know how to use the grievance system, how to report a complaint, and that they can do so without fear of retribution or retaliation. It's really important that these systems don't rely on solely a case manager or a provider as a primary reporting mechanism, because at times, there can be a conflict-of-interest concern there. So individuals need to feel like the system is accessible to them. We're uplifting here some best practices on this slide to accept complaints in a myriad of ways, whether that be a 24-hour hotline or through a state ombudsman program. It's also really important to note that there's no magic language that is needed to initiate a grievance, or that there's no incorrect pathway for an individual to file a grievance, that basically, if an individual has a concern, the systems within the state, whether that be the critical incidents system, the grievance system, a particular entity, like Adult Protective Services, that they are all going to work together to address an individual's complaint or concern.

Now, I want to talk about the critical incident management system that's included within the rule. So states must have incident management systems that identify, report, triage, investigate, resolve, track, and trends, critical incidents. The system must enable electronic data collection, tracking of incidents and investigation resolution, and trend analysis. The critical incident system is aimed at identifying and addressing serious incidents of harm. The definition included in the rule is broad, and at a minimum, it must include verbal, physical, sexual, psychological, or emotional abuse, neglect, exploitation, misuse or unauthorized use of restrictive intervention or seclusion, medication error causing emergency, and unexplained or unanticipated death. And the purpose of this part of the rule is to establish a minimum floor across states regarding critical incidents, both to identify and then remedy these concerns, and then prevent them from happening in the future.

So the rule establishes requirements for both states and providers. The provider is obligated to report critical incidents within state-established timeframes that occur during the delivery of services, or are the results of failure to deliver services. The state is required to identify unreported incidents by analyzing claims data and through other strategies. The state is responsible for enabling information sharing and collaboration across government agencies in order to pursue an investigation. And states are also required to investigate incidents, for example, like if a state licensing agency misses a deadline, to ensure that that investigation is adequate.

So under the rule, there are minimum performance standards established for states. These are focused on timeliness. Remember that for critical incidents, the timelines are established by the state. So specifically, the rule requires that states must achieve at least 90% compliance with the state-specified timelines,

specific to initiating and completing an investigation, determining a resolution, and ensuring that corrective action has been completed. So generally speaking, states have three years to implement this portion of the rule, but they have an additional two years to conduct these actions via an electronic information system.

Okay. So opportunities for advocates to improve upon the floor that's included within this portion of the rule. As you recall, going back to my description of the grievance system, the grievance system allows beneficiaries and their support systems to file a complaint against the provider or the state, specific to the person-centered plan, the planning process, the settings rule criteria, and due to our advocacy, the quality-of-care concerns that an individual might have. The critical incident system, which has a broader scope of subject matter, is entirely focused on provider or self-reported information, and then additional activities from the state to identify under reporting. The requirements contained in the rule do not, do not allow beneficiaries, their family members, and other stakeholders, to report critical incidents. We would assert that this is a real shortcoming of the rule, and that it's extremely important for individuals that are receiving these services, and their support networks, to be able to report critical incidents.

Additionally, as I've noted previously in the grievance system, and then the same is true within the critical incident management system, there are various descriptions contained in the rule that lack detail or are ambiguous, and we would encourage you all to work with the state to really define the requirements to ensure compliance. Get really granular in that implementation process to define what a robust oversight system is, to define what a meaningful resolution entails, to define actions that will prevent these issues from happening in the future. The goal here is not just on documenting what's happening, the goal is to remedy and then prevent these issues from happening in the future, and to get providers to improve their level of care that they are delivering.

Additionally, in the spirit of constructive criticism, we would question, or offer the question, about why we're satisfied or settling with a 90% compliance rate. 90% compliance disregards 10% of incidents, and it warrants the question of why we aren't striving for 100% compliance. Additionally, even in this description, where states are required to achieve 90% compliance for initiating an investigation, for determining a resolution, and ensuring a corrective action plan, there's a lot of lack of detail there too. So what is determining a resolution mean? Has that resolution been completed, for example? And where's the feedback from the recipient to ensure that their concerns have been met? The key takeaway here is that there are opportunities to expand beyond the floor contained in the rule, and that we collectively, this movement, needs your advocacy and your analysis and your persistence to move the needle to ensure high quality care that's delivered to HCBS recipients.

