PUBLIC MEETING

Hemisphere Room
Ronald Reagan Building and International Trade Center
1300 Pennsylvania Avenue NW
Washington, D.C. 20004

Thursday, December 12, 2024
10:32 a.m.

COMMISSIONERS PRESENT:

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P R O C E E D I N G S

[10:32 a.m.]

CHAIR JOHNSON: Good morning, everybody. Welcome to the December MACPAC meeting. As always, we have a very packed agenda with some critical topics that align with our mission, of course, of improving Medicaid and CHIP.

I do want to thank you all in advance for your time and dedication for today, and with that, let's get started with our very first session. And this will be the first of a few focused on managed care. So the first is called "State and Federal Tools for Ensuring Accountability of Medicaid Managed Care Organizations," and this will actually highlight some of the important work we're doing around accountability tools for Medicaid managed care organizations.

We'll hear from Allison Reynolds, who's our Principal Analyst, and Chris Park, our Policy Director and Data Analytics Advisor, about some federal and state-level approaches to ensure compliance with contractual obligations.

So, with that, I will turn it over to the two of you.

STATE AND FEDERAL TOOLS FOR ENSURING ACCOUNTABILITY OF MEDICAID MANAGED CARE ORGANIZATIONS

* MS. REYNOLDS: Good morning, Commission. Thank you.

Managed care is the predominant delivery system in Medicaid, and the effective oversight of Medicaid managed care programs is a priority for stakeholders. Today we are introducing a new project on Medicaid managed care accountability with a focus on the tools available to federal and state regulators to oversee states' managed care programs.

Specifically, how does CMS regulate state Medicaid agencies and ensure compliance with federal regulations, and how do state Medicaid agencies oversee their contracted MCOs' performance and incentivize plans to exceed contractual requirements and performance measures?

Additionally, what evidence can we identify that these tools, both incentives and penalties, improve plan performance over time?

Lastly, we want to understand how state Medicaid agencies incorporate MCO performance from existing

contracts into their procurement process for new contracts.

This discussion of federal and state accountability tools for Medicaid MCOs will be the first of several over the next year and extend into the next analytic cycle. The goal of this session is to provide a foundation for our future work.

Today we will provide background on the use of full-risk comprehensive MCO contracts to deliver Medicaid benefits and place this new project in context with a brief review of MACPAC's previous managed care accountability work. We then provide an overview of federal policy relevant to managed care procurement, state Medicaid agency responsibilities when contracting with MCOs, and CMS's role in providing direct oversight of MCO contracts.

We will present our initial findings from our 40-state environmental scan conducted with our contractor, Mathematica. The scan was a thorough review of accountability tools found within recent MCO materials, including requests for proposal or RFPs, MCO contracts, and MCO performance information available on state websites. Our focus was on accountability tools states utilize and any potential impact MCO performance may have on

procurement opportunities.

In the second phase, we will conduct stakeholder interviews with representatives of federal agencies, CMS, OIG, and GAO; state Medicaid agencies; MCOs; Medicaid managed care national experts; and beneficiary advocates.

Lastly, we will detail next steps in our work, including areas of further inquiry based on the Commission's feedback to the work presented today.

Under Medicaid managed care, states pay MCOs to cover a defined benefits package through fixed periodic payments referred to as capitation payments. States may implement managed care for many reasons, including: providing more control and predictability over future costs; improving efforts to measure, report, and monitor performance, access, and quality; allowing for greater accountability for outcomes compared to fee-for-service; and providing additional opportunities to improve care management and care coordination.

Managed care is the predominant Medicaid delivery system in most states, with 73 percent of beneficiaries enrolled in a comprehensive full-risk MCO.

In fiscal year 2023, managed care capitation

payments accounted for 56 percent of Medicaid benefit spending.

In recent years, MACPAC has focused on Medicaid managed care accountability by studying managed care policies regarding MCO procurement practices, external quality review, or EQR, processes, and denials and appeals in utilization management.

In 2022, MACPAC examined the procurement process, wherein state Medicaid agencies select and contract with MCOs. The study confirmed procurement is an area where CMS defers to states but also found that opportunities exist for CMS to assist states and MCOs with meeting contractual requirements and program goals, including through the federal readiness review process.

In 2022, MACPAC began a comprehensive study of the EQR process, one of the few statutorily required tools the federal government and states have to engage in Medicaid managed care oversight.

After analyzing the study findings in the context of the 2024 managed care rule, we identified gaps in how the EQR process and findings are used to oversee MCOs and improve quality. The Commission is currently evaluating

proposed recommendations to focus EQR activities on meaningful outcomes over process and to improve the usability of EQR findings through digestible, actionable, and accessible reports for stakeholders. Those proposed recommendations are the focus of our next session during this morning's meeting.

In 2023, MACPAC examined the oversight of denials and appeals in Medicaid managed care and the beneficiary experience with the appeals process.

Our work concluded in 2024 with the Commission making seven recommendations in our March report to Congress to improve the appeals process and enhance monitoring, oversight, and transparency efforts. These recommendations included requiring external medical reviews of denials, states conducting clinical audits of denials to assess clinical appropriateness, and CMS and states making denials and appeals data publicly available in accessible formats.

CMS has issued three comprehensive updates to Medicaid managed care rules in 2016, 2020, and 2024. In totality, these rules reflected CMS's efforts to promote state and MCO accountability for enrollees' access to care,

quality, and health outcomes while balancing appropriate federal oversight with state flexibility.

Since 2021, CMS has supplemented this increasingly complex regulatory framework with a series of four annual informational bulletins to provide tools for states and CMS to improve the monitoring and oversight of managed care in Medicaid.

There are few federal rules governing the Medicaid managed care purchasing process, and CMS's involvement once contracts are awarded focuses largely on state reporting requirements and providing technical assistance to states.

States contract with MCOs, selecting them through a competitive procurement process, RFPs, or a noncompetitive application process. The procurement or application documents establish the state's performance expectations, which are then formally agreed to in the contract between the state and its selected MCOs. Medicaid managed care procurements are often among the largest contracts awarded by states.

From our prior work, we found that the federal government defers to states and their respective

procurement laws when selecting Medicaid managed care plans. Therefore, states manage their own MCO procurements, deciding whether to have a competitive or noncompetitive selection process, the selection criteria, the evaluation panel, how many MCOs to contract with, the frequency of re-procurement, and the content of the contract beyond the required federal provisions. States may, but are not required by federal statute or regulation to, incorporate MCO past performance in future procurement cycles. These are decisions that can influence the success of a managed care program, including MCO willingness to contract, the responsiveness of participating MCOs, provider participation, enrollee access, quality of care, and continuity of care.

The uniform administrative requirements, cost principles, and audit requirements for federal awards implemented by the Office of Management and Budget, known as "OMB's Uniform Guidance," does not apply to Medicaid managed care procurements. The only aspect of federal procurement guidance that states must apply when procuring Medicaid MCOs is to establish conflict of interest safeguards. Federal statute and regulations specify the

types of organizations with which states are allowed to enter into comprehensive risk Medicaid contracts.

CMS verifies that each selected contractor meets the definition of an MCO or is one of the other types of entities as part of the annual contract review process. By statute, an MCO must offer benefits to enrollees consistent with that state's Medicaid fee-for-service program, have adequate protections from insolvency, and enrollees are at no risk for the debts of the MCO.

The managed care procurement process creates enormous potential for state Medicaid agencies to improve access, quality, and health outcomes for enrollees. States require MCOs demonstrate innovative ideas to improve the managed care program in their bids and often binds MCOs to their commitments to make in RFP responses in the resulting contracts.

However, achieving the goals articulated in the procurement process depends on strong federal and state oversight of MCOs' contractual obligations. While CMS promulgates regulations to establish requirements that govern how Medicaid managed care programs should operate, CMS generally does not have a direct role in ensuring that

MCOs are complying with federal and state regulations or other contractual terms because CMS is not a party to the contract.

For the past eight years, CMS has supported states' implementations of the managed care rules through sub-regulatory guidance, technical assistance, informational bulletins, and training.

Both the Social Security Act and implementing regulations impose specific responsibilities on state Medicaid agencies when they choose MCOs as their managed care partners.

First, Section 1932 of the Act requires states to develop and implement a Quality Assessment and Improvement Strategy, or QAPI, that includes performance measures MCOs must meet and monitoring procedures the state will undertake.

Second, Section 1903 of the Act requires states develop capitation rates that are actuarially sound. The managed care regulations at 42 CFR 438 clarify that soundness includes states ensuring that capitation rates are adequate to meet MCO contractual requirements regarding availability of services, assurance of adequate capacity

and services, and coordination and continuity of care. These rates may cover special contract arrangements between states and MCOs, including incentives, withholds, and risk-sharing mechanisms. Total payments under the incentive arrangement, for example, capitation rate plus incentive payment, cannot exceed 105 percent of the approved capitation payments.

Third, the Act provides that a state may not enter into contracts with MCOs unless the state has established intermediate sanctions that it may impose on an MCO that fails to comply with specific requirements. Medicaid managed care rules implement this requirement for state Medicaid agencies to hold MCOs accountable for performance on access, quality, and costs. However, actually imposing the sanctions is entirely within the state Medicaid agency's discretion.

Since 2023, CMS requires states submit Managed Care Program Annual Reports, or MCPARs, including information on sanctions and CAPs states imposed on their MCOs the previous year.

States are required to post MCPARs on their state Medicaid program website, and CMS has begun posting MCPARs

from states in a central repository on Medicaid.gov.

Federal regulations at 42 CFR 700-708 provide the basis for states to establish sanctions and require states to establish intermediate sanctions for specific instances in which the MCO acts or fails to act.

States must include this intermediate sanctions language in their MCO contracts, and CMS confirms this language is included during the review of states' managed care contracts as part of readiness review.

Federal regulations do provide CMS with direct oversight and enforcement authority in specific instances. For example, CMS must approve states' actuarial rate certifications with MCOs. CMS must also review and approve state Medicaid agency contracts with MCOs to ensure they include all of the federal requirements specified in 42 CFR 438.

CMS has authority to deny federal match on state capitation payments to an MCO that does not comply with the applicable requirements of Section 1932 of the Social Security Act.

Under Section 1903 of the Act, CMS may also deny federal match for new enrollees of an MCO for the same six

reasons for which the state must establish intermediate sanctions: failing substantially to provide medically necessary services to an enrollee; improperly charging enrollees for services; discriminating against enrollees based on their health status or need for services; providing false or misleading information to CMS or the state; providing false or misleading information to enrollees, potential enrollees, or providers; and failing to comply with physician incentive plan requirements.

In the 2024 Managed Care Rule, CMS increased managed care oversight through additional reporting requirements, particularly around beneficiary access to care. The rule requires states to submit and implement a formal remedy plan for any of its managed care plans when monitoring and oversight activities by the plans, states, or CMS demonstrate a managed care plan needs improvement in meeting required access to care standards. That part of the rule is effective in 2028.

Traditionally, CAPs have been imposed and monitored by state Medicaid agencies or their contracted external quality review organizations, or EQROs, as part of the annual EQR process.

Under this new requirement, states must submit a remedy plan to CMS for approval within 90 calendar days of the state becoming aware of a managed care plan's access issue. The remedy plan must address the issue and improve access within 12 months and must demonstrate those improvements are measurable and sustainable.

States must submit quarterly progress reports to CMS, and if the remedy plan does not result in improving the access issues within one year, CMS may require changes to the remedy plan and/or continuation of the remedy plan for a second year.

CMS and states have made concerted efforts to strengthen oversight of managed care programs, but little is known about the accountability tools state Medicaid agencies use to ensure MCOs comply with contractual requirements and meet or exceed performance expectations.

States have a range of mechanisms, including withholds and incentive payments, for achieving quality standards, quality-based auto-assignment of enrollees, fines for late or incomplete report submission, corrective action plans or CAPs, and financial penalties, sometimes called liquidated damages. Few studies have systematically

examined states' use of these mechanisms or their effectiveness.

Working with Mathematica, we conducted a systematic review of Medicaid MCO contracts executed between 2021 and 2024 for 40 states operating comprehensive risk-based managed care. Of the 40 states in the environmental scan, we also reviewed 23 RFPs that were publicly available.

Let's begin by taking a look at the key findings from the 23 RFPs we reviewed. Our review found that all 23 state RFPs required bidding MCOs to provide past performance information in their response. Of the eight specified categories of performance issues states required MCOs to disclose in RFP responses, the most frequently required were non-renewal or early termination of contracts, which were required by 17 states. Corrective actions or CAPs were required by 16 states and monetary penalties for 12.

In addition to the categories of past performance states included in RFPs, we made several other initial findings regarding procurement. In regards to disclosing past performance issues, only two states did not specify a

look-back period. The other 21 states varied in their look-back period requirements ranging from two to eleven years. More than half of the states required MCOs disclose issues occurring in the previous two through five years. Seven states required between six and ten years, and one state required MCOs to provide eleven years of past performance issues.

States also took a range of approaches in the specific information requested within these broad categories of performance issues and how the information may be ultimately used in awarding a contract.

For example, one state primarily used past performance as a tiebreaker between similarly scored proposals. Another had RFP language that would allow the state to refuse to consider any proposal from a bidder that had violated contract provisions. A third state not only asked whether a bidder had a Medicaid managed care contract terminated, it also requested information on whether bidders voluntarily terminated a contract with a state Medicaid agency, withdrew from a service area, or requested a reduction in enrollment levels. A fourth state required bidders to its 2023 RFP to explain how they will avoid

contract noncompliance in the future if awarded a contract, even if the bidding MCO did not have any deficiencies from the past three years to report. And in one of the rare instances where procurement decision documents were publicly available, one state specifically noted that a bidder's disclosure of PHI breaches, as required in the RFP, was a deciding factor in the state not awarding that MCO a contract.

It is worth noting that state Medicaid agencies allow bidding MCOs to submit disclosures of past performance under the confidential and proprietary process common to RFPs. Therefore, our line of sight into whether MCO disclosures were a factor in the state's evaluation of, scoring, or selection of MCOs will only be known to us if publicly available evaluation documents specifically reference the deficiencies identified for bidders, as in the PHI example.

Our review of 40 contracts executed between state Medicaid agencies and MCOs from 2021 to 2024 found overwhelmingly that financial sanctions and incentives were the most frequently cited accountability tools available to states. States were also universal in citing deficiencies

in MCO performance, quality of services, and enrollee access to services as reasons for sanctions.

The contracts we reviewed touched on potential differences in how states could use similar tools but frame their approaches differently. For example, some states frame public reporting or auto-assignment as an incentive or reward for high performance, while others frame these tools as penalties.

We identified 11 different types of sanctions that states may impose on MCOs: administrative corrective actions, enhanced monitoring and oversight, CAPs, enrollment penalties, capitation payment penalties, monetary penalties, temporary management of a contractor, contract termination, refusal to renew the contract, referral for investigation, and public reporting.

And we identified three types of incentives state Medicaid agencies included in their contracts with MCOs: capitation payment bonuses to meet or exceed performance standards or targets, auto-assignment of enrollees, and public reporting of MCO performance.

All 40 state contracts we reviewed had some type of sanctions provisions. At the high end, two states each

had nine sanction types included in their contracts. Eighty percent of the states, 32 of the 40, included between five and eight sanction types in their contracts. One state, a non-competitive application state, had the lowest number of sanctions provisions in its contract with three.

The most common sanction types states included in their MCO contracts were monetary penalties, present in all 40, CAPs and contract termination, present in 38, administrative and corrective actions in 32, enrollment penalties in 24 state contracts, and capitation payment penalties in 21.

Our study found that the underlying reasons states cited in contracts to impose sanctions included issues with access to services, contractual noncompliance, and operational deficiencies with an MCO as well as its subcontractors, among other reasons.

All 40 state contracts we studied had language allowing state Medicaid agencies to impose sanctions of some type in response to identified deficiencies in performance, quality of, or access to service requirements. This broad category includes noncompliance with federal

requirements such as external quality review, provider network adequacy, or delays in service authorization.

All but one of the 40 states included incentives in their contracts to encourage MCOs to achieve or exceed performance standards. Ninety percent, or 36 of the states, had MCO contracts allowing for capitation payment bonuses to meet or exceed performance standards or targets, followed by 17 states providing incentives through the auto-assignment of enrollees. Three states included explicit contract language allowing the state to publicly report individual MCO performance on quality measures and other performance indicators.