So now, I'm going to touch on person-centered planning requirements contained in the rule. A little bit of background on this, prior to the access rule, there were already person-centered planning requirements that were established via the settings rule that aim to ensure that a recipient's care plan reflects their needs and preferences. Unfortunately, many person-centered plans fail to reflect beneficiaries' needs and goals, and instead largely remain a checkbox in the process, they're often very medicalized or very provider-oriented. And so, the access rule acknowledges that and aims to strengthen the person-centered nature of this process. So they remove some old language and add new language, stating that an individual or their authorized representative will lead the person-centered planning process, so this is good language that really prioritizes the individual being at the center of that planning process.

Both before and after the access rule, assessment and service plans have to be addressed every 12 months, when necessitated by a change in condition or when requested by the beneficiary. The access rule adds a compliance component to this, stating that states must achieve 90% compliance for reassessing beneficiaries every 12 months, and reviewing their service plan every 12 months. And this is another area that we would assert, again, why are we settling at 90% compliance, why aren't we trying to achieve 100% compliance here?

So the timeline, states have to comply with this 90% standard by July 9th of 2027, so they have three years. On paper, this might seem easier, but as I mentioned, this is a real challenge to move the needle when it comes to person-centered planning, to really develop a process where the individual feels to lead their person-centered planning process, that they're aware of the various services that are available to them, and that they can use these services to create a system of support that reflects their needs and goals. This is incredibly important, but based upon the previous implementation takeaways from the settings rule that I shared, it's proven very difficult to achieve. So a lot of attention is going to be needed to focus on this particular part of the rule, and we need measurement standards, for example, that really capture the beneficiary perspective to ensure that these plans reflect their objectives. And you're going to be hearing more from the community living policy folks about the HCBS measurement pieces included within this access rule.

And then quickly, before I conclude my portion of the presentation and pass it off to our friends at the Community Living Policy Center, I want to quickly discuss the additional reporting requirements and some website transparency requirements contained in the rule. So you already heard me touch upon various reporting requirements when it comes to critical incidents and when it comes to the person-centered planning process, these are both focused on timeliness. There are additional reporting requirements when it comes to home and community-based services wait lists. Right now, there are approximately, last I checked, I believe, about 700,000 people across the United States waiting for these services. The way that wait lists are managed varies significantly from



state to state. So the access rule begins to gather this information, specifically requiring states to report how they maintain their wait lists, the number of people on their wait lists, and the average amount of time on the wait list before being approved for services.

Additionally, states must report the time difference between approval and provision of services, and then the percentage of authorized services being provided. We at Justice in Aging are really interested in this particular measure. We hope that this data will allow us to produce more granular policies to identify where there are barriers to services. There are additional reporting requirements for the quality measure set, which you're going to hear about shortly, and then also specific to payment adequacy, which we are not covering today. So this information must be reported to CMS, and then it must be posted on a state website, and the deadline for compliance with this particular piece of the access rule is July of 2027.

And I would just note that this is, again, another area where your collective advocacy and input is needed to make sure that the dashboard that's created via that website, however the information is shared, that it's accessible to you all as advocates, that the information not only considers accessibility features, but it contains a process for you to actively get it in a timely manner so that it can lead to quality improvement efforts. And with that, I'm going to pass it off to my colleagues. Thanks so much.

Joe Caldwell:

Great. Thanks, Hannah. My name's Joe Caldwell. I'm at Brandeis University, and I'm the director of the Community Living Policy Center. I'm a white middle-aged male, and I'm wearing a blue shirt today, and my background is a college campus, it's the campus of Brandeis University, which is just outside of Boston. We're going to talk about two other provisions of the access rule, where we've been, I think, most excited about, and also doing a lot of thinking about how to really meaningfully implement these provisions.

So if you go to the next slide. The two provisions that we're going to talk about, the first one that I'm going to talk about is the Home and Community-based Services Quality Measure Set. And this is establishing, really for the first time, a core set of HCPS quality measures. And then, I'm going to turn it over to a colleague of mine, Syd, and she's going to talk about the Interested Parties' Advisory Group, and that's an important part of the rule, that's a stakeholder advisory group, and there's unfortunately a lot of flexibility in this, so we have some ideas that she's going to share about how we can really work together to meaningfully implement that provision.