States have wide latitude to develop incentive strategies that encourage and reward MCOs for meeting and exceeding performance measures and contractual requirements. Our study revealed a variety of approaches for each incentive type that demonstrate the considerable flexibility state Medicaid agencies have in designing an MCO accountability program that meets their state's particular needs. For example, one state tied incentive payments to increased access to preventative, early intervention, and behavioral health services by school-

affiliated health care providers.

The second most common incentive we found in the contracts we reviewed were provisions allowing state Medicaid agencies to auto-assign enrollees to MCOs based on performance.

Seventeen state contracts had auto-assignment language to reward high-performing MCOs with greater enrollment. These methodologies were frequently tied to performance on quality metrics such as HEDIS scores or beneficiary satisfaction surveys.

Public reporting was only explicitly stated in three contracts reviewed. For example, one state had a provision in which it could include quality and performance indicators on materials developed to help beneficiaries select a plan. While not explicitly stated in the contract, we did find that many states do publish some MCO performance indicators on their websites.

In the second phase of the project, MACPAC will work with Mathematica to conduct stakeholder interviews with representatives of six state Medicaid agencies, their respective MCOs, as well as federal agencies, Medicaid managed care national experts, and beneficiary advocates.

We will also review the MCPARS to see what information is being reported by states to CMS.

At this meeting, we hope to get the Commission's feedback on the project's direction and the initial findings from the federal policy review and 40-state environmental scan. We also welcome Commission feedback on topics to explore through our interviews.

Thank you.

CHAIR JOHNSON: All right. Thank you so much. I thought that was very helpful.

So, Commissioners, any thoughts or questions, particularly around the direction we want this project to go?

All right. Angelo.

COMMISSIONER GIARDINO: Thank you for that. That was really informative.

One thing I'd be interested in understanding as you think about your analytic framework is if there's a way to think about tiering or stratification of those sanctions, because clearly terminating the contract is like a nuclear option. There must be some thought process to more intermediate steps if there's a sense that the plan

can improve and how can you nudge them versus this plan is near fraud and we have to get rid of them. So I would just like to understand best practices and how people think about that tiering.

Thank you.

CHAIR JOHNSON: Thanks, Angelo.

John?

COMMISSIONER NARDONE: This is one we could do like the whole meeting on this, right? I mean, just one hour. I could go on and on about the procurement and different pieces like that.

So one of the things that I would like you to look at, if possible, going back to measurement, is can we do some type of regression analysis looking at how sanctions are used? Is there anything that looks at sanctions versus HEDIS measure outcomes?

It's kind of going to be the same thing on pay for performance. If states use a withhold versus the bonus methodology, do you see some type of better outcomes when it comes to those things? Because this has always been the issue.

Yes, states do these things, and we're in essence

talking about here's how they do oversight, but does the oversight lead to better outcomes? I know the only way we can do it is through HEDIS measures probably, and those aren't outcomes. Those are measurements, but that's what we have right now. So I'll leave it to that, if there's any analysis you guys can do going forward, we can do any type of regression analysis to predict some of those things.

Thanks.

CHAIR JOHNSON: Thank you, John.

Tricia.

COMMISSIONER BROOKS: Thank you.

This is -- I can only imagine the amount of work that went into reviewing all of these contracts and trying to figure out what they did and didn't say. So thank you for this.

I have a couple of things. First of all, on the slide that summarized the -- go back, and I'll find it. Whoa, whoa. No. Go down one more. It was -- there were three things on the slide. I think it was at the end. Yeah, this must be it.

Okay. The public reporting of MCO performance,

is that that the contract specifies for the MCO to publicly report? Is that what that is?

MS. REYNOLDS: So these were incentive tools that were included in contract language where the state Medicaid agency was contractually permitted to publicize MCO performance information. But we did find that even if it wasn't included in contracts explicitly, that many states are publicizing that information, even if they didn't include a provision like that in the contract.

COMMISSIONER BROOKS: Got you.

And on this same slide, there's no mention of withholds, and I heard John mention it. Where do withholds come in?

MS. REYNOLDS: So they'd be captured in the first, in the capitation payment bonuses.

COMMISSIONER BROOKS: And do you know the breakout on that?

MS. REYNOLDS: I don't have it available, but I can certainly look and see if the data broke that out.

COMMISSIONER BROOKS: Okay.

And then my last question is just it's one thing to have these contract provisions, right, that say we're

going to do this or that if you don't. Do we have any information on how often sanctions are applied or, you know, their withholds? I mean, how often do states actually take these provisions and use them as they're intended to be used?

MS. REYNOLDS: Those are questions that we can explore in our interviews with stakeholders.

MR. PARK: And also, we are trying to look at the MCPAR reporting. It's fairly new, so we're not sure to what extent it's fully complete. But, you know, we will get some information about what states are reporting to CMS on whether we actually applied a CAP or financial penalty and for, like, broad reasons.

COMMISSIONER BROOKS: Yeah. Thank you. That's helpful, because I really -- I have a sense, but it could be wrong, that, yeah, the provisions are there, but is the oversight and holding the feet to the fire actually being used for accountability? So I'd be interested in any more information we could get on that.

CHAIR JOHNSON: All right. Thank you, Tricia.

COMMISSIONER NARDONE: So just following up on Tricia and John's points, I mean, I think we're coming to

the same point of, like, what -- okay, how often are these tools used, and which ones are most effective in accomplishing the results, and what are the results we're trying to achieve? So I would just reinforce those points.

I think one of the things that I'm really interested in is what is the state infrastructure that states have to actually manage the managed care process, and I think I'd be interested in maybe some of the ways states do this.

I just reflect on my time, and I'm sure some of the former Medicaid directors around the table could also reflect on this, is, you know, we had to put structures in place where managed care plans are reporting on a regular basis, and it was real -- more real-time. I mean, it was somewhat real-time.

One of the challenges with some of the HEDIS data is that it's so far past, in a way, that, you know, like, right now we're getting data for 2023, right? So I think having some feeling for that as how states, like, actually put that in place, I think, would be helpful for people to appreciate and understand.

And also, just given how strapped, you know, all levels of government are, like, what -- you know, how are they managing that is what I'd be interested in. I guess it's kind of also following up on what you were saying, Tricia, but it's also kind of understanding the real resource constraints that, you know, federal/state government is under.

And then I guess I just want to ask, in this context, do -- and this is kind of a separate topic that I'm particularly interested in. In terms of value-based purchasing strategies, will that be -- is that part of this analysis in terms of accountability around, you know, achieving quality outcomes for beneficiaries? Which I don't know if that's kind of taking us to a different place, but it's something I'm interested in.

MR. PARK: Yeah, it wouldn't be specifically included in this project unless that is, like, one of the specific outcome measures that a state would have built into their contract in terms of, like, you know, you need so many VBP arrangements and we expect these types of outcomes. If you don't, you know, maybe there's a penalty or incentive attached to that, but we're not specifically

going to ask about VBP.

COMMISSIONER NARDONE: So I think that's what a lot of the -- I think that's where a lot of the contracts are headed, right, like, with threshold requirements around how many contracts have to be in value-based purchasing agreements. Are there particular models of VBP that states have to be implementing?

And I think it all kind of goes back to what are you trying to measure, and if you're trying to improve performance and hold plans accountable for improvements in maternal and child health, for instance, you know, a lot of contracts will have actual models that have to be put in place for those populations. So I'm just -- I think it's got to be a little part of that. I'm not sure how -- I know, as others have commented, this is, like, an incredibly broad topic, right? And so I know there's a need to kind of stay focused, but I think as contracts move increasingly to more value-based payment arrangements, I think it'd be interesting to kind of at least have awareness or insights into that.

CHAIR JOHNSON: Yeah. Thanks, Mike.

And just kind of following back up on your

resource and constraints comment, it would be interesting to know, like, what additional resources states may have in terms of the ideas around how they can use these tools more effectively, I think would be really helpful. And then also, too, there are differences between more mature states and smaller states or other demographics or other areas that may be helpful to you as well.

All right. Adrienne.

COMMISSIONER McFADDEN: Yes. Thank you for the work. I appreciate it. There's really not a state scan that I have not appreciated. So I really enjoyed reading through this.

So I have a general comment and then sort of an area of curiosity, which I think thematically is very consistent with the other Commissioners. So the general comment is the past performance information that was in the reading materials. I think just a little nuance there, it comes both in the form of disclosures from the MCOs, but also, there's this sort of underlying state reference, whether it's official or unofficial. So I think that's something that could come out as well as you're exploring more.

So general curiosity, like everyone else, I think the ultimate goal is to really optimize MCO performance, and so I'm going to dissect your language a little bit more and say I sort of looked at it in two ways. One, it's sort of the consequences of the performance. So that may be the auto-assignment that may be direct sort of financial impacts, whether it's a penalty or a sanction or a bonus, et cetera. And then sort of the approach that is taken by the states, which is either the carrot or the stick approach. And so I would really be curious as to sort of what are the more effective consequences.

And then the second one would be what's the more effective approach to the consequences, whether it's a carrot or a stick.

And then to the resourcing sort of theme, really understanding how much resourcing or the burden of administering or executing these sort of tools actually factored into how the state went about it.

CHAIR JOHNSON: Thank you, Adrienne.

Patti.

COMMISSIONER KILLINGSWORTH: I don't want to sound like a broken record, but I do want to reinforce the

importance of really understanding the efficacy of the various tools that are available. I just think it's very difficult to make recommendation about the use of tools if we don't really understand which ones are having the desired impact.

And I think John said it well. You know, does it lead to better outcomes? I would add and/or improve performance. I think there are aspects of performance that may not sort of get to the level of HEDIS outcomes, but they're really important from a performance perspective. And so I would just encourage us to really focus on that as we do this work.

The other thing I would just mention that I think is kind of important is just kind of bearing in mind the CMS oversight and making sure that we continue to honor the fact that CMS oversight is really to the state, which is the CMS contractor, if you will, and then the state is responsible for overseeing the plans. And so when we think about CMS's oversight, I just want to be sure that we kind of keep in mind that CMS should be overseeing how the state oversees the health plans and not kind of put -- not sort of renegotiate that relationship, if you will, and put CMS

in a different position when they really don't have that contractual responsibility over health plans.

Thank you.

CHAIR JOHNSON: Thank you, Patti.

Dennis.

COMMISSIONER HEAPHY: Thanks.

So my question is really about transparency and the procurement, the reporting, like what CAPs are in place and overall performance, because transparency is key to, I think, the performance of a plan. It would be helpful to understand why certain states, if it was three, actually have that public reporting, and why do they do that? What's the purpose of it, and what's the outcome that they get from that?

And then other states, why aren't they more transparent about the entire process? And especially for consumers, for folks who are going to be joining or assigned to a plan, that they should know what the quality of the plans are. So the lack of transparency is really a big issue for me.

And then network adequacy, the states have different definitions of network adequacy, because some

states may require more restrictive time, time and distance, or they may have accessibility requirements that the plan needs to show that the X number of providers in that area have such specialties or just accessible, like, disability ADA requirements.

The other question I have is, given the variation in the state definition of performance, it would be helpful, I think, to understand where the common requirements are for performance or where performance outcomes vary. Does that make sense?

MS. REYNOLDS: Yes.

COMMISSIONER HEAPHY: Okay, thanks.

CHAIR JOHNSON: Thank you, Dennis.

Heidi.

COMMISSIONER ALLEN: Thank you for this work. A lot of the things that I had on my list, other Commissioners have already mentioned, so I'll try not to be too redundant.

I was really intrigued by the levers that were used both as incentives and sanctions and, like, particularly auto-assignment. Is auto-assignment something that when you're new into the market that that benefits

you, but when you've been there for a long time, it doesn't because you would prefer for people to be able to just directly select? I just would love to understand that more.

And building off of Dennis's question about public reporting, I'm curious about the differences when it's used as an incentive versus used as a sanction. Are there different ways of reporting? Like, are the incentives more consumer friendly? So, you know, you go on the website, and you're like, this is the one that the state thinks is doing really well and, therefore, I want to apply. And are sanctions hidden in some report somewhere on a website that the consumer would never see? I'm kind of interested in that relationship.

And then, you know, what many people have said is it's all about trying to make meaning on these tools in terms of how they impact behavior, and it seems like monetary penalties are a really big one, and I just would love to kind of get an understanding of the scope of the penalty relative to the financial benefit for the behavior that was being penalized.

So, you know, sometimes you'll hear about, oh,

this company was fined a million dollars for doing X, Y, and Z. But then you're like, oh, well, they made $75 million doing X, Y, and Z. So, really, it isn't going to drive behavior change because it was still in their benefit.

And related to that, I'm interested in the concept of, like, too big to fail. Are there managed care organizations that are so important for provider networks or so well established that these levers are kind of weakened because states really can't say, "I'm not going to work with you anymore," or is that just not something that exists?

And thinking, like, particularly like Oregon and the CCO model, how has a model like that, which has really fully tried to get the managed care organizations in deep contractual relationships with their providers -- how would you negotiate that, you know, like being able to pick somebody else who doesn't have these kind of already established relationships?

It's pretty complicated, but I'm curious as states are trying to do these innovative things to restructure the delivery system and the relationship

between the managed care companies and the delivery systems, like, how that changes the contractual process and procurement.

And that's it for me.

CHAIR JOHNSON: Thank you, Heidi.

Carolyn?

COMMISSIONER INGRAM: Well, thank you so much for starting this work, and I think I agree with my fellow Commissioners that this could be a lot. So I'm going to just go down my list of things and happy to talk if clarification is needed.

One of the questions I had is if you found any states providing for consumers' report cards or dashboards. I'm familiar with what TennCare does or Tennessee does, but wanting to know if there's something that's more consumer friendly. That goes off of some of our other work that we're talking about later today.

The other piece that I'm wondering about is the number of members who are auto-assigned versus actually choosing. So in your work, a lot of the states, it looks like, use auto-assignment as a way to award managed care companies, but I'm curious if that's really a reward or are

most of the members assigned already, are they really actually choosing, and what the variance is on that piece.

I think Heidi raises a good point about recognition for outcomes, and John raises this as well. In the performance oversight, are managed care companies ever recognized for the extra things they may do? Oregon is a good example, but there's a lot of states now that have approvals, or if they don't have approval, encourage their managed care companies to do something around social drivers of health, such as providing supportive housing, meals, work training. And I'm wondering if there's anything ever done in terms of measurement to look at outcomes with those types of services and some of the unique things that managed care companies bring to the table.

Commissioner McFadden brought up the issue around background checks and reference checks being used in procurements. I'm curious if in any of your data, you found how many states are actually willing to do those reference checks anymore.

Back when I was Medicaid director, you know, it was common usually to get calls from other states off the

cuff and not in a formal process to respond to an RFP, and I think one of the things we're finding is that due to these procurements being protested so much, there's a caution around the legality of providing references that could be scored, and so states are now deterred from actually providing those. So I'm wondering if you've found in your research any states willing to still share that reference information actually on the record, or if they're now doing it in a different format or a different way that, again, consumers won't openly see.

And then lastly, I think Dennis's point on common performance measures would be really helpful to see. So I just want to back up his question there, how much we're looking at common measurement tools so there can be some comparisons for consumers to be able to look at in terms of outcomes.

CHAIR JOHNSON: Thank you, Carolyn.

COMMISSIONER INGRAM: Thank you.

CHAIR JOHNSON: Jami.

COMMISSIONER SNYDER: Allison, Chris, thanks so much for digging into this really important and really complex topic.

I've had the opportunity to work in a couple of states, and what I can tell you -- and you alluded to this throughout your presentation -- that there's tremendous variability in terms of what states review, the frequency with which they review various performance measures, and the magnitude of penalties and incentives.

So I'm going to echo the sentiments of many of my colleagues just to really dig in as you conduct your interviews and try to identify best practices that really contribute to improved performance and improved outcomes.

The other thing that I did want to mention, as we all know, with the managed care regulation that was finalized earlier this year, by 2028 states will be required to post the performance of health plans via the quality rating system report card, I guess you could call it, but I think there are a host of measures, 16 or 17 measures that they've identified, that states will be required to report on and post the information on their websites. That might be an important monitoring tool to note that's upcoming in the future.

CHAIR JOHNSON: Thank you, Jami.

Doug?

COMMISSIONER BROWN: Like other Commissioners have said, thank you both for the detailed report here today.

One comment that I want to make here is that I think as we talk about ensuring accountability, we're focusing on kind of the negative. What are the penalties in place that spur action upon the MCOs to do better?

I want to make sure that we're looking at this as a bell curve, because I think there's some MCOs that are performing very well, securing bonuses, or in states where they only have penalties, you're focused on one penalty associated with one MCO. But if they have five MCOs, four MCOs are not getting penalties. And so it goes to the totality of the state and the plans in those states and how well those plans are operating. And I don't just want it to look like -- you know, I'd like to make sure that we're kind of accounting for the fact that penalties only occur in certain instances versus all instances.

Thanks.

CHAIR JOHNSON: Thank you, Doug.

Jenny?

COMMISSIONER GERSTOFF: I have a few things that

I think would be worthwhile to look into. One is to what extent sanctions or incentives affect risk margin assumptions and capitation rate setting and then variation in planned financial performance and how that might be correlated to assessed penalties or incentive payments and then state oversight of penalties and incentives when MCOs delegate a significant portion of their business to another entity, subcontractor.

And then are we considering incentives that are incorporated into risk mitigation arrangements, so like outside of the capitation rates? There could be some that are more inherent there.

CHAIR JOHNSON: Thank you, Jenny.

And then Dennis.

COMMISSIONER HEAPHY: To Doug's comment, I really appreciate that. I think it would be helpful to understand, like, on what basis states actually provide incentives to the plans that have done really well. And there's no more criteria that states to do that.

But I also want to comment on Heidi's statement about too big to fail. I see that as a big concern for folks in the community. There are plans that may have a

disproportionate share of the population, Medicaid population, and therefore, it would be too difficult for the state to do away with them.

And so I guess the question to ask folks is, is there a concern about a David and Goliath sort of situation where states have challenges? We're asking states or stakeholders why underperforming plans are permitted to maintain their contracts. Like, what are the reasons they're permitted to do that? You can word it whatever way you want, but it would be helpful to get at that sort of ability of these plans to continue to perform as underperforming in states over time.

Thanks.

CHAIR JOHNSON: Thank you, Dennis.

Any other Commissioners?

[No response.]

CHAIR JOHNSON: So, Allison, I think you can tell there's a lot of interest here. So I think we're going to be looking forward to a lot of different conversations around this. So thank you again for your efforts. All right.

MS. REYNOLDS: Thank you so much for all the

thoughtful feedback.

CHAIR JOHNSON: Thank you.

All right. So you are all staying right there. We are going to go to our next session here, and Allison and Chris will help us to continue our discussion on potential improvements to the EQR process.

Are we doing public session now? You have that up. Okay. Just making sure. Making sure. Okay.

So I'll turn it over to both of you to get the conversation started around the draft recommendations that we have.

[Pause.]

EXTERNAL QUALITY REVIEW (EQR) DRAFT RECOMMENDATIONS

* MS. REYNOLDS: Good morning, Commissioners, again.

Today we will continue our discussion of Medicaid Managed Care External Quality Review, or EQR, from the September and October MACPAC public meetings.

At the October meeting, Commissioners expressed interest in moving forward with potential recommendations to improve the managed care EQR process. These proposed

recommendations are intended to build on MACPAC's ongoing work examining effective oversight of Medicaid managed care programs to ensure beneficiaries have appropriate access to needed services, work that continues, as you heard from this morning's earlier presentation.

We will begin with a brief overview of key elements of the current EQR process, including those impacted by the 2024 Medicaid Managed Care Final Rule. Next, we will recap the five limitations and challenges with the current process identified by our study. We will then spend the majority of our time this morning presenting three proposed recommendations for the Commission's consideration, intended to address those limitations. We will conclude with next steps, including a decision by the Commission to advance any of the proposed recommendations to a vote at our January 2025 public meeting.

Let's briefly review the key elements of the current EQR process relevant to our study findings and proposed recommendations.

As of 2024, Medicaid agencies in 45 states and the District of Columbia contract with managed care plans that are subject to the EQR process. These state Medicaid

agencies are required to contract with qualified independent entities, referred to as EQROs, to conduct periodic reviews of the quality, timeliness, and access to care provided by the managed care plans operating in their state.

Federal rules describe four mandatory quality review activities that EQROs must conduct and report on as well as seven optional activities that the state can choose to have their contracted EQRO conduct.

CMS provides technical assistance to states, EQROs, and managed care plans with EQR protocols for each mandatory and optional activity. Section 1932 of the Social Security Act requires CMS coordinate with the National Governors Association and to contract with an independent entity, such as the National Committee on Quality Assurance, or NCQA, to develop the protocols.

Once the EQRO has completed the mandatory and any optional activities for a state Medicaid agency within a calendar year, the EQRO produces an annual technical report, or ATR, summarizing those activities, each plan's performance, and the state's managed care program overall.

The 2024 Medicaid Managed Care Rule requires the

ATR include outcomes data for three of the four mandatory EQR activities but not for the triennial compliance review. States are required to publish the ATR on their individual state websites and provide the reports to CMS.

Now that we've reviewed the key elements of the current EQR process, we'll recap the limitations and challenges with that process revealed by our previous study and our analysis of the 2024 Medicaid Managed Care Final Rule.

As we detailed for the Commission at the September 2024 public meeting, our in-depth study conducted from 2022 through 2024 included 18 interviews with more than 60 stakeholders representing five state Medicaid agencies, three external quality review organizations, three managed care plans, four consumer advocacy organizations, as well as NCQA and CMS.

We've identified five gaps in how the current EQR process and findings from EQR activities are used to oversee managed care plans and improve quality. First, the EQR process and state quality strategies are not always aligned. Second, the EQR process and the protocols used for EQR activities do not focus on outcomes. Three, states

vary on their enforcement of EQR findings. Four, the annual technical reports recapping EQR activities are not always accessible and the findings within them are hard for stakeholders to use; and five, CMS oversight of the EQR process appears limited.

At MACPAC's October 2024 meeting, Commissioners expressed interest in moving forward with potential recommendations to improve the managed care EQR process. Commissioner feedback during the September and October '24 public meetings shaped the proposed recommendations.

The three proposed recommendations seek to shift the focus of EQR activities from process and compliance to meaningful outcomes and actionable data and to improve the usability of that data through reporting standardization and summarization. These proposed recommendations are intended to build on MACPAC's prior and ongoing work examining effective oversight of Medicaid managed care programs to ensure beneficiaries have appropriate access to needed services.

Our first recommendation is the Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare and Medicaid Services to amend 42

CFR 438.364(a)(2)(iii) to require the external quality review annual technical report include outcomes data and results from quantitative assessments collected and reviewed as part of the compliance review mandatory activity specified at 42 CFR 438.358(b)(1)(iii).

Our first proposed recommendation is regarding the triennial compliance review, a mandatory EQR activity to determine the extent to which states' managed care plans policies and procedures are in compliance with 14 federal standards detailed in 42 CFR 438, including standards related to access, coverage and authorization of services, and care coordination.

The triennial compliance review is the most comprehensive EQR activity required by CMS, assessing each plan's core operational areas – from health information systems, through coverage and authorization of services, to grievance and appeal systems.

Many stakeholders we interviewed, including state officials and managed care plan representatives, identified the compliance review as the most important EQR activity and detailed the extensive time and resources devoted to preparing for, executing, and responding to the review.

Despite this view of the activity by stakeholders, the triennial compliance review was the only mandatory activity left out of the 2024 Managed Care Final Rule requiring outcomes data be reported in the annual technical report. Therefore, this first proposed recommendation closes that gap.

In the preamble of the rule, CMS stated that the new requirement for reporting outcomes data would result in more meaningful ATRs. Consequently, the ATR would become a more effective tool for states to use in quality improvement and managed care plan oversight.

MACPAC and other stakeholders noted in their comments to the proposed rule that this change to require outcomes data and quantitative assessments for EQR activities may help place a greater emphasis on performance outcomes and comparability.

In its commentary, CMS did not explain why the triennial compliance review activity was not included in this new requirement to report outcomes data and results from quantitative assessments. In discussions with CMS after the release of the 2024 Managed Care Rule, they did not identify a specific rationale for excluding the

triennial compliance review from this new requirement.

In addition to closing the gap in the 2024 Managed Care Final Rule, this recommendation also builds upon the existing EQR protocol for the triennial compliance review and carries outcomes data gathered into the annual technical report.

The existing protocol already includes suggested questions the EQRO ask plan representatives and suggested reports the EQR gather, such as on service availability and accessibility, data on enrollee grievance and appeals, data on claims denials, and performance measures.

If the EQRO is required to include in the ATR any outcomes data and the results from quantitative assessments reviewed or generated as part of the triennial compliance review activity, it could demonstrate the outcomes associated with the plans, policies, and procedures, particularly around the availability and furnishing of services and timely access that would not necessarily be captured in other mandatory EQR activities.

Finally, we want to make clear that this recommendation is not intended to create new measures or mandate specific data be collected and reported, but rather

to report information that EQROs are already reviewing as part of the compliance review.

In evaluating the impact of this first proposed recommendation on key stakeholders, we do not anticipate that it would require fundamental changes to the triennial compliance review EQR protocol issued by CMS nor preparations for this activity by state Medicaid agencies or managed care plans. We will get an official score for any recommendations from the Congressional Budget Office, but we do not anticipate this recommendation increasing federal spending.

There could be increased administrative effort on CMS, but this could be reduced by leveraging efficiencies and consistencies across all four mandatory EQR activities. Nor do we anticipate an increase in state spending or administrative effort for state Medicaid agencies or managed plans.

Finally, states, managed care plans, and enrollees could benefit from new insights generated by the outcomes data being reported in the annual technical report that could improve Medicaid managed care quality and access to care.

Our second proposed recommendation is the Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare and Medicaid Services to issue guidance and external quality review (EQR) protocols that include more prescriptive and consistent standards for reporting on EQR activities to improve the usefulness of report content and alignment of the EQR process with the overall federal quality and oversight strategy.

Our second proposed recommendation is in response to feedback voiced by stakeholders and the Commission regarding the need for the EQR process to be streamlined as federal managed care quality and oversight requirements become increasingly complex and for EQR activities to be aligned with other federal requirements to reduce states' burden to provide duplicative information.

In our interviews, both state Medicaid agencies and plans valued the flexibility CMS has given states to design their EQR process but think this flexibility can be better balanced with standardization and consistency to help stakeholders find, interpret, and align EQR findings and bring efficiency to the EQR process.

Stakeholders we spoke to reported that flexibilities in the implementation of EQR protocols can lead to inconsistent interpretation and reporting across states, programs, and EQROs.

Additionally, inconsistent reporting makes it difficult for stakeholders, including state and federal officials, to extract key findings from the annual technical report, place EQR findings in context, or synthesize EQR findings with other required quality and oversight activities.

MACPAC's review found that ATRs are lengthy, detailed, and often hard for audiences to comprehend. The vast majority of ATRs are hundreds of pages long, often with additional appendices or attachments.

Additionally, our review found states used different approaches for evaluating plan performance, making it difficult for individuals to clearly determine the extent to which a plan was compliant or the extent to which a plan's non-compliance was significant.

A more standardized structure for summarizing and reporting EQR activities, results, or actions taken by the state Medicaid agency in response to findings would make it

easier for interested stakeholders to review these reports and glean the key takeaways on plan performance.

As part of our second recommendation, we suggest CMS should consider the following design considerations when providing guidance and updating the EQR protocols. First, reduce EQR reporting requirements that are duplicative of information included in other federally required reports. Second, develop a standardized template that synthesizes and summarizes key findings and recommendations; for example, an executive summary. Third, establish a clear link between EQR processes and the state managed care quality strategy. Four, identify key indicators of plan performance based on stakeholder input, which should be consistently reported in the template in order to track performance across plans and states over time. And finally, require additional information that clearly identifies a plan's level of compliance and puts its performance into more context; for example, through comparison to national benchmarks.

We do not anticipate the second recommendation would increase federal spending. There could be some increased administrative effort for both CMS and state

Medicaid agencies initially, but this could be offset by alignment between EQR processes and other federal quality and oversight reporting requirements. We anticipate managed care plans could benefit from efficiencies gained through standardized EQR activities. Finally, enrollees could benefit from increased transparency and accessibility to managed care plan information.

Our third proposed recommendation is the Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare and Medicaid Services, CMS, to require states to publish external quality review, EQR, annual technical reports in a 508-compliant format and for CMS to publicly post all state EQR reports in a central repository on the CMS website.

While there are federal requirements for states to post their annual technical reports publicly, our project found that the most recent reports can oftentimes be hard to find. Given that EQR is an important statutory oversight mechanism related to managed care, the lack of accessibility of some reports can hinder the ability of stakeholders to monitor health plan performance.

CMS could improve transparency by developing a

central repository for these ATRs on the Medicaid.gov website, similar to the way they began posting the Managed Care Program Annual Reports, or MCPARS.

This recommendation addresses a gap in the current process, which is that CMS publishes summary tables based on the ATRs on Medicaid.gov, but the summary tables do not include any findings from the ATRs. As such, stakeholders are not able to use these summary tables to assess plan performance.

Officials at CMS indicated that it was challenging to post the ATRs on the Medicaid.gov website due to issues with 508 compliance. CMS has been able to post other reports, such as MCPARS, because there is a standardized template. To address these issues, CMS should require states and their EQRO provide the EQR technical reports in a 508-compliant format.

Alternatively, CMS could require a standardized executive summary in a 508-compliant format in addition to the entire report. This executive summary would simplify the process of making the EQR findings 508-compliant so that CMS could post these summaries in a central location and provide stakeholders easier access to the key EQR

findings across states.

We do not anticipate the recommendation as increasing federal spending. There could be some increased administrative effort for CMS, state Medicaid agencies, and managed care plans to initially create and report using the 508-compliant template, but this would diminish over time and across states due to standardization.

Finally, enrollees could benefit from increased transparency and accessibility to managed care plan information in one central location.

During this meeting, we look forward to the Commission's feedback to the three proposed recommendations and the rationale for each. If the Commission decides to move forward with any of the three proposed recommendations, then we will be back in January 2025 for the Commission to vote on those recommendations and to review a draft of the chapter to be included in MACPAC's March 2025 report to Congress.

Once again, here are the three proposed recommendations for the Commission to consider. We look forward to your feedback. Thank you.

CHAIR JOHNSON: Thank you so much. That was very

helpful.

So let's go ahead and get your feedback. I know you've all read this and digested this information, and Allison's presentation was very helpful. Let's go ahead, and let's do it by each of the different recommendations. So let's start with Recommendation 1, if you have any particular feedback.

Sonja.

COMMISSIONER BJORK: Well, 1 seems very logical, and isn't that great that it doesn't cause any additional budgetary impacts or administrative impacts? So I'll save the rest of my comments for the other recommendations.

Thanks.

CHAIR JOHNSON: Okay. Anyone on Recommendation 1?

Jami.

COMMISSIONER SNYDER: I have one quick comment on Recommendation 1. I'm totally in agreement with the recommendation and support it. I wonder if it would be helpful, because you do mention in the memo supplied to Commissioners, that our real interest when it comes to outcomes is around the availability and timely access to

services. Would it be helpful to include that language in the actual recommendation as an example of outcome data that we'd like to see included in the reporting?

MR. PARK: Well, there's always kind of this tricky balance between how much we include in the actual recommendation language versus, like, the rationale, because we don't also want to suggest that's the only area where, you know, we would want the data. So, certainly, we can think about, you know, maybe ways to reinforce, you know, the importance of that. But, we also don't want to -- you know, this got into some of the comments from the Commission about to what extent should there be required measures or outcomes to be reported versus the state flexibility and, like, how they design their EQR, you know, what measures they have implemented, where they are actually collecting data versus process, you know, measures.

So, you know, we can certainly think if you do want to include more specifics in the actual recommendation language, but that's always a tricky balance as to kind of, like, what's there versus in the rationale.

COMMISSIONER SNYDER: Yeah, it may be the case

that it would be just as impactful to just include some additional detail when we talk about the availability and timely access to services in the chapter, so we're giving states some examples of the kind of information that we'd like to see included in the reports, if that makes sense.

MR. PARK: Yeah, yeah.

CHAIR JOHNSON: Thank you, Jami.

Mike?

COMMISSIONER NARDONE: This is a question in terms of all the data elements that are part of the triennial review. Will some of those overlap with information that's provided in MCPARS and the access reporting? I'm just trying to figure out, like, we're trying to make a requirement, right, that isn't duplicative, kind of streamlining this. So we're getting the necessary information, but we're not kind of creating different reports that maybe even conflict with one another. So I'm just curious, is there overlap? And I guess that's a point we would make in the chapter, right, around that we want to minimize the duplication.

But just for my own information, I don't know all the different items that are in both sources.