So if you go to the next slide. It's important to remind people the HCBS Quality Measure Set, what's the real purpose of this, and there's really two main purposes. The first is to, really for the first time, have some consistent reporting on quality across all states, so we can look and compare states on how they're doing on important quality measures. And then, the other is for states to really

use these measures to drive quality improvement within their states, working with their stakeholders and improving home and community-based services quality.

So if you go to the next slide. So I wanted to give just a little bit of history about how this provision came to be. And it's been a really long process, it's been over a decade process, so it's not just something that CMS came up with and just put into this regulation, this is something that really has a history and a lot of advocates and people at CMS and people working on quality measures have really been working on this, so we're excited about it. But if you go way back to, say, 2010, when the Affordable Care Act passed, we started to see a lot of states move to managed care and duals integration, and a lot of the advocates that were working on those issues really realized that quality measures are really important here. That's really a consumer protection thing that you can work on, having good quality measures to hold the plans accountable, to set benchmarks and incentives for improvement, like getting people out of institutions and back to the community.

But unfortunately, at that time, we really didn't have good home and community-based services quality measures. We had a bunch of medical measures, but not really the HCBS measures that we needed, and there wasn't even agreement on what measures we needed. So the first thing that happened was there was a National Quality Forum committee on home and community-based services quality, that I co-chaired, along with Steve Kaye, who was at the University of California, San Francisco. And this brought together multiple stakeholders, advocates, people with disabilities, plans, states, and surprisingly, we all came to agreement on a framework for home and community-based services quality, and we also came to an agreement that we need a core set of measures. So that was about a decade ago.

The next thing that happened was we needed to develop the measures, and over the last 10 years, there's been a lot of measure development that has happened at CMS. They developed something called the HCBS Consumer Assessment of Healthcare Providers and Systems, or the HCBS CAHPS Survey. They also developed some administrative measures, that included measures about rebalancing and measures about preventable hospitalizations. And then, outside CMS, there was a lot of measure development happening, particularly the National Core Indicators and the National Core Indicators Aging and Disability Survey, which I'll talk about in a minute.

So finally, we had the measures. And I really give CMS a lot of credit, they started to work on developing this core set of measures, so taking really the best measures that we have and putting them into some sort of core set. And even this, there's been a lot of pre-work before the regulation, where they put out a request for information, they got a lot of public feedback, they revised the core set, put out a state Medicaid director letter and some other guidance, and

then finally, what we have is the access rule that would really codify this development of a core set.

So if you go to the next slide. And so, what the access rule does is it establishes this core set, and in the future, states are going to have to report on a core set of measures. That's going to happen in 2028, which may seem like, okay, we have a lot of time, but really, we don't, and states need to start thinking about this now to put the measures in place, so that when that time comes, they'll have the measures to report. CMS will help states, they're going to use Medicaid claims data to report some measures on behalf of states if states want that. And the other thing with the rule is states have to establish performance targets and quality improvement strategies along with CMS's guidance. This is going to take some time, and the phase-in or the reporting is going to take some time, there'll be a subset of measures that states will have to report on, and then that'll evolve over time.

And another thing that's really important is the stratification of the measures, so that we can look at equity and we can look at race and ethnicity, age, rural/urban differences, hopefully someday looking at disability and language. And again, that's going to take some time to phase in what the requirements will be around stratification. But the goal there is to really look at equity and look at how different populations are doing on quality.

If you go to the next slide. So as an ongoing process, and that's really what the reg sets out is really a process to get this started, the reg doesn't identify specific measures at all that states need to do, it sets up this process, and through this process, the measures will be identified. And then, it has to be a continuous process, because as new measures are developed, we might want to add those to the core set, and we might find that there's some measures that we don't need, so they can be taken out of the core set, or they might not be as important. And so, this process has actually gotten underway already, CMS contracted with Mathematica and formed really the first advisory group, this committee that is charged with developing the first recommendations for the core set. And those meetings are going to happen in March, they're open to the public, and hopefully people can tune in and see what the discussion is, and there'll be votes on the actual measures that would be included. And then, following that, there's going to be more opportunity for public comment and input from the public.