MS. REYNOLDS: Sure. So given the breadth of the triennial compliance review and the 14 standards that are evaluated, it does evaluate sort of the whole operational organization, and there is some aspects. Its focus is mostly on the policies and procedures.

So, for example, care management is evaluated, but often it's asking the plan to share their stratification formula and their care management process and not really the numbers, if you will, whereas some of the other EQR activities, HEDIS measures, other -- the performance measure validations, et cetera, have very specific measures and targets, et cetera, whereas the compliance review focuses more on the process. But there is the data component that naturally comes about and the opportunity in this recommendation to link those two together.

MR. PARK: And what I would say is some of the duplication, potential duplication of reporting is more addressed in Recommendation 2 versus this specific recommendation.

CHAIR JOHNSON: Thank you. That was a good segue.

Let's go to Recommendation 2, proposed Recommendation 2.

All right. Patti.

COMMISSIONER KILLINGSWORTH: I'm actually backing up to 1 for just a second and want to ask if I'm thinking about this in the right way.

So to the extent that we would duplicate some reporting that's available in the annual reports, wouldn't sort of doing -- including those in the triennial, give us an opportunity to actually look at trends, if you will, and improvement or not over time? Some of the things that we've been thinking about, could you do that on your own by going and getting all that information and putting it together? Yes, but maybe that's a way of thinking about some of the value of including it in this report as well. It's kind of putting it all in one place in a longitudinal way, at least for a short period of time.

As it relates to Recommendation 2, I think where I get a little anxious -- and we've had these conversations before -- is when we start to talk about prescriptive and consistent standards, and we kind of begin prioritizing, if you will, for states what they are focused on in their

quality strategies.

And maybe some things should sort of be universal, but then states also need flexibility because programs are different, and objectives and goals are different. And so I would hate for this to all become a very structured, standardized process where we kind of lose sight of some of the very innovative things that states are trying to accomplish through their programs.

I also worry, quite frankly, if the kinds of data that we have available really reflect the true outcomes, and I'll give you an example of that. Like, we can measure denied claims, but that doesn't necessarily -- it doesn't tell us why the claims were denied, right? We can measure the services that require prior authorization, but requiring prior authorization isn't necessarily a bad thing for certain kinds of services where we want to be sure that they're kind of not the default inpatient being one of those.

And so I want us to proceed with great caution as it relates to beginning to be really prescriptive about what gets measured, at least in total in these reports.

CHAIR JOHNSON: Thank you, Patti.

Sonja?

COMMISSIONER BJORK: So I also appreciate the need for consistency and the ability to compare, but I want to touch on something that Patti brought up last time, which is it's really difficult to compare for access between really urban places and rural places. There's never going to be certain kinds of specialists in a really small town in rural Northern California, but you can still measure access. Does the health plan offer telehealth opportunities? Do they cover transportation if a person needs to go in person all the way to San Francisco and have a visit there?

And so when we're looking at the reporting, how do we have an overlay or a category or a data element that accounts for rural and really shows the true picture instead of looking at an urban setting and saying, "Wow, they have great access," and then look at a rural setting and say, "Oh, that's a terrible health plan. They don't have access there"? So we just have to pay very close attention to rural considerations when we set up the data reporting.

Thanks.

CHAIR JOHNSON: Thank you, Sonja. Good point.

John?

COMMISSIONER McCARTHY: I just don't agree with this recommendation, and it kind of gets to what Patti and Sonja just said.

Having worked in -- Medicaid director in two states, well, the District and a state and then worked with a bunch of states, the purpose of the EQR is to measure what's going on in that state and what's particular about that state. So I get nervous when we're doing recommendations to standardize things nationally, because that's not, in my opinion, the purpose of these reports. It was more of a deep dive into that state.

And so to try to use this to do comparisons across, I don't think that's the reason for the EQR reports. That's the reason we've got the MCPAR that has come out. That's the way to compare things across different states. So on this one, I'm concerned that as we standardize things, we'll be measuring the wrong things or we'll be comparing apples to oranges.

MR. PARK: So just to clarify -- and maybe this requires some tweaking to the recommendation language, but

we are not necessarily saying access would be measured by a particular standard. But when the state is, they are currently assessing whatever it is that they're reporting in the EQR, that they should be clearly identifying that information in the report. So it wouldn't necessarily standardize to say all states must measure urban and rural in a specific way, but when they report their findings and assess the plan's compliance with those access standards, they need to be clearly highlighted, maybe like an executive summary or some way to really make that information more transparent and accessible but also provide some more information about why they think the plan is compliant or non-compliant.

So instead of just providing, saying like 70 percent of X is the outcome, well, is that compliant or non-compliant? Is that a range? Provide some more information about is that 70 percent -- like, if the national benchmark is 50 percent, then that's good. If it's 90 percent, maybe it's bad. Just providing a little bit more of that context to make the report a little bit more usable, but it wouldn't necessarily require states to report all the information in the same way, collect the

exact same outcomes data. It's more about trying to make that information and synthesizing the results more clearly in the report and reporting it so that it's a little easier to find and providing some more of that context about the nuance of the different numbers that might be reported.

COMMISSIONER McCARTHY: I understand what you're saying, Chris, but I still, even at that level -- so two things.

Number one, I think Mike is going to talk next, and he has some new language that he's going to propose is my understanding around fixing that.

COMMISSIONER NARDONE: I don't know if it answers your --

COMMISSIONER McCARTHY: But even with what you're saying, it is a slippery slope on those different pieces because we do say standardized.

And then the second part of it is like when you said there are examples of, oh, and there would be a measure and you say if it's compliant or not compliant, well, sometimes the EQR is doing things that's not about compliance. You're just trying to find out information in there. So that's what's in there.

So I think I hear what you're saying, and I think the recommendation as we have it written now doesn't get to that. So if that is the direction we want to go, we probably have to work on it a little bit. I still have to decide whether I agree with it or not.

COMMISSIONER NARDONE: So, you know, for me, the key points around what I think is important in this recommendation is that it's summarized and that it's information that is helpful to stakeholders. Right now, I'm not sure that the EQRO report is really presented in a way that's particularly helpful, and I think kind of what came out in my mind when we were talking about this the last couple of meetings was it would be helpful to have a more user friendly document that had some standardized aspects and kind of summarized what was in the EQR report.

And I think it's also important that we're not -- to the extent that we're providing this report, that it's not duplicative or it minimizes duplication with other reporting that's out there.

So, you know, I know I was kind of put on the spot to develop language, right? But actually, I think that you may have already provided it. I mean, for me, the

key pieces were a more standardized structure for summarizing and reporting EQR activities, results, or action taken by the state Medicaid agency to help make it easier for interested stakeholders to review these reports and glean key takeaways on planned performance.

You don't have to use all those words, right? But I think that's where I was trying to get to when we talked about this recommendation. I don't know if that helps with, you know, John's concerns, or maybe I'm kind of not -- maybe I don't represent what other Commissioners are thinking, right? So that's where I was -- wanted us to go with this recommendation, and that was my -- that's my two cents and my best effort to give you some language to work with.

CHAIR JOHNSON: All right. Thank you, Mike.

Dennis.

COMMISSIONER HEAPHY: My comment actually echoes what Patti has been putting in the chat, and that is the recommendation doesn't really match what you seem to be trying to accomplish as it's written, because I was viewing it as a standardization of reporting requirements across all the EQROs in different states as opposed to

standardization within reports of how information is going to be reported out. And I think that's what Mike is trying to get at is standardization within the reports, so there's consistency in how they can be read.

And I also just put forward that -- I don't know how you put this in language, but putting a plain language format that supports the ability of stakeholders to read the report. I don't know if that needs to be in the recommendation itself, but so in the chapter. To me it is about accessibility and usability by stakeholders.

Thanks.

CHAIR JOHNSON: Thank you, Dennis.

Heidi.

COMMISSIONER ALLEN: So I disagree with John. Not the first time, probably won't be the last time. But I do like you very much.

I think that we need more opportunities to utilize the function of state policymaking as a laboratory. We talk all the time about how states are supposed to learn from each other, but then we lose all these opportunities to be able to compare apples to apples. And it's part of transparency. And many of these managed care companies

operate in multiple states. Why do they perform differently in one state or another? I mean, I think these are important things that consumers and CMS and its role of oversight should be able to look at.

And so I'm not saying that it has to be entirely prescriptive and everybody needs to do the exact same thing, but I think some -- I think that, like, data without context is meaningless. And we see this all the time in MACPAC when we're reading these reports and we see that there's variation, but we don't know what it means. We're constantly like, well, what does it mean that 7 states do that and 15 states do that and 13 states do that? I mean, like, we need to be able to connect data to, like, meaning. And so often we collect the data, but then we miss the opportunity to make the meaning.

And so, yes, it would be nice if the reports are standardized in the same way so that they look alike, and you can know which section to look at to find this information and the executive summary. Like, that is indeed useful. But to me, what's more useful is to understand across states, which have really different policy environments and are using these levers and

strategic ways to get these outcomes, what levers are more effective than others to achieve the outcomes that we care about? And the only way to do that is through the reporting that goes to CMS from states, and so any effort to make that reporting more useful for CMS and more useful for states to understand why things are happening that look different in their areas.

Yes, populations are different, but partly what's different are the policy levers that our states are using. And one way of evaluating those policy levers is to be able to compare apples to apples. That's my perspective. So I support the recommendation as written.

COMMISSIONER ALLEN: Thank you, Heidi.

Angelo.

COMMISSIONER GIARDINO: I support the concept that's in here, and I like Michael's conceptual overlay. So I'm sure you all will be able to word this correctly.

But I do say, fundamentally, I think it's wonderful that Medicaid is a joint federal/state program and there's some variation in the states, but I'm not willing to say all the variation is perfect, we don't need to look at it, everybody in the states knows what they're

doing, so we don't have to ask. That, to me, just is not a viable option.

This is a jointly funded federal/state program, and we should be able to compare apples to apples across states. And if there's some unique element to that state, I suspect there's a footnote in this standard report, and that can be explained. I have never heard anyone who's interested in quality say that benchmarking is not helpful, And the way you do benchmarking is by having standard definitions and a shared understanding.

That's why HEDIS is valuable. No one's arguing that HEDIS should be 50 different measures. We all figure out what the vaccines are, and you report them.

So I think from a quality perspective, providing guidance so that standard language is used and you can find what you're looking for in a very easy, simplified way is the way that stakeholders hold states and the federal government accountable.

So I support this recommendation with Michael's suggestions.

CHAIR JOHNSON: Thank you, Angelo.

Carolyn.

COMMISSIONER INGRAM: A lot of discussion on this, which is good, I think, and healthy for the commission, And I support the direction Mike was going with doing some rewriting to get to the goal of what Chris was talking about. I don't think the language quite gets there. So if we could rewrite it and come back and consider it, I think that'd be great.

Just to address Heidi's question about the differences between states, it takes, just for some background, over six hours to drive across New Mexico, And we've got some really rural communities and most Tribes, I think, with lots of different health disparities and issues, and it's very different to provide care there than it is in New York, for example. A lot of rural areas where we don't have any providers. We have more cows than people in some areas and no maternity care, so very different than providing care in New York. So that's what I think John was trying to get to, is there's differences between states.

But I think if we rewrite this and we're trying to get out some standardization so we can start to look at the data, that's what we're trying to get to. It is just

being able to see the data reported in a standardized way and have that transparency. I think that's what we're trying to get to.

So anyway, I support working on the language and coming up with something better. Thank you.

CHAIR JOHNSON: All right. We'll go to Tricia and then Heidi.

COMMISSIONER BROOKS: We needed more time for the sessions.

CHAIR JOHNSON: I'm realizing that. Your lunch is a little bit shorter, unfortunately.

COMMISSIONER BROOKS: So I'm in Mike's camp in terms of tailoring the language a little bit.

I also react to the word "prescriptive" in a different way than I react to "specific," and I think they're trying to get at the same thing, but "prescriptive" sounds harsher, like we're trying to be punitive or something, so just a comment there.

But I am definitely in Heidi's camp in terms of being able to compare what we can compare. Those EQR reports are very dense, very complex, and if we could highlight key findings, I think it's important.

And one of the things that we're missing here in the discussion is that it's helpful for identifying who's doing something well, right? Because isn't that what comparability is all about? Yeah, let's weed out the bad, but let's also see who's doing things well and learn from whatever it is that they're doing that we can implement elsewhere. So I'm all for this recommendation with some edits.

CHAIR JOHNSON: Heidi and Dennis, and then we're going to go ahead and go to Recommendation 3.

COMMISSIONER ALLEN: Great. I totally get that New Mexico is different than New York City. I grew up in Idaho. That's very, also different from New York City. But I think that it would be nice to be able to compare Oklahoma and New Mexico, places that have big Tribe enrollments. And so ideally, if you do have that comparability, you can start making more specific comparisons that allow you to understand context and think about the policy.

But my question is, Mike, I didn't quite understand if your edits were to get at the report consistency or measure consistency, and that's why it's

hard for me to know when people say they support the edit, which one you're talking about, because I think that I would support both of those things, consistency of what the reporting looks like so that people can know where to look in the different sections or consistency in how things are measured and some consistency across what is measured.

COMMISSIONER NARDONE: I guess I was focusing more on some sort of summarization of some of the key findings and having those so that the findings could be usable for people and easier to understand.

The EQRO report in Pennsylvania is probably like 250 pages long. And I guess the question is, can we take away from that certain key things? Like, if you have a performance in -- you know, I'm not exactly sure I know specifically, but maybe performance improvement projects that states are engaged in, and what are the results of those performance improvement projects? That's a possible suggestion, but, I mean, I think kind of distilling, trying to distill some of the key elements that would be helpful in kind of assessment of how the managed care plans are working in the state. Because I think having the variability in the EQRO report, you could still have all

that information, that, you know, if you're a Medicaid staff and you want to really dig into that, you can do that. You have the EQRO report.

But I think really making it more understandable and having the key findings summarized, to me at least, is what I would like to see. Even as a Medicaid director, when I would look at EQRO reports, it would have been helpful to know like, okay, what are the takeaway messages I should have from these 250-page documents? So that's where I was going. That was my reaction. I thought that's where this recommendation was going, and I didn't -- it's in the language if you read it really carefully, but I don't think it's stressed, for me anyway.

COMMISSIONER SNYDER: Heidi's question was exactly my question. I think what you're advocating for, Mike, is consistency in the summary reporting, right? Not in the measurement, right? Okay.

CHAIR JOHNSON: All right. Thank you. We'll go ahead. Let's flip to Recommendation 3, but I think Dennis -- and then, Jami, do you have some more comments around recommendation -- okay. So Dennis.

COMMISSIONER HEAPHY: I'm wondering, they're

still going to have multiple, different reports. If we're going to hunt around, I'd have to hunt around to find out similarities and differences in the outcomes in different states. So is it possible to have a synthesized report that's put out by CMS that shows what's actually happening in different states if there are similar outcomes or reporting measures, the EQROs? Does that make sense? I just think there's got to be -- otherwise, we're going to be hunting and packing in different states to find out what the data is. So there's got to be somewhere to centralize it, at least key elements of it.

MR. PARK: Yeah. I think -- and this gets to some of the other comments and part of the recommendation is that there may be greater alignment in certain reporting elements within, like, the quality rating system or these network -- I don't remember the exact, like, what it stands for, but, you know, as part of the new access requirements, you know, there's going to be a little bit more information coming from, like, satisfaction surveys and other things like that in terms of -- or, like, minimum wait time standards in this network, like NAAAR, N-A-A-A-R, report that's going to -- you know, that's required.

And so, you know, I think part of the recommendation is for CMS to really think about where certain things should be reported, where there might be overlap, and, you know, what's the best vehicle for that to be reported. And so, some of the outcome measures may be more useful in the quality rating system because that will be -- it's supposed to be designed to be a little bit more beneficiary-friendly where they can compare plans on these outcome measures. And so is that the best place for that to reside versus, like, trying to make that part of the EQR report when it's also part of the quality rating system?

COMMISSIONER HEAPHY: I think I'll dispel some of that in the chat.

COMMISSIONER NARDONE: Yeah.

CHAIR JOHNSON: All right. So even more important than your lunch are the public comments. So what I'd like to do is go to Recommendation 3, and if you all could let us know if there's any comments around that. So let's see. Looking at all the Commissioners. I see shaking heads. Everyone is in agreement with the way it stands, it sounds like.

Okay. All right. Perfect. All right. Well,

thank you so much.

Do you need anything else from us?

[No response.]

CHAIR JOHNSON: You have -- definitely, I think, Recommendation 2, you are going to do some rewriting, it sounds like.

MS. REYNOLDS: Stronger readers.

CHAIR JOHNSON: There we go. There we go. Thank you so much, both of you, for your efforts on this. We appreciate it.

All right. So with that, let's go ahead and go to public comments, and, you know, we invite people in the audience to raise your hand if you would like to offer comments. Please make sure you introduce yourself and the organization that you do represent, and we do ask that you keep your comments to three minutes or less. That'd be very helpful for us. So let's see who we have.

We have one. Arvind?

PUBLIC COMMENT

* MR. GOYAL: Can you hear me, all?

CHAIR JOHNSON: We can hear you. Thank you.

MR. GOYAL: My name is Arvind Goyal, G-O-Y-A-L.

I'm the Medical Director for the State Medicaid Agency in Illinois.

A couple of years ago, I was also the Chair of the Medicaid Medical Directors Network, and with that perspective, I submit to you that this discussion has been extremely educational, extremely helpful. And I'm so glad that Commissioners are so engaged.

I want to say that there are three reasons why MCOs came into being somewhere between 15 to 20 years ago, depending on which state you're in, and so one was access. The second was quality, and I add to it outcomes. I would not separate them because quality is definitely tied to outcomes. With bad outcomes, quality, you can't measure. And the third part is the cost savings that should go with an MCO. I'll give you examples of each, and then I have two small comments.

As far as the access is concerned, I am sure you've heard recently about ghost networks being published and some legislative remedies, both at the federal level and some states who want to fix it. But access is as much an issue or more as it was with fee-for-service. I just want to put that on the table.

As far as quality and outcomes are concerned, one, I think the emphasis on NCQA in your reporting and also on HEDIS measures is misplaced. You're also shutting out innovation by other organizations. There are multiple other organizations in this space, and I won't waste my three minutes on this.

However, think about it this way. HEDIS measures are not performance-based. For the most part, they are process-based. It was important when they came out because at the time, medical community, clinical community wasn't really doing those things. And I used an example at one of your previous meetings, like measuring hemoglobin A1c for diabetes is a HEDIS measure. But if you don't pay attention to it or you don't look at the result or you don't improve diabetic control, then you haven't done anything. Same thing for opioids. If you do MAT, but your mortality and morbidity rate due to opioid overdoses is going up, you haven't made a difference. So that is the example of quality and outcomes.

I also want to say that as far as the cost part is concerned, think this way. The cost is not only to the state agency, to write the contracts, to monitor them, to

take whatever actions you need to take if they don't comply. Cost to the MCO itself -- and that's a third party -- taking away Medicaid money, both federal and state, to be able to organize and have an army of people help it.

And then think about the provider stress and cost to them, both in time and money, and beneficiaries, the last thing, very, very important.

Having said that, I also want to say that 30 to 40 percent of patients in many states do not have any claims during the year. However, you're paying for them. So they're not getting any service. And if it was fee-for-service, you would save that money, but because it's an MCO per member per month or whatever your metric is, you're not saving any money.

So I say this to you, that our reporting needs to hold their feet to the fire, and I do believe that as of this time, the report does touch some important points.

I'm especially troubled by some regulation that will become effective in 2028. In the meantime, how many beneficiaries, how many providers could be affected? Why not 2025? Why not earlier than later?

So I would stop at my comments. I remain

available for stakeholder interviews when they come. But again, please don't limit or diminish your participation in this process. I'm thoroughly impressed that you're looking at it.

Thank you.

CHAIR JOHNSON: Thank you so much for your comments.

Any other comments?

[No response.]

CHAIR JOHNSON: All right. Seeing none, I just want to remind everyone that if you do have some additional comments later, you can submit those comments on our MACPAC website.

And with that, I want to thank you for your engagement this morning, and we will be back from lunch at 1 p.m. Eastern. We will see you then. Thank you.

* [Whereupon, at 12:17 p.m., the meeting was recessed, to reconvene at 1:00 p.m., this same day.]

AFTERNOON SESSION

[1:00 p.m.]

CHAIR JOHNSON: All right, everyone. Welcome back from lunch. We're going to go ahead and get started.

We are going to hear from Linn Jennings, our Senior Analyst, and Ava Williams on the transitions of care for children and youth with special health care needs, some policy considerations and options. And last time was a robust conversation. So I have no doubt this will happen again today. So let's turn it over to both of you.

TRANSITIONS OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN): POLICY CONSIDERATIONS AND OPTIONS

* MS. WILLIAMS: Thank you, and good afternoon, Commissioners.

Today Linn and I will be presenting policy considerations and options for our work on children and youth with special health care needs, transitions of care.

I will start by giving a brief recap of our findings we presented in our previous meeting in October. I will then start our discussion of policy options before turning it over to Linn to continue discussion of policy

options before ending with next steps and questions for Commissioners.

As a reminder, our objective for this project was to examine how state Medicaid programs and MCOs operationalize their transition of care policies for children and youth with special health care needs, how beneficiaries and their families experience transitions, and to identify barriers to transitions that can be addressed in federal policy.

During the course of this project, we have completed a literature review, a federal and state policy scan, stakeholder interviews, and beneficiary and caregiver focus groups.

As a reminder, for this work, we narrowed our definition of children and youth with special health care needs to those covered by Medicaid under an SSI pathway under the Tax Equity and Fiscal Responsibility Act, also known as TEFRA, and Katie Beckett authorities.

Next, I will present a recap of the stakeholder interview and beneficiary focus group findings.

There is no federal requirement for states, and states often do not develop a transition of care approach

for children and youth with special health care needs and publicly document or communicate this approach. Some states have developed or require their MCOs to develop transition of care approaches. However, these approaches are not publicly documented, which makes it difficult for beneficiaries and their families to find information related to the expectations around the transition from pediatric to adult care.

Additionally, not all children and youth with special health care needs receive a transition of care plan, and of those who do, the plan is not always useful because it does not address key components of the transition approach. These key components can include a readiness assessment, connecting with adult providers, or designating a care coordinator or transition specialist to support the beneficiary and their family through transition.

There are no federal restrictions on covering services to support transitions of care for children and youth with special health care needs, and some states cover these services through existing state plan or waiver authorities, such as MCO contracts, TCM, or CPT codes.

However, some states may be unaware of how these different authorities can be used to cover transition-related services.

Additionally, transition-related CPT codes may not cover all aspects of transition needs, such as warm handoffs between pediatric and adult providers.

An additional finding is that state Medicaid agencies are not required to, and often do not, measure the experiences of children and youth with special health care needs transitions of care, and their outcomes. There is a lack of commonly used measures to assess children and youth with special health care needs, their transitions of care, and their health outcomes because of this population's wide range of health conditions and needs.

The lack of data collection limits states' and researchers' understanding of children and youth with special health care needs experiences with and needs during the transition from pediatric to adult care.

State Medicaid and Title V agencies are required to coordinate with each other on their overlapping children and youth with special health care needs population but not on their transitions of care, and we found that many state

agencies do not coordinate on this population's transitions. The lack of coordination can lead to a lost opportunity for sharing experiences and needs of children and youth with special health care needs. State officials have shared interest in increased coordination between the agencies because it would be helpful in supporting children and youth with special health care needs during their transitions.

Next, I will start the discussion of the policy options that address the challenges we have identified.

Here are the identified challenges, what objectives we are trying to accomplish, and the policy options we developed to address these challenges.

In the following slides, we'll discuss each of these policy options. Our first policy option states that Congress should direct states to develop an approach for transitions of care for children and youth with special health care needs. The population for this recommendation would include, but not be limited to, children and youth with special health care needs enrolled in Medicaid through SSI-related eligibility pathways, those eligible under TEFRA and Katie Beckett authorities. This option requires

states to specify their transition of care approach that would include an individualized transition of care plan.

Beneficiaries, families, caregivers, and family advocates have indicated that beneficiaries and their families have difficulties with finding information on their state's transition of care approach and do not feel supported by the state Medicaid agency during their transitions. Findings from the course of this project have indicated that a structured transition approach that includes an individualized care plan can improve transition outcomes for children and youth with special health care needs.

For example, a meta-analysis of 43 studies and a meta-analysis from the Agency of Healthcare Research and Quality found that children and youth with special health care needs who had an individualized transition of care plan experienced better outcomes, such as greater transition readiness, reduced anxiety related to their health, decreased hospital visits, and increased primary and specialist visits.

However, despite the evidence indicating the need for these transition of care plans, findings from the 2022

National Survey of Children's Health showed that only 42 percent of children have worked with their provider to create a transition plan.

Our findings from the state policy scan show that some states have developed or require MCOs to develop a transition of care plan for individual children and youth with special health care needs, but based on our findings from interviews and focus groups, these transition of care plans may be missing some key components that are important for supporting the beneficiary during the transition; for example, the steps needed to transition, roles and responsibilities of those involved in the beneficiary's transition, available services to facilitate the transition, and questions that youth and family can ask providers, service, and care coordinators.

* MX. JENNINGS: So moving on to Policy Option 2, we developed this policy option to address barriers related to the lack of guidance to states on covering services to support transitions of care, and so this recommendation directs CMS to issue guidance to states on the existing authorities to cover services to support transitions of care for children and youth with special health care needs.

And we use the minimum definition, as Ava defined, also with Policy Option 1, and so this would be minimum related to children enrolled in Medicaid through SSI-related eligibility pathways and those eligible for Medicaid under TEFRA or Katie Beckett authorities.

So there are no federal restrictions on states covering services to support transitions of care. CMS has not issued guidance on how to use existing authorities to cover these services.

Findings from our work indicate that although some states do use these existing authorities to provide these services, other states may not be aware. And given these findings, states need clarity on the use of existing authorities for paying for transition of care services, and stakeholders identified four areas where CMS may need to provide guidance on the applicability to transitions from pediatric to adult care.

And these include targeted case management. Nothing precludes states' Medicaid programs from providing transition of care services as part of TCM, but CMS has not provided guidance on how this benefit could be used for transitions.

There are also no federal restrictions on covering transition of care-related CPT codes, but many states do not include these codes in their Medicaid fee schedule, and they may be unaware of which services may be already covered using existing CPT codes.

Additionally, states with managed care should ensure that transition-related services are included in their MCO capitation rates.

Related to payment for interprofessional consultation, in 2023, CMS published a state health official letter and provided states with guidance for reimbursing for clinical consultation and discusses the importance of warm handoffs and same day appointment or services in the context of behavioral health for youth but does not discuss these types of services in the context of pediatric to adult care transitions.

And finally, payment for transitions of care covered through EPSDT. The 2024 guidance to states on EPSDT indicates that care coordination and case management can be used to facilitate the development of a plan and to outline the transition of care process, but doesn't provide specific details on how this would be done.

And for Policy Option 3, we developed this to address barriers related to measuring transitions of care for children and youth with special health care needs. And with this, the Commission recommendation would direct CMS to design, develop, and require states to measure and collect data on transitions of care, and these measures should be developed with input of beneficiaries and their families and caregivers.

There are no federal Medicaid transition of care measurement requirements, and so states are not required to collect or report these types of data. And in general, from our findings, we learned that the majority of states are not collecting or monitoring these populations.

The literature does indicate that there are a few available data sources that do measure the experiences of youth with special health care needs with the transition of care process, and this includes the National Survey of Children's Health. But there aren't standardized outcome measures. And designing health outcome measures, in particular, is challenging, given the varying health conditions and needs of this population.

And so based on our findings, data collection is

needed to understand who is transitioning and when, to understand their process and their services and whether they are accessing services that are related to their transition of care plan and their health outcomes and also to evaluate whether there are gaps in their access to those services.

And for Policy Option 4, we developed this policy option to require that state Medicaid agency IAAs, or interagency agreements, with state Title V agencies specify roles and responsibilities for supporting children and youth with special health care needs and their transitions from pediatric to adult care.

Just as a reminder, that Title V programs are required to use 30 percent of their funds towards children and youth with special health care needs, and these funds can be used for direct services, but they often are also used by Title V agencies to partner with or fund other organizations that support this population. And this can be for educational purposes or to help them enroll in Medicaid coverage, and this can also be used for transitions of care.

Medicaid and Title V programs are required to

have an interagency agreement, and in this, they outline roles and responsibilities related to providing services for this population and their overlapping children and youth with special health care needs. But there are no federal Medicaid IAA requirements related to transitions of care in ensuring that Medicaid-covered children and youth with special health care needs do transition to adult care.

So findings from our review of state IAAs and stakeholder interviews indicate that very few states coordinate on transitions of care for this population, and stakeholders indicated that the lack of coordination can also be a barrier to cross-agency information sharing on beneficiary challenges with this process and a barrier to collaborating to ensure that children do transition to adult care.

And so based on our findings, state Medicaid and Title V agency IAAs should specify the roles and responsibilities for these agencies to ensure that the transition of care process is transparent and understandable to the beneficiary and their family and to identify which agencies should be providing direct services, should be providing training and educational

information and resources for plans, providers, the beneficiaries and their families, and which agencies are providing other supports to facilitate the transition of care.

So moving on to our next steps and discussion questions. Today we'd appreciate your feedback on the policy options and which of these you would like to advance to the June report to Congress. The four policy areas are viewed as complementary efforts to improve children and youth with special health care needs transitions of care, and we could combine these options into one recommendation package.

We've also included the discussion questions on this slide, which are also in your materials, and I'll leave this figure up to guide discussion. And I'll turn it back to the Chair.

CHAIR JOHNSON: Thank you so much, Linn and Ava. That was very helpful.

So let's go ahead and get the Commissioners' reactions to the policy options that were presented. You did have a couple of questions in there that I'll continue to draw out, but let's go ahead and get started.

And Bob, Bob is up first.

VICE CHAIR DUNCAN: Well, again, Linn and Ava, thank you so much for this amazing work. I appreciate it.

And I'm actually in favor of all four options that you have put on the table, because I think it takes a holistic look at addressing those children that are transitioning to the adulthood. So I just want to throw my support and say thank you.

CHAIR JOHNSON: Thank you, Bob.

Tricia.

COMMISSIONER BROOKS: So Bob certainly has lived experiences with this, and so I would certainly defer to his thoughts on it. But I had a couple of questions.

So in the recommendation to Congress, it would appear that what we're asking for is a mandatory requirement for states. Is that what we're getting at?

MX. JENNINGS: Yes.

COMMISSIONER BROOKS: Okay. And just so people are clear, we're, you know, adding a mandatory benefit, I guess you'd call it, or service to the plan, which is not necessarily a bad thing, but I just wanted to make sure we were on the record there.

And also, you limit it to SSI kids or kids on Katie Beckett or a waiver, and yet there are a lot of children with special health care needs that don't qualify for either of those pathways of eligibility. Is there a reason that we're limiting the recommendations at this point in time to those pathways?

MX. JENNINGS: So we initially kind of scoped out this work looking at a broader definition, but then limited it to a narrow scope to have higher needs, but also to allow for a little bit more comparability across states. And so our thinking behind limiting it is that really our evidence that we've collected is related to this narrowed scope population, but then by recognizing in our recommendations that it's a minimum population.

So a state, it doesn't preclude a state from using a broader definition or using a definition that they already use, but it allows for kind of setting a minimum population.

COMMISSIONER BROOKS: So that would be the mandatory group, whereas it would be optional otherwise.

And then on Recommendation 3, about the transition of care measures, I had -- you know, I play with

this concept of measures because I think about quality measures. There are national performance measures that are developed by HRSA that Title V agencies have to adopt a certain number of them. I don't know a lot about the interaction or the collaboration between Title V and Medicaid, but I just think we need to clarify that what types of measures or data that we're asking for here. I mean, even if there's a way to define transition of care measures such as kind of thing, that would just be a point that I would make here.

But no, this is important work. It's a population that struggles throughout life, but this is a period of time when the struggles are even more significant for not only the kids, but their families as well. So thanks for the work.

EXECUTIVE DIRECTOR MASSEY: So, Tricia, can I just respond to your first comment in terms of what Policy Option 1 is intended to do?

COMMISSIONER BROOKS: Okay.

EXECUTIVE DIRECTOR MASSEY: Because I think your characterization of it was as a new mandatory benefit, and I think from our perspective, we were looking at it as

states being required to articulate or codify an existing policy and make that public and transparent.

But, Linn, did you want to add and maybe kind of spend a little bit of time talking about what the intention is of Policy Option No. 1?

MX. JENNINGS: Sure. Thank you.