So if you go to the next slide. These are some things that I think we can do right now, and states can do right now. For sure, the measure set is going to include what's called experience surveys, surveys that talk to beneficiaries and consumers and get their input. And those are really the most meaningful, I think, measures in the core set, because of the nature of home and community-based services. So these surveys exist already, the National Core Indicators Intellectual and Developmental Disabilities Survey, and the National Core Indicators Aging and Disability Surveys, and the HCBS CAHPS.

So if your state is not doing these, really the advocacy is to really get them to start doing these now, not just because of the access rule, but because they're really important to improving quality. And there's plenty of assistance financially for states to do this already. If your state is in Money Follows the Person, and there's 40 states, including D.C., that have Money Follows the Person programs right now, and if you don't, you can still get into Money Follows the Person, and you can use some of your MFP money to help implement some of these quality surveys.

If you go to the next slide. I talked about the National Core Indicators, and this is one of the consumer experience surveys that we've done a lot of research with at Brandeis and find it tremendously useful. And just to give you some background, these are surveys that are done in person with HCBS beneficiaries. During COVID, they did open it up to some remote or Zoom technology if states want to do that. But they randomly pick a sample of people that are receiving HCBS, and they go out and do a pretty extensive survey with them, and it gives you really valuable information about person-centered planning, about whether they're participating in the community as much as they want, whether they're seeing family and friends as much as they want, unmet needs for things like home modifications and assistive technology, so it's a really rich data source.

And there's a map here that it indicates in blue the states that are currently participating in the NCI-AD survey now. Now, the good news is 30 states are actually doing the survey, and I think because of the access rule this past year, there was a big uptake of the survey, including California and Massachusetts got in for the first time. So again, if your state isn't doing this, they're going to have to do it probably sooner or later, and you might as well get in sooner, and it is a really important survey.

If you go to the next slide. The other thing that advocates and states should be working on right now, pretty much regardless of the access rule, but definitely in light of the access rule, is improving their data and their data systems. States have to report claims data through this what's called T-MSIS, it's this Transformed Medical Statistical Information System. It's relatively new and there's still a lot of issues to work out that states aren't reporting particularly their home and community-based services data very accurately, and there's major problems in some states, like California who's really under-reporting their HCBS data. So now's the time to really try to improve that, because these measures really rely on, first of all, being able to identify who's getting HCBS. And then, the other thing is the quality of the race/ethnicity data. If we're going to look at disparities and try to look at equity, you've got to collect race and ethnicity data. And unfortunately, this is a big problem in Medicaid in a lot of states.

If you go to the next slide. This is according to CMS, the states that have very high concern about the usability of their race ethnicity data, so those are states that are indicated in red, and some of those include Massachusetts and

Tennessee and Utah. The states that are in orange, they have very high concern, they're missing up to 50% of their race/ethnicity data, so it's really almost impossible to look at disparities in those states. And so, some of those states include New York and Iowa, even Oregon and Wyoming. So there's a lot of work to be done to improve the race/ethnicity data.

If you go to the next slide. Lastly, I think with this quality measure stuff, the measures are only as good as what you do with them, so it's very important to work with stakeholders to have some sort of ongoing process where you meet with the stakeholders, the beneficiaries, the advocates, the health plans, the providers, and share the quality data, and have discussions about how they can work together to set benchmarks for improvement. And lastly, I'd be remiss if I didn't say to partner with universities and partner with researchers who can look at this data and help the state understand what to do with their quality data. And I think with that, I'm going to turn it over to Syd for the next provision she's going to talk about.

Syd Pickern:

Thanks so much, Joe. My name's Syd Pickern, and I work with Joe at the Community Living Policy Center at Brandeis. I am a white middle-aged person with pink and brown hair, pink glasses, and a black shirt with white eyes and eyelashes.

So we are going to talk about the Interested Parties' Advisory Group, and this name doesn't provide a ton of detail on what this provision is all about, but we are going to go with it. And the important thing is what this group is supposed to do, and it really gets at the whole heart of the access rule, which is about determining if the payment rates for direct care workers are adequate enough to ensure access. So this advisory group is really important to think about, not only in terms of how states are going to implement this provision, but also opportunities for advocates. Next slide, please.