So our intention with the first policy option is that many states already have maybe some approach for transitions of care, but to ensure that that is made public and transparent. And since one of the key things we heard from focus group participants and advocates that there's just really no -- they don't know where to find that information and understand the process. So the intention isn't really to have that it creates a new benefit. In many cases, an approach exists, but to make it public and then leaving that approach and kind of the design of that approach up to the state, but including an individualized transition of care plan within that approach.

COMMISSIONER BROOKS: Do you have any examples of statutory language that talks about requiring an approach to something? I guess it seems a little not in my vernacular that I would see this in statutory language.

MX. JENNINGS: I would have to get -- I would have to come back with that, and we can look into that a little bit more.

COMMISSIONER BROOKS: Yeah, I think it'd be helpful to know how such a statutory provision might be crafted. What would it say, or do we have other things in statute that are similar to that, that we can point to and say this is what we have in mind? That would be very helpful.

Thank you.

CHAIR JOHNSON: Thank you, Linn. Thank you, Tricia. That was a good call-out.

All right. Patti.

COMMISSIONER KILLINGSWORTH: Just a couple of quick comments. One, with regard to the applicable groups, I think I've raised this before. I'm going to raise it again. I would encourage us to think about including all children who meet institutional level of care requirements, whether by virtue of 435.217 participation in a 1915 CHCBS waiver or any equivalent sort of authority that might be provided under an 1115 demonstration or, as much as I hate to admit it, kids who might actually be institutionalized,

right? So I think any child that we know is either institutionalized or significantly at risk of institutionalization probably needs a transition of care process. I think that's really important.

And the other thing would say with respect to -- I think it is the third -- no, it is the -- which measure is it? It's the third measure on sort of measuring transition of care data. I would caution us against becoming too focused on services as kind of the measure. I think it's important for there to be flexibility to deliver this kind of transition support as a service and to provide reimbursement for it, but I think there's a lot of ways of handling it also through care coordination processes that may fall within the purview of a managed care organization's responsibility pursuant to a state contract. And so I would just -- I'd hate for us to sort of look at, is it being paid for as a service as kind of our measure of the process.

CHAIR JOHNSON: All right. Thank you.

Heidi.

COMMISSIONER ALLEN: Thank you for this. I love that we're moving into the policy option stage of the work.

That's always exciting.

I agree with Patti. I think it's worth considering expanding to all kids that would meet the institutional level of care requirements, and I wonder if that would also -- I think often of like foster kids too, which as they age out, they also probably need transition of care. And I know that we're very specific to special health care needs, but many of those kids have special health care needs too.

But the thing that I wanted -- my most -- the comment I really feel the most strongly about is in Recommendation 3, when we're trying to understand beneficiary experience. I think it's also important to center caregiver experience. When you think of kids aging out and being able to stay in the community, the health and well-being and ability of their parental caregivers often and then maybe sometimes sibling caregivers, is really, really important. And if undue stress and pressure is put on that system, it can have really significant implications for the young adult, and so I'd love us to be able to bring that forward as well.

CHAIR JOHNSON: Thank you, Heidi.

Dennis.

COMMISSIONER HEAPHY: Thanks.

Can we go to the slide for the Recommendation 4, the one after? I think that's it. Yes. So for me, I guess my concern is that these kids and their families are losing all the supports that were available to them under Title V once they turn 22. And so it seems like there's still a siloing in the recommendation and not a recognition that there needs to actually be a transition from Title V too as part of the kids are receiving their occupational therapy, their physical therapy, all these different therapies in school. So much of what they've done, what's being done in school, and that will no longer be there. All those things will be moving on.

Also, care coordination is done in the school. And so how is the care coordination going to transition to the adult world once those supports are gone? And I think it's not just about medical, but also the HCBS side of it. So much of the HCBS really is developed in coordination with the school and Title V.

So as I look at this, I'm thinking, how can this really be strengthened? I'm sorry I don't have language.

But how can we strengthen this to show that Medicaid really has an obligation to ensure that the state Medicaid offices have the capacity and the responsibility to ensure that these folks, they transition and their families, and they get the support they need so that they're not just -- those supports under Title V don't just disappear, but there's someone there at the adult side to catch them.

CHAIR JOHNSON: Thank you, Dennis.

John?

COMMISSIONER McCARTHY: So a couple of things. Number one, I'm a little confused, and maybe I just missed this, because our third -- we always say we make recommendations based on evidence. But our third recommendation is to measure things in order so we could have evidence.

So then is our first couple of recommendations based just on the interviews of what we heard from people? Because it kind of gets to my second piece, which is, shouldn't we do the third recommendation first of try to get measurement to see what's working in these different areas before we make recommendations on what to do around telling states what to do around transitions? That's my

first question and second question.

MS. WILLIAMS: The evidence for the first two policy options come from the state policy scan and federal policy scan interviews and focus groups, as well as literature, and from the literature, we found literature on all the things. There's not many approaches that state Medicaid agencies are doing, and because of this and because of what we heard from focus groups and what we heard from beneficiary advocates and the literature, it's important and helpful for these beneficiaries to at least have some sort of approach.

COMMISSIONER McCARTHY: I assume that's what it would be, and I agree with that. It should be documented, and there should be some things, but I just want to make sure we're following what we've said in other places.

The other piece is on the third recommendation from CMS. One of those issues is we talk about having CMS give guidance around payment structures and what can be paid for. We talked about this last time a little bit, and I hadn't thought of it then, and when I was reading through the memo this time I did. But in our memo, one of the things is state Medicaid payments for transitions -- and

CMS should talk to states about that, of how to use those, but I think we probably need to look into that a little bit more, because if you cover some of those CPT codes and you're doing it through a state plan, I don't know if you can necessarily limit it to just this population we'd be talking about. And I am not a CPT code expert, okay? But having set rates and been in Medicaid, those are things that sometimes why those codes don't get covered, because yes, you want to pay for this, but if you added that code, it wouldn't just be for this population. It would be for a much larger population, so it would cost you additional dollars maybe you don't have. So that would just be one of those things I'd want us to look into before we necessarily make that recommendation, making sure that it would align with exactly what we're talking about. We're limiting it to the population we're talking about, whether it's the narrower definition which you guys have proposed or the expanded definition that Patti and Tricia talked about.

Thanks.

CHAIR JOHNSON: Thanks, John.

Patti?

COMMISSIONER KILLINGSWORTH: Let's circle back on

just a couple of comments. So one, with respect to Heidi's comment, wholeheartedly support modifying Policy Option 3 to include not just the experience of beneficiaries, but also the experience of families and caregivers, which I think is critically important.

A couple of responses to John's comments. I love that John always holds us accountable for consistency to our own commitments. I do think that there is sufficient evidence to warrant adjustments, even while we're trying to develop better measurement processes, right, so that we have more consistent and reliable access to information. But I would hate for us to wait to take steps to improve the experience for these beneficiaries while we kind of collect information to sort of bear out what we already have some evidence to tell us is problematic.

And then kind of on the third point, with respect to making the benefit available, I wonder, John, if in practice, this wouldn't be a point of medical necessity, right? You would only kind of provide reimbursement for transition services when there's a need for them, right, by virtue of the child's level of challenge in navigating transition and really the importance of doing that. So

maybe that would help to kind of mitigate any concern over utilization of that.

I think as a practical matter, it's already there, right? It's already covered. We're just kind of articulating what's already available under the EPSDT program currently for these kiddos, but correct me if I'm wrong.

CHAIR JOHNSON: Do you want to respond?

[No response.]

CHAIR JOHNSON: All right. Thank you. Thank you, Patti.

Carolyn?

COMMISSIONER INGRAM: Thank you, and thanks for putting these great ideas forward so we could start to consider them.

If we could go to No. 3. In your work and your interviews, did you gather any information on how folks envision carrying this recommendation out that's worth sharing back with us? When I review it -- and I think Tricia brought up a point about focusing on services when we're really looking at focusing on outcomes, and so I was sitting here looking and thinking, if I were the Medicaid

director of Medicaid agency, how would I put this into practice? So did you all gather any information about that, about what people envision?

MX. JENNINGS: I think one thing we really heard in our state interviews is that although -- and I think we will do a better job, I think, of strengthening this in our rationale for next time since there may -- there was some confusion over what specifically we would be measuring. But I think one of the things that we really are lacking in is just understanding who this population is, who is kind of at this transition of care age and are they getting -- like, if they have a plan -- like, do they, like, do they have a plan? What does that plan look like?

And so our understanding from state interviews is states often actually have this information potentially but have never looked into it. They couldn't tell us who was transitioning, but said it might be possible. It's just not an area that they're -- like, it's not on their dashboard of measures that they're looking at. And so I think some of these measure -- and maybe measures aren't -- maybe isn't the right -- but some of this data collection is there. It's just a matter of kind of finding those data

and maybe having specific -- I guess, we can continue to use measures, but it's having some measures that kind of point to those specific data points to help states understand what they could be looking at.

COMMISSIONER INGRAM: Maybe we could dig into that a little bit more to address the question about what we are trying to get to in terms of outcomes.

I struggle a little bit with just putting this kind of blanket thing out there and then states are supposed to figure out what folks mean by that, and I suppose that's the job we're telling CMS to do in this policy option, but maybe focusing more on outcomes instead of just the access to the services.

Folks have, as you mentioned in your research -- they've got the access to the services. It's whether or not people are carrying them out appropriately to get the outcomes, right? And they're not helping this population the way we should be. So that's what it sounds like. So I think trying to focus on the outcomes maybe more is what we're trying to get at.

Anyway, I struggle with that one a little bit. We got to -- I think we need to refine it a little bit

more.

Thank you.

CHAIR JOHNSON: Thank you, Carolyn.

Doug and then Mike.

COMMISSIONER BROWN: Thank you.

As I read the chapter and the pre-read and then sat here, the one thing that kind of keeps running through my mind -- and some folks have mentioned here -- is EPSDT. And you're checking for kids and testing them along the way early on. It seems to me like if you could test them at the end before they get ready to leave the program, somewhere between age 16 1/2 and 18, you could work a transition plan in at that point. Not that that's the answer here, but it could be a start.

I see the recommendations. It seems like between Title V and Medicaid, there's programs here, there's funding. It's just kind of closing the loop in some degree here, and I don't know if EPSDT is one way to help close that loop. Just a general question for the group.

CHAIR JOHNSON: All right. Thank you, Doug.

Mike.

COMMISSIONER NARDONE: I was going to respond to

John's comment, and I guess I was wondering if -- and I don't know if this is what you all were thinking about -- is some of the things and clarity that John was looking for, I assume, would be something that would actually be covered in the CMS guidance, right, like around how different authorities could be used to support transitions. At least that's the way I was interpreting that.

So, I mean, I think -- to John's point, I think it'd be good -- you know, you always -- lots of times, you want to know kind of what the answer is before you, like, put a recommendation up. But I mean, I think it does seem like that that's something that CMS could help flesh out as part of the guidance that they were providing. So that was my comment on 2.

I guess on 3, I assume -- and maybe this is something you would -- and maybe others who have more familiarity with this topic than I do, it doesn't sound like we have measures, right, like, that we have to develop them. And I assume that's a process that wouldn't just be CMS, that it would be a process that involved a lot of stakeholders in the development of that. And I guess that's assumed, and maybe that's something you would cover

in the chapter. But I wouldn't want CMS just to go off and design, even though I worked at CMS. But I'm assuming that there would be that sort of input.

And then in Title IV -- not Title IV -- in terms of the fourth recommendation and Title V, I'm probably not as familiar with the Title V requirements. And so I'm just wondering, do we have some good examples of agreements and how they're structured to kind of integrate with Medicaid? It's not something I'm familiar with. So I'm wondering if there are some examples around that that might be helpful to just kind of talk about.

And I guess I also kind of reflect that -- are there good examples of kind of putting forward, like, what are -- are there good examples also of good transition planning that states are engaged in? Are there some models that we should be looking to?

CHAIR JOHNSON: Thank you, Mike.

Patti and then Tricia and then Sonja.

COMMISSIONER KILLINGSWORTH: Just a quick comment about Carolyn's and now Mike's comments about measures. I do think there are some ready things that we could mention as examples if we're inclined to do so. We've talked about

the public availability of information, about the transition of care process, making sure there are clearly defined responsibilities in the state for who will -- who's responsible for transitions of care. We could measure whether transition meetings actually occur timely, whether there's a transition of care plan. We could look at continuity of services and providers and then finally develop processes to measure beneficiary experience, and those are just examples, right?

But I always think that perfect is the enemy of good, and sometimes we don't measure things because we don't have the perfect measures that are available yet to start measuring. But we have to start somewhere, and so even if we start with some process measures and some experience measures, I think those bring value, even while there may be a more rigorous process to develop HEDIS measures going forward.

CHAIR JOHNSON: Thank you, Patti. Couldn't agree with you more.

And I think I'm going to skip over Angelo.

COMMISSIONER GIARDINO: Thank you.

Once again, thank you for taking this work on. I

know it's a heavy lift.

I just want to make a couple comments. I think the first one is that there's ample evidence that a systematic approach to the transition from pediatric to adult care is helpful in terms of the management of either the physical or the mental condition of that child who's now becoming an adolescent and young adult. I don't think there's any evidence that an unplanned transition is beneficial, and in fact, there's ample evidence that unplanned transitions, particularly for children that have heart disease, kidney disease, neurologic problems -- and the list goes on -- if it's unplanned, that transition leads to unplanned hospital visits to the emergency department, fragmented care. And some of those conditions, if you don't manage it consistently, there's end-organ damage.

So I think the evidence is absolutely available for the need for planned transition, because there's a lot of evidence for unplanned transition that ends up with kids as they become adults ending up in the emergency room and getting care in a fragmented way.

So I don't think we're actually unanchored or

unmoored from an evidence perspective. There's ample evidence.

Second, I would say there has been at least 20 years of national centers, the National Center on Transition -- and now the current one is Got Transition. And they have decades of work in terms of the approaches. And as you had said in some of your briefing materials last time, there's really two major approaches. The American Academy of Pediatrics has a policy statement, and Got Transition has the six core fundamentals.

So it is not -- if you're talking to people who are doing this care, they're not at a loss for what the basic approach is, and they're all the same. There's an assessment of readiness. There's partnering with the child and family, and then there's getting the pediatric provider connected to the adult provider.

So, again, we're not unmoored here. We have approaches. I would just encourage you to look at -- HRSA for about 10 years had -- I think it's called the "D70 program." So they funded all 50 states to do some type of demonstration project in transition. So there's going to be some models that emerge as best practices. So I think

there could be some information there.

And then finally, I guess I'm operating under the assumption -- and you can correct me if I'm wrong, but when we ask CMS to develop a guidance, that they, in fact, would do some work to think about what information would be helpful. So some of the concerns that John has, I assume that's going to be in the guidance. I don't think we have to write the guidance before we approve a recommendation to have a guidance. So I'm assuming they would talk about the CPT codes, and that they would say this is the appropriate guidance around using that CPT code. So I don't think we have to know the wording of the guidance before we propose a guidance, because I think then CMS works on what is appropriate for the stakeholders.

So I'm in full support of your moving forward with this. Thank you.

CHAIR JOHNSON: Thank you, Angelo. I'm sorry about missing you.

All right, Tricia.

COMMISSIONER BROOKS: Thank you.

I just wanted to point out, I was interested in Doug's comment about doing some kind of EPSDT screening at

that stage, and we have examples of that for former foster youth and justice-involved youth that is coming online as of January 2025, that they have to have an EPSDT screening within 30 days of release or aging out. And they have to be set up with prescription drugs and referrals and other things that they need. I think these transitions of care would have to be more robust, but there is, you know, something happening in this world that is similar to that.

And just to Mike's point, there are very specific requirements for interagency collaboration between HRSA and, you know, the Title V agency and CMS on both sides. But this is not an area I concentrate in on our work at CCF. But I don't ever recall seeing one of those agreements, right? So, I mean, then the starting point is that they have to enter into an interagency agreement and to have certain components, and I would just be interested to know what we can gain by a review of those and seeing what they do and don't say about this relationship. I think it would end up being broader than children with special health care needs, but I thought I'd raise it at this point, just because it's important.

I mean, if 30 percent of Title V money is

supposed to go to special needs kids, that's important, and they're boosting, you know, maternal access and, you know, other things that are closely knitted with Medicaid. So understanding that relationship would be helpful.