So IPAG membership. So there's consensus among advocates that the requirements for the advisory group could be more robust. However, the plus side is that there is a lot of flexibility when you're implementing this. And so, the counter to that, of course, is the risk of the group potentially being tokenistic, if it's not thought through and implemented well with strong partnerships between advocates and the states. And so, there's minimum requirements for who should be on the group, including direct care workers, beneficiaries, their authorized representatives, and then other interested parties, which may include beneficiary family members and advocacy organizations. States also have the option to use their Medicaid advisory committees to implement this, but both distinct group requirements must still be met if that's the case, so there's definitely nuances there. And the process by which the state selects group members and convenes its meetings must be made publicly available on the state agency website. So again, there's a lot of flexibility in implementation here. Next slide, please.

So purpose and reporting requirements. So the group is required to meet at least every two years, starting in July of 2026. Again, the purpose of the advisory group is to make recommendations to the state Medicaid agency on the adequacy of direct care worker payments. States are required to respond to recommendations from the advisory group in connection with any state plan amendment submission that proposes to reduce or restructure Medicaid rates, and then share this analysis with CMS. So the group will have access to current and proposed payment rates when it meets for the first time next year. But it's important to note here that the group may not yet have access to care data or the payment adequacy data at that time, but it's still important for the group to meet, not only to operationalize it, but also because there may be other publicly available data that the group can look at. Next slide, please. And then, Hannah, we're going to skip this slide, please.

Okay, so establish right group and process. So these are just some thoughts on how the interested party advisory group could be implemented in a meaningful way. The first thing really is that you have to think about establishing the right group and the right process, and going beyond what's in the reg and really thinking about who needs to be on this group. We talked about beneficiaries, the potential for family caregivers, workers obviously, advocates, providers, plans. But it's also really about the diversity in terms of the disability populations, agencies versus self-directed care, race and ethnicity, and of course geography. And you've really got to have a representative group here, because these issues are complicated.

So supporting the group's meaningful engagement, this would be an opportunity for CMS to provide guidance on stakeholder engagement and supporting that for this group, and then thinking about this as an ongoing process, so meeting more frequently than every two years. And also, the potential for expanding the purpose of the group to not only adequate rates, but also developing additional solutions for direct care worker recruitment and retention barriers. So this group could in fact be a larger group that takes on more of the direct care workforce crisis. Next slide, please.

So provide the right data and information to allow the group to make informed decisions. So the other thing is you really have to arm this group with the right data and you have to give them the right information. So if they're supposed to make a decision about whether payments and rates are adequate, they need as much information as possible, and of course, there are some data sharing requirements in the regulation that I mentioned earlier, for example, the payment adequacy and the access reporting requirements, and those are really getting at gaps in care, and that's definitely important, but the work groups have an opportunity to really look at additional data. For example, states could use, as Joe was discussing, the National Core Indicators data and the HCBS CAHPS data. Those actually have really good questions about the direct care workforce, the quality of the workforce, whether there is high turnover.

And there's also this whole new survey that folks should be aware of that NCI-AD and NCI-IDD have implemented called the State of the Workforce Survey, and that could also be really useful as well. So states are encouraged to take part in these surveys, because they can give the work groups data on turnover and retention, and all of this would be really useful for the advisory group to look at. The advisory group could also look at the Bureau of Labor Statistics data, where you can compare the wages of direct care workers with the wages of workers in other industries in your state that might be competing for jobs. And the advisory group can get creative, because there's a lot of other data sources, including public comments, testimonies, and stories, to get a sense of whether rates are adequate or not. Next slide, please.

So use the analysis and the report. So similar to the quality measures that Joe discussed, this is about using the recommendations that are developed by the advisory group. The state has to respond to the recommendations from the group and share this with CMS in certain circumstances, but there's not a lot of teeth in the regulation in terms of the adoption of the recommendations. So we really encourage that these advisory groups use the recommendations they develop to, for example, inform their state legislatures, who may actually have more power in terms of setting the rates.

And so, that's the final slide on the IPAG, and we're going to get into some of the questions and comments here. And I think the first one that we really wanted to address, and this is a two-fold question for the panelists, is what is the reality of the risks of this rule being overturned, and what are the implications for these rules if the next administration either cap or block grant Medicaid?

Hannah Diamond: I'll start with this response. I appreciate this question. There is a possibility that this rule, components of it could be repealed. There's also a possibility that the implementation could be very much delayed. That said, I would encourage us, as advocates, to think that this is really important work for us to continue on. We need to just keep on being persistent, holding state officials accountable, holding our government officials accountable. States are required to meet the minimum floors that were contained within this rule, but they can do this also on their own and they can go above the minimum floors. So it's really, I think, our job as advocates to keep persisting, and continue under the assumption that it is going to be implemented via the timelines that are established that we discussed today.

Joe Caldwell: Yeah. This is Joe. I would just add a lot of the things that we talked about today are very bipartisan and have to do with reporting and accountability and quality, and I think those are things that a lot of folks agree on regardless of where your political background. So I'm optimistic that a lot of these provisions of the rule are going to be implemented going forward. I agree with Hannah, we should just move forward as things are right now, because some of the provisions, like

the quality stuff, is coming up pretty quickly. And like I said, it takes time to build these quality systems before you start reporting.

Syd Pickern: Thanks Hannah and Joe. So there's a few specific questions in the Q&A regarding what we presented on, and so I think just answering those initially could be useful. One of them is, can you clarify the application of the access rule to fee-for-service and managed care? And another part of that is, does the new rule apply to D-SNP advantage plans with Kaiser?

Hannah Diamond: Sure. So home and community-based services are provided via various Medicaid authorities. This can be 1915(c) waivers or state plan benefits or self-directed benefits or community-first choice, 1915(k) or 1115 demonstrations, there's a lot of different ways. Unless explicitly noted in my commentary at least, for example, the grievance system only applies to fee-for-service Medicaid services because there was already one for managed care, but otherwise, it's going to apply to others. And there, if you have a very specific question, please reach out to us about a particular provision. But the scope of what we're talking about holistically in terms of creating these floors, it will apply to the various Medicaid authorities.

Regarding D-SNPs, that's a little bit more tricky. There are various types of D-SNPs, all of them coordinate Medicaid services, but not all of them cover Medicaid services. So for the D-SNPs that are offering higher levels of integration that cover home and community-based services, they would be required to abide by all of the regulatory requirements for home and community-based services.

Syd Pickern: Thanks, Hannah. And there's a couple of questions in the chat related to grievances specifically, so if a grievance lasts longer than 90 days, who can we notify?

Hannah Diamond: Each state is going to have a different process, but I would first say that it would be your state Medicaid agency, and if it's not addressed, then you're going to go to CMS. But again, each state could be different. But that is a huge area for advocacy, so would really encourage you all...

And I saw another question that's related to that regarding delays that I just want to touch on, and someone brought up a really good point here, I think it was Misty. Whenever we introduce a new system or there is change, there can be unintended consequences that result, like delays in terms of access or barriers that we didn't anticipate. And so, I think this echoes the point that Joe made earlier regarding the measure set, these deadlines to come into compliance, even though they might be two years from now or four years from now, that time is going to pass very quickly, and by leveraging lessons learned and really thinking through the unintended consequences that could happen, then the delays, like the ones that were noted in the chat, or any harms that could be associated with change, those are less likely to occur. So I just want to



say that that's, again, another reason for your continued advocacy and persistence, even though something might be four years away in terms of implementation.

Syd Pickern: Thanks, Hannah. And then, another quick question on grievances, you said families or other supporters cannot file concerns/grievances, only the recipients themselves, does that apply to those who have guardians?

Hannah Diamond: Okay, so I just want to clarify here. So the grievance system is really focused on the beneficiary being able to vocalize a complaint or a grievance, but that would include their support system as well, or a guardian as well. Right now, the critical incident system does not accept that type of information, it's really oriented at the provider. And then, there are state processes to identify under-reporting. So that's where we want to make sure that we are able to have the beneficiary and their support system being able to participate in that system as well. I hope that helps to clarify.

Syd Pickern: And then, a question for Joe, and you talked a little bit about this, Joe, but where can we find a list of the quality improvement measures, if that exists?