MX. JENNINGS: So for our state policy scan, we did review all IAAs, and I believe I'd have to go back, but I think only about four or five mentioned transitions of care for this population. And it isn't a requirement to include it in the IAAs. So I think, in general, states are not including it there.

Although from our interviews and from our scan and from other sources, it does seem like there are states that are collaborating, even if it isn't in the IAA. But very little is included in those.

COMMISSIONER BROOKS: Maybe that's an idea is that it should be included in those interagency agreements as one way to trickle it out from perhaps Congress talking about the approach.

CHAIR JOHNSON: Thank you, Tricia. Thank you, Linn.

Sonja?

COMMISSIONER BJORK: For Policy No. 3, I do like

it when we offer up some suggestions or examples. So we could not act like this is an all-inclusive list of what the measures should be, but, you know, for example. And when we do that, we often turn to experts, right? So we can check in with beneficiaries and their family members as well as some of the agencies that serve them as we come up with these.

So Patti already mentioned, you know, was there a transition of care plan developed? You can check yes or no on that for outcome measure, right? And then you can check things like, was a primary care -- was a new primary care provider assigned after they turned 22? Now, that's kind of a yes or no. You can also look and see, did the person have any visits with anybody that first quarter after they, you know, got to age 22? That's not hard to find out, because if someone who has really serious and special needs hasn't gone to the doctor or gotten any prescriptions filled or gotten any labs, it's a cause for concern.

So I know we're looking back, but you can see what happened during a certain period of time after they reached a certain age. That's not that hard to measure. So I would like it if we came up with some examples to

offer up when we do this policy.

And also, I'm glad that what John raised, but I don't want to wait until we have a huge amount of data to move forward with the first two policy options. I get so impatient. I want to charge ahead. So I appreciate John bringing up, you know, do we need more evidence? But I really thought you did a great job with the literature review and the scan and all of that. So I feel like we're rolling. We're moving forward.

That's it for me.

CHAIR JOHNSON: Thank you, Sonja. Appreciate that.

Jami?

COMMISSIONER SNYDER: I just wanted to go back really briefly to the issue of definition. I, too, want to be able to move forward with the policy recommendations. I'm fully supportive and supportive of the narrower definition that you've developed for the purpose of the policy recommendations that we have in front of us.

I do think it would be helpful in the chapter to just articulate that it's really a baseline and that states can extend the framework that we're recommending to a

broader population.

CHAIR JOHNSON: Thank you.

Any other Commissioners have comments before we wrap up?

[No response.]

CHAIR JOHNSON: All right. So, Linn and Ava, do you think you have what you need? I know you had a lot of questions. You were able to answer many of them. You're going to go back and do a little bit more of a deeper dive on some issues. There were some other factors that Commissioners had brought up that it sounds like you all are going to put into this as well. But anything else from us that you need?

MX. JENNINGS: No, this was very helpful, and thank you.

CHAIR JOHNSON: Thank you. Great job. We appreciate it.

All right. So we are going to switch gears a little bit, and we're going to go to the CMS proposed rule on Medicare Advantage for 2026. We're going to welcome Drew Gerber as our analyst and welcoming back Chris Park.

I feel like you've been up here a lot this go-

around. We need to work on that and give you a break a little bit more. Of course, our Policy Director and Data Analytics Advisor.

They're going to present key aspects of the proposed CMS rule for Medicare Advantage and Medicaid, and normally, we would not necessarily have comments on MA rules, but we did want to make sure that we were shaping a MACPAC response on the issues that really affect eligible.

So, with that, I'll turn it back over to Drew and Chris.

POTENTIAL AREAS FOR COMMENT ON CMS PROPOSED RULE ON MEDICARE ADVANTAGE (MA) FOR CY2026

* MR. GERBER: Thank you, and good afternoon, Commissioners. Chris and I will be providing an update on the contract year 2026 Medicare Advantage and Part D proposed rule.

We, the staff, regularly review this annual rule for its implications for dually eligible individuals and for the Medicaid program. This presentation will also identify potential areas of the proposed rule on which the Commission may wish to comment.

CMS published a notice of proposed rulemaking

earlier this week for Medicare Advantage (MA) and Part D for contract year 2026. We've grouped the relevant provisions of this rule into three areas for potential comment: mandatory coverage of anti-obesity medications, or AOMs, such as the new class of glucagon-like peptide-1, or GLP-1, medications like Wegovy; integrated care for dually eligible individuals; and access to cost-sharing tools.

Finally, we'll turn the conversation back to the Commission to provide staff with feedback on where, if at all, the Commission would like to make comment.

So beginning with mandatory coverage of AOMs, in the Medicare title, the definition of a Medicare Part D-covered drug is tied to the definition of a covered outpatient drug under the Medicaid Drug Rebate Program in Title XIX of the Act. The Medicaid Drug Rebate Program, in Section 1927, excludes coverage of agents for anorexia, weight loss, or weight gain, which means that these drugs are currently excluded from coverage under Part D.

AOMs are not covered under Medicare when prescribed for weight loss. While states may optionally cover them under Medicaid, it is important to note that

AOMs that are prescribed for other medically accepted indications, such as for diabetes, do receive coverage under Part D and Medicaid.

CMS proposes to reinterpret this statutory exclusion to allow coverage of AOMs for obesity. The agency pointed to growing consensus around obesity as a chronic disease in its own right, and it said that such an interpretation would mirror its previous interpretation of the statute to allow for coverage of certain drugs related to weight gain for diseases such as wasting syndrome and AIDS.

The proposed rule distinguishes obesity from overweight, which is not recognized as a disease, although some states do currently cover AOMs prescribed to those with overweight.

As the statutory reinterpretation revolves around Section 1927, the proposed decision to mandate coverage of AOMs for obesity would apply to both Medicaid as well as Medicare. Should the rule become final, statute also creates the potential for a gap in the applicability dates of the mandated coverage between the programs.

Medicare's statute prohibits significant changes

to Part D except at the start of a calendar year, while the Medicaid program has no such prohibition.

CMS notes that coverage would become mandatory in Medicaid on the effective date of the final rule, which is typically 60 days after publication in the Federal Register. This means that there could be a period of time in which Medicaid is required to cover and pay for AOMs for duly eligible beneficiaries, which we'll discuss.

Over a 10-year window, CMS estimates that mandating coverage of AOMs will cost $11 billion to federal Medicaid and $3.8 billion to state Medicaid programs, although it's unclear whether this estimate accounts for the amount states may have to pay for duly eligible beneficiaries should there be a gap in the applicability dates.

In the proposed rule, CMS noted that states would still have access to cost-control tools that it currently has, such as preferred drug lists and prior authorization. For states that currently cover AOMs for weight loss, a KFF survey found that nearly all require prior auth or had body mass index, or BMI, requirements to receive coverage.

There are several comments that the Commission

could make on mandatory coverage that are supported by our prior work. First, the Commission could ask CMS to issue guidance on what it would consider allowable prior auth criteria for coverage of these drugs in Medicaid. In the proposed rule, CMS declined to define obesity, instead allowing Part D sponsors to develop their own definitions for prior auth purposes, so long as the criteria were not more restrictive than the drug's label. However, CMS also noted that labels for AOMs have removed reference to specific BMIs in certain cases. Without a definition of obesity, there may be uncertainty as to whether a drug should be covered for a specific beneficiary and whether that beneficiary would be considered overweight or obese.

The Commission's June 2019 report to Congress highlighted some of these challenges that states face in developing their drug coverage policies, especially as it relates to Part D.

The Commission could also ask CMS to link the Medicare and Medicaid effective dates for mandatory coverage to avoid the potential for any cost shifting to Medicaid program. However, if the agency moves forward with an earlier applicability date, CMS could or should

issue guidance on its expectations for Medicaid coverage of AOMs, especially as it relates to duly eligible individuals. In statute, the Medicaid exclusion of coverage for Part D drugs or cost sharing is actually tied to the definition of a Part D-eligible individual, not to the definition of a Part D-covered drug.

Moving on to integrated care for dually eligible individuals, the proposed rule also includes a number of new requirements and technical changes related to integrated care. Two of these provisions would apply to applicable integrated plans, or AIPs. AIPs, if you remember from our prior work on integrated care, are a category of MA dual eligible special needs plans, or D-SNPs, with exclusively aligned enrollment, which means the D-SNP only enrolls individuals enrolled in the affiliated Medicaid managed care plan.

Other provisions would apply to all MA special needs plans, or SNPs.

CMS proposes to require that AIPs issue integrated member ID cards. The IDs would have to meet existing ID requirements for both programs, and most states, with a few exceptions, already require their AIPs

to do this. CMS also proposes to require AIPs to use a health risk assessment, or HRA, an assessment conducted by SNPs, combined with similar Medicaid assessments for functional need.

The flexibility to align these assessments already exists, and combining assessments can reduce duplication and burden on beneficiaries faced with repeated intensive questions.

Finally, CMS also proposes to codify for all SNPs timelines for conducting HRAs and developing integrated care plans, or ICPs, which are informed by the HRA.

The proposed rule would put into regulation the requirement that HRAs be completed at least 90 days before or after enrollment, add a requirement that ICPs be completed within 30 days of the HRA, or the effective date of enrollment, whichever is later, and also sets some specific requirements for plans to conduct and document their outreach to enrollees about the HRA and ICP.

At several places in the Commission's body of work on integrated care, we've noted how exclusively aligned enrollment can be a tool to increase integration, including through allowing for integrated member materials

like an ID, which beneficiaries have expressed satisfaction with.

The Commission might choose to voice support for the new proposed requirement, as recent CMS rulemaking that we presented on back in December 2023 is likely to increase the number of AIPs by 2030, including among states that may not already require an integrated ID.

Similarly, the Commission's recent report on state Medicaid agency contracts, or SMACs, highlighted how timely HRA and ICPs are important in advancing state goals for integration and D-SNPs for dually eligible individuals.

Separately, CMS did request comment in the proposed rule about whether the agency should publicly post SMACs, noting that CMS is not party to those contracts between states and plans. While our prior work underscored the challenges states face in developing and retaining D-SNP expertise -- and the Commission's heard from panelists previously about state interest in peer-to-peer learning -- this question fell outside the scope of our work at the time, and therefore, we don't have information on the amount of potentially confidential or proprietary information that may be in these contracts that would be a

consideration for publicly posting them.

And then finally, I'll discuss some access to cost-sharing tool provisions. The proposed rule would require MA agents and brokers to discuss with beneficiaries their potential eligibility for cost-sharing supports. These include the Medicare Part D Low-Income Subsidy; the Medicare Savings Programs, or MSPs, for partial- and full-benefit dually eligible individuals; and supplemental Medigap insurance.

CMS proposes that these brokers and agents would also need to provide a pause to allow beneficiaries to ask questions about what they've heard, and they must offer to connect beneficiaries with the state to learn more about programs such as the MSPs.

MA plans are also able to offer supplemental benefits, a category that includes benefits beyond what Medicare fee-for-service offers, such as dental, as well as benefits that enhance existing fee-for-service benefits.

Increasingly, CMS says in the proposed rule that plans are offering these supplemental benefits, including reduced cost-sharing through debit cards, also known colloquially as flex or cash cards. In light of some

concerns from stakeholders over their use and beneficiary confusion about these debit cards, CMS proposes to codify existing requirements dictating plan processes for administering benefits via debit cards and further require plans to provide enrollees with instructions and access to customer service for using the cards.

After reviewing a number of MA plan advertisements focused on the debit card dollar value or without directly connecting the debit card to actual covered plan benefits, CMS proposes to also prohibit plans from advertising this way.

So MACPAC has monitored enrollment in the MSPs for several years, initially identifying some issues with enrollment and recommending changes, which CMS did implement in part. In the Commission's June 2024 report to Congress, MACPAC found enrollment in MSPs had improved, although millions eligible for the programs still remain unenrolled. Therefore, the Commission might support requirements intended to raise awareness of the MSPs and to facilitate connections with the state for individuals to potentially enroll.

And now, while regulations governing debit cards

and MA are a Medicare issue, dually eligible individuals may be drawn away from integrated care models that the Commission feels are better suited to providing care by attractive debit card offers.

We would note that we've heard from stakeholders and read in evaluations of the integrated Medicare-Medicaid plans under the Financial Alignment Initiative that competition from MA plans has been a persistent challenge for enrollment in these integrated models. The Commission may then choose to voice support for the proposed prohibition on prominently advertising these debit cards to consumers.

Next steps. Comments are due on the proposed rule by January 27, 2025. If the Commission decides to comment, we'll take back the comments we hear in your discussion today and draft a letter for your review.

And I'll turn it back to the Chairwoman for this discussion.

CHAIR JOHNSON: All right. Thank you so much, Drew.

All right. So I am assuming that people want to comment, but if not, then definitely let us know in your

remarks. And then also, if you can group them into three areas that Drew outlined, too, in terms of where you think we should comment and what we should comment about, that'd be really helpful.

So, with that, let's see if we have any Commissioners.

Adrienne.

COMMISSIONER McFADDEN: So I am supportive of the comment. My comments here today will just be around the anti-obesity medications.

As a physician, I think there's a very prescriptive sort of language around individuals with obesity having these medications. The medications are effective. They fall below the threshold on the BMI scale of being obese, and therefore, some might argue they should then come off the medications, but there's a large subset of individuals who need to stay on these medications for potentially lifelong to maintain the healthy weight as well as the other health benefits there.

So I think the comment for the Medicaid side of the house is making sure that the estimated cost to Medicaid contemplates sort of the lifelong coverage of the

anti-obesity medications.

CHAIR JOHNSON: Thank you.

Carolyn.

COMMISSIONER INGRAM: So I think I would say, yes, we do need to comment in these areas, and it just is another example of why we need to do a better job of integrating Medicare and Medicaid back together for people who have complex needs on the ground. All of these things that are raised in here are just examples of the issues that hit members on the ground and providers when they're trying to coordinate care better for people out there.

I'd be interested in what some of the other Commissioners, especially Doug, feel about the drug coverage and the drug recommendations, to hear some of their feedback. I have to say I would agree with the frustrations enrollees have about not having one card or having to be screened several times through an HRA process by different entities. It just doesn't make sense. So I think some of these recommendations are kind of no-brainers, even if they are things that might take time to operationalize on the ground.

Along with the SMAC agreements being publicly

posted, I don't know what would be in them that is proprietary. A lot of organizations gather those and get them and look at them. So I don't quite see the harm in that, but I'd be open to if some of the other Commissioners are able to share their feelings or thoughts on that.

My understanding is that because it's signed by a public entity and the health plan, they are public documents, and they should be shared as such, in my opinion.

And then the last is just the instructions on the debit cards and the use for those. I echo the concerns that it can be confusing to consumers when they get those, and it would be helpful to have that clarity and transparency for people out there. And I'd be interested in if Dennis has any feedback on those pieces.

So, anyway, I'll turn it back over to you, and maybe some of my colleagues would have comments on there that they could share from their own lived experiences.

CHAIR JOHNSON: Oh, great. Thank you, Carolyn. Good points, and definitely respond to some of the questions that Carolyn raised, if you'd like.

John?

COMMISSIONER McCARTHY: I agree with what Carolyn said and others have said. I, too, struggle with the portion on the GLP-1s from the standpoint of they are very expensive, and so they have a big impact. But the return on investment can be huge, and so there could be huge savings for the Medicaid program.

So the point I want to make, though, is when the early drugs came out for hepatitis C, states tried to put some limitations on there. For instance, we had put limitation on it, you had to be sober in order to get one of the drugs, because our clinical people were telling us -- both our pharmacist and our medical director were saying that if you were to take that drug and then stop taking it and you weren't sober, the next time you try to take it, it's less effective and the next time. So that's just my concern on this one is I would assume some states would have put some type of logical clinical criteria around some of those drugs, like seeing weight loss over a period of time, so that there isn't something like diversion or something like that going with it.

So I think that's where I'm struggling with this one is I know as Medicaid directors, we always think of the

negative because we see those bad things, but on this one, there's a huge positive, too. So I think it's going to be -- I agree with what Carolyn said of this is why you need that integrated program to have those two things work together.

CHAIR JOHNSON: Thank you, John.

Doug?

COMMISSIONER BROWN: Thank you.

I was going to go right where John went with hepatitis C. If you wind back the clocks, 2013, 2014, hepatitis C, $84,000-per-treatment drug in the market, millions of people that need to be treated, multiply them together, you get budgets bigger than all the pharmacy budget together. Care was rationed at that point, treating the sickest patients first, and then you basically -- as prices began to come down, you could treat more and more people to where it is today, where generally, in most states now, drugs are available for people that have hepatitis C.

$11 billion is a lot of money in the estimate. I think it's probably underestimated, and the reason I say that is because you have GLP-1s that are driving trend in

Medicaid. In the prime Medicaid trend report, GLP-1, that class is the second largest class-driving trend. Weight loss is the sixth largest class that's driving the trend right now in Medicaid from a pharmacy perspective. And that's looking at 2022 and 2023 data.

The other thing that's important to understand is in the new drugs that came out that are originally indicated for weight loss, Medicaid didn't have to cover those products, because they were indicated strictly for weight loss. Subsequently to that, those drugs got additional indications for cardiovascular indications, and then states had to provide coverage for that. As a result, you see a number of states have now added those drugs to preferred drug list programs with the edits and the requirements around the prior authorizations around BMI, around sustained weight loss, and the like.

But I go back to what we've always known about weight loss is without diet and exercise, you're not going to maintain a lower weight. And to just have a program that says, yes, we have to cover these drugs and people are going to be on them for long periods of time, when they go off of them, the weight is likely going to come back,

right? And so how long do you continue to pay for this? What's the long term? What's the game plan here or the rollout of this? And so that's my concern here is the kind of opening access to this.

And this is much different than AIDS wasting where for weight gain, they made drugs available so states cover products for cachexia, and so that to me is completely different than weight loss in that regard. I understand the long-term side effects. I understand, Adrienne, your points about that and relative health. I get all that.

There is a concern about what this costs. How do you fund this in a program where we can't fund everything that we want to cover today?

The other piece I want to comment on is I'm absolutely in favor of linking the dates between the Part D program and Medicaid for coverage and making sure CMS -- my recommendation would be CMS would have to do that, or you're going to see Medicaid having to cover that for the year prior before Part D is going to jump in there and cover that.

So I'll stop my comments there but reserve the

right to come back into the discussion.

CHAIR JOHNSON: You do have a right to come back if you need to. Thank you so much.

All right. Tricia.

COMMISSIONER BROOKS: Just a quickie on a point others haven't made is I definitely think we should comment on requiring agents and brokers to present the MSP options. But I say that with the caveat that there needs to be some kind of oversight or quality assurance to make sure that's happening. That gets so far away from Medicaid. I don't know to what extent we would see an impact, but I think it's an important policy to have in place.

CHAIR JOHNSON: Thank you, Tricia.

Patti and then Heidi.

COMMISSIONER KILLINGSWORTH: I would like to focus my comments on the second potential area of comment around sort of the unified HRA and the codifying timelines for the HRA and integrated care plan.

If we just think practically about what are the primary Medicaid benefits that are being delivered to a dually eligible beneficiary, it's long-term services and supports and behavioral health, right? So we're talking

about in this context, people who have pretty significant care needs. And part of my frustration in integrated care is we tend to align to the Medicare requirements or the Medicare timelines, and so 90 days to do an assessment, 120 days to develop an integrated care plan for someone who needs or uses long-term services and supports or has significant behavioral health needs is just too long.

Now I realize we're setting minimum standards, but my fear is always that we default to the minimum standards, right, because that's what the law now says. And so I would like to see us include some sort of a -- not just in the -- well, this isn't a chapter. This is a memo, but making it clear that it would be, you know -- or the minimum timeline prescribed or established by the state Medicaid agency for integrated long-term services and supports and our behavioral health services, right, really making clear that the state is already prescribing timelines for these other really important benefits, and we shouldn't begin in a unified approach to default to a later timeline, which is less responsive to the needs of a population who may need benefits now or end up in an institution.

CHAIR JOHNSON: Thank you, Patti.

Jami, did you have a comment?

[No response.]

CHAIR JOHNSON: Okay, all right.

Heidi?

COMMISSIONER ALLEN: Thank you.

I just wanted to comment about the GLP-1 drugs and the potential for these to really widen health disparities in the United States, particularly racial and ethnic health disparities. I think that -- and, you know, obviously in common class disparities, but the compounds of these drugs are pretty widely available for anybody that can shell out a couple hundred dollars a month. And that's what people who are not getting it through their ESI and they're -- you know, are doing right now or through Marketplace coverage. But people on Medicaid don't have that as an option, and low-income people in Medicare don't have that as an option either.

And so I fear that, you know, with the research suggesting that they're effective well beyond diet and exercise has ever been and that that results in downstream improvements in cardiovascular health, I think that if

Medicaid doesn't step forward to make sure that these are available to our enrollees, that we will be seeing trends where low-income minority populations have, again, this, like, widening health outcomes of disparities. And we are always like, how can we fix disparities? What can we do about disparities? Well, I think this is a prime example of something that we can do about disparities, and I think that we definitely should.

CHAIR JOHNSON: Thank you, Heidi.

Dennis.

COMMISSIONER HEAPHY: I agree with Heidi's comments and Patti's, and just building on Patti's a little bit, what's missing is the quality of those plans, because having a plan in place does not mean it's worth much.

And so I don't know how this actually fits into this, into the recommendations, but unless we tie quality to this, it really -- 30 days, 90 days -- doesn't really mean anything. And we're discovering that in all the work that we're doing with dual eligible plans. When the state actually looks at those plans, they find that the plans really aren't necessarily aligned with what a member's needs are or what a member would want or in the member's

own words. So I think it's really important that we look at some of the existing best practices and in determining the quality of these ICPs.

And then the other piece is, the issue is the brokers, not the advertising of the cards. And so I think it's like -- I totally agree with doing away with the advertising, the cards, and maybe secret shoppers to make sure the brokers are actually sharing information appropriately. We need to do that. But what we really need to deal with -- and I think CMS is trying to deal with this -- is really reducing the ability of brokers to exist.

And so how can we prevent -- how can we build up states' capacities that should provide people with -- what do you call it? -- conflict-free information about the options that are available to them, to be on the -- what's the program? The SHIP program. Yes, I think we need to look toward that.

So yes, it's great, but I think a statement about we need to do further work is important.

CHAIR JOHNSON: Thank you so much, Dennis.

Jami?

COMMISSIONER SNYDER: Yeah, I think I just have a

clarifying question. I know during the presentation, when we were talking about the GLP-1 issue, there were a couple of recommendations in terms of how we could comment on the particular matter. And one had to do with just the definition of overweight versus obesity. The other had to do with based on some work that we've done historically around state's ability to implement prior authorization criteria.

Clearly, a lot of the discussion today has been around the larger policy issue, and just curious to know, in terms of protocol for the Commission, how we incorporate or do we incorporate information around that larger policy discussion into our comment letter.

EXECUTIVE DIRECTOR MASSEY: Yeah, sure. So why don't I start, and then maybe, Chris, you can finish, which is that when it comes to the comment letters on any NPRM, the basis for MACPAC offering a comment is prior work that we can rely on.

I think some of the conversation that we've been having this afternoon is really interesting in terms of the approaches, the appropriate use of GLP-1s, what the potential effect that may have on budgets, et cetera. But

because we as a Commission do not have clinical expertise, we will likely not opine on those elements in the letter because that is not traditionally the role that we have adopted as a Commission.

So, Chris, what would you add to that?

MR. PARK: Sure. And I think, you know, some examples of like the hepatitis C drugs came up today, which is a good example of where, you know, states had a wide range of different prior authorization criteria linking it to like liver damage scores, the sobriety type of, you know, certain time of not using drugs or before you could get the treatment. And also, as Doug mentioned, kind of like follow up, you know, like how many times do you necessarily cover it if it wasn't successful or things like that?

So that is where -- you know, there's this gray area, and particularly without like a clear definition of obesity, you know, there are common definitions of like BMI that are used, but, you know, without that clear definition of what obesity is versus overweight, there's some leeway potentially, you know, where states could have some flexibility of determining what that might be. And, you

know, are there any guidelines that CMS could provide that, you know, clarifies that a little bit, like a common definition of BMI may be acceptable -- or, you know, to Doug's point, like if they stop taking a drug, gained the weight back, you know, can states kind of limit how many times they potentially cover the drug in their situation?

So I think that's kind of where we would necessarily land without like saying like this is what obesity is or, you know, overweight, just trying to provide maybe a little bit more parameters of what CMS would think would be like acceptable within the parameters of the rebate program.

And the other thing is just, you know, potentially clarifying what Medicaid's responsibility might be for dually eligible beneficiaries, particularly when if there's a period when it's not considered a covered Part D drug at that point, because, the statute prohibits Medicaid for paying for Part D -- for drugs for Part D individuals. And the statute is tied to kind of the definition of, you know, this is for Part D individuals, for coverage of such drugs and what does such drugs mean? And so it's not -- I don't think it's super clear that states definitely have to

cover it, and I don't think it's super clear that they don't have to cover it. So, you know, some more guidance there as to what the expectation might be, you know, with more of a legal expertise than I have.

EXECUTIVE DIRECTOR MASSEY: That's helpful. Thanks so much, Chris.

CHAIR JOHNSON: Thank you, Chris.

Michael, Mike.

COMMISSIONER NARDONE: I was just going to say that I appreciate the work of going through the guidance, and I'm very supportive of the provisions that seek to better integrate services between the two -- for dual eligibles. And so, generally, I'm very supportive of those with, I think, Patti's very good caveat about other instances where the plan needs to be developed more expeditiously because people are at risk of institutionalization.

On the drug coverage for obesity drugs, you know, I think the coordination between Part D and Medicaid, I think, is an important point, and so that's kind of what I would be highlighting.

So I guess I just want to just comment around

just generally being supportive of where you're headed with the guidance as you've kind of laid it out in this memo.

CHAIR JOHNSON: Thanks, Mike.

Dennis?

COMMISSIONER HEAPHY: Thanks.

And I just have to throw it out there because it's been on my mind since looking at the document, and that is the narrow definition of "obesity" versus being overweight. There are folks who have complex medical conditions. They have asthma and a heart condition, and the doctor is going to say just gain six more pounds, and we'll be able to get you on the medication. And so it's this like warped sort of -- like, you can't just look at the weight itself. You have to look at the person's totality and what their overall health needs are.

I'm not trying to, like, bust the budget, but how much do we actually give to the providers to actually determine, based on the criteria that could be used, but to look at the overall person's health to see if this medication would actually be helpful in reducing EDs and hospitalizations and improving overall quality of life. Again, also looking at, like, different SDOH aspects.

Thanks.

CHAIR JOHNSON: Thank you, Dennis.

And then Heidi.

COMMISSIONER ALLEN: Yeah, I just wanted to follow up with that. I think that's such a good point, Dennis, that you really don't want to incentivize people to have to gain weight in order to get access to treatment. And Wegovy is approved for overweight in combination with other health risk markers, and so by saying it only is obesity and it doesn't consider overweight, you're taking out an indication for which it's FDA approved.

But the reason I hop back on here is that I want to hesitate not to go too far down the hepatitis C comparison route for thinking about utilization management, because my understanding is that hepatitis C drugs were a cure, and that these are not at all considered a cure. They're considered chronic disease management. And so the assumption is that, yes, absolutely, people stop taking it will gain back the weight, and I think there's been a number of clinical trials to show that that's true. And so by saying, okay, if you failed treatment -- like, framing that as a treatment failure that then can be used for

utilization management to say, oh, we helped you lose 100 pounds, and then we stopped giving you the medicine, and then you gained it back, and so you're not eligible for treatment, I don't think that that is an appropriate comparison to the hepatitis C. I think that whatever medical indications and treatment protocols exist for the drug should be the ones that are implemented in Medicaid.

CHAIR JOHNSON: Thank you, Heidi.

Any other commissioners?

[No response.]

CHAIR JOHNSON: All right. So, Drew and Chris, I think you heard overwhelmingly that anytime we can better align the Medicare and the Medicaid programs, we want to do that. And so, hopefully, you have enough feedback to start that draft letter. But any other clarifying questions from both of you or additional thoughts?

[No response.]

CHAIR JOHNSON: Okay. All right. Thank you so much.

Yeah.

UNIDENTIFIED SPEAKER: [Speaking off microphone.]

CHAIR JOHNSON: We have a list of people, right.

Oh, no, you're good. Okay, thank you.

All right. Thank you both.

So now we're going to go back to public comments. We're going open it up. We do invite people in the audience to raise their hand if they'd like to comment. Make sure, though, that you introduce yourself and the organizations you represent, and we do ask that you keep it to three minutes or less if you can. So we appreciate that. Let's see what we have.

Peggy?

PUBLIC COMMENT

* MS. McMANUS: Yes. I'm Peggy McManus with the Got Transition Program, and I want to thank the staff and the Commissioners for taking up this topic.

There were four things that I just wanted to add. Regarding measures, we have an article that I'll share with the MACPAC staff on suggested measures for transition planning, transfer, and integration.

Regarding improving access and measurement, it will depend a lot on EMR functionality, which right now is very limited. And so what could be done in terms of improving the tracking of the transition-age youth, keeping

track of the receipt of the transition readiness assessment, the medical summary, the identification of primary care provider, the final pediatric visit, the exchange of medical summary, the initial visits, that is still very much a gap in our field.

The importance of using EPSDT was measured. I think that's a fabulous idea, building on CMS's recent guidance, and including more timely notification of when the changes are going to happen in care and coverage, particularly explaining what will happen when you lose EPSDT, and ensuring receipt of an up-to-date medical summary before they leave EPSDT.

And finally, on some value-based payment options, to think about ways to promote pediatric and adult system processes and increasing the adult primary care workforce capacity.

Thank you very much.

CHAIR JOHNSON: Thank you so much, Peggy. We appreciate it.

Any other comments?

[No response.]

CHAIR JOHNSON: All right. Looking like we don't

have any.

We do want to remind you in the audience, if you have some questions that you have later on that you'd like to submit, you can do so through the MACPAC website.

And with that, we will be taking a short break. We'll be back at 2:40. Thank you.

* [Recess.]

CHAIR JOHNSON: All right. Thank you. Welcome back.

So for the remainder of the afternoon, we're going to be exploring the critical topic of self-direction in Medicaid HCBS, and so to begin, we have Brian O'Gara, who's our analyst, and Gabby Ballweg, who's our research assistant. And they're going to provide an overview of what self-direction models and key considerations for strengthening these programs look like. And then, we're going to have a great panel conversation that I'm very excited about.

So I will turn it over to both of you to get us started.

INTRODUCTION TO SELF-DIRECTION FOR HOME- AND COMMUNITY-BASED SERVICES (HCBS)

* MR. O'GARA: Great, thank you. Good afternoon, Commissioners. Gabby and I will be discussing the kickoff of a new project focusing on self-direction for home- and community-based services.

So just to quickly level set, I know that MACPAC, we previously considered self-directed providers as part of our work around Medicaid payment policies for the direct care workforce. I just want to be clear that this work is not stemming from that or is not in the same vein, and we shouldn't think of this work as particularly tied to either payment or workforce policies.

The objective of this new project is to produce a foundational resource on self-direction and to examine it as a mechanism through which states deliver HCBS to beneficiaries and also as a starting project to kind of gather input from stakeholders and to identify potential policy areas for future work.

To that end, I'll be providing a brief background and overview of the statutory framework that guides self-direction, and then Gabby will be diving into more detail on a lot of those elements, including state flexibilities, program administration, evaluations, and the next steps for

this work.

So some background. Medicaid home- and community-based services are, of course, provided to individuals with long-term services and supports needs. They're designed to allow them to remain in the community and live independently, and one of the ways that states deliver HCBS to individuals with LTSS needs is through self-direction, which is a consumer-controlled model of delivery as opposed to a traditional agency-delivered model.

Participants in self-direction control their own care by hiring representatives or -- excuse me -- by hiring workers or -- with the assistance of representatives, hiring workers, overseeing and terminating those workers who are often family members, friends, or other acquaintances. And self-direction affords participants greater autonomy to choose and control their own care compared to that traditional agency-delivered model.

The guiding tenet of self-direction is that participants are capable of determining the types of assistances and services they need to remain independently and independently in the community, and to that end, CMS

has several requirements for states to help support beneficiaries in controlling their own care and services.

CMS requires that states, when offering self-direction, implement person-centered planning processes. These are led by the participant with optional assistance from a chosen representative, and they focus on identifying the participant's strengths, preferences, needs, and desired outcomes.

States also require a service plan for self-direction, which is a written document outlining the specific services and supports the individual will receive to meet their needs and stay in the community.

Information and assistance services and supports help individuals navigate the self-direction process from identifying personnel needs to ensuring services are properly managed.

Another key element is financial management services, or FMS entities. These entities