Joe Caldwell: Yeah, yeah, I saw that question. It's on CMS's website, but it's always hard to find things on CMS's website. Maybe we could try to put a link or something in one of the follow-up emails. But it is on the website, there's a list of the draft core set. And it was also in a state informational bulletin that came out in April of last year, there was a list of all the measures. And then, if you actually want to look at the National Core Indicators surveys and... Well, really the indicators from the National Core Indicators, they both have a website, there's one for NCI-AD and there's one for NCI-IDD, and if you go to their website, they put out annual reports, and you can see the states that participated, how they did on different quality measures. And I think if you look at those reports, you can really see the value of doing this, because you see big differences between states, like on things like person-centered planning, you see a lot of variation. So it's good to look at those reports, but that would give you a sense of what is in the actual surveys.

Syd Pickern: So the next question is a bit more of a high-level question, is there an attempt to educate primary care providers in order for them to make proper referrals for home and community-based services? Ours have lacked the knowledge of the regulations for medical care for severely disabled patients.

Hannah Diamond: Yeah, I saw that question. I think that speaks to the bigger issue, I'm going to take it away from just primary care doctors and make it other types of providers as well. There needs to be more training on home and community-based services, what services are available, what residents' rights are, how individuals can access these services. These systems, as we talked about, there's a need for more resources in general to support the existing systems, and then to expand the systems to make sure that people can access the critical care that they

need. And so, I think that, to answer that question, it's targeted training and outreach to particular provider communities on behalf of the state to make sure that those providers are aware of these services and individual's rights within the context of home and community-based services.

Joe Caldwell: Yeah. I'll just add, there's nothing specific in the rule, but yeah, it's a huge issue, and we're thinking about how to save money and save money in Medicaid. When people don't have access to HCBS or know about it, then they end up going to nursing homes and institutions which cost more money. So yeah, it's an issue at the state level, and hopefully with the new administration, that we can continue to work on.

Syd Pickern: Thanks, Joe. And then, Hannah, again, on the grievance process, do you have any thoughts, suggestions, re: states contemplating using the same grievance process across managed care and fee-for-service? What are some things to look out for?

Hannah Diamond: So I mentioned that the managed care regs explicitly cover quality of care issues, so that's a good thing to make sure it gets into the fee-for-service regs. And then, the other big points that I mentioned, I think, are consistent throughout my slides, just making sure that you're really identifying opportunities that need to be more granular, more detailed, to ensure that individuals are getting a meaningful resolution, and that the system is responsive to them, and that they can participate in it. Each state's grievance system is going to look very different, so that's hard for me to manage, but the recommendations that we cover today will give you some high-level ideas in terms of places to start. And then, if you have a more specific question, our contact information, or my contact information, is at the end of this presentation, so reach out and we'll connect.

Syd Pickern: So I think we've answered broadly a lot of different kinds of questions. Looks like we have another minute, so I wanted to throw it to Hannah or Joe to see if there was anything else you wanted to answer?

Hannah Diamond: There was one that I saw in relation to Olmstead and how this relates to Olmstead, and I would just say Olmstead was a Supreme Court case that basically reaffirmed that individuals have the right to receive services in the least restrictive setting possible, and rules like this, the access rule, are attempting to achieve the promise of Olmstead. And so, it is, again, our responsibility as advocates to hold states accountable to the promise of a rule like this one of the access rule. So I would say that this is directly moving the needle, stemming from the Olmstead rule, and actualizing and improving the quality of care and the availability of care that is available to anyone receiving these services. I wonder, Syd or Joe, do you have anything else to add on that one?

Joe Caldwell: I absolutely agree. If you take a step back, this rule, as it applies to HCBS, is really getting at the direct care workforce crisis, or trying to get at the direct care workforce crisis, that we know is going on. And without access to workers and adequate wages for workers, yeah, it is an Olmstead issue, I would argue, because it's going to drive people into institutional settings and not being able to stay in the community, so I think it is, definitely.

Hannah Diamond: And I think with that, we are out of time. Thank you all for being with us today. A big thank you to Joe and Syd for co-presenting with me. And thank you so much for joining us and learning about the access rule, we really appreciate your participation. Have a good day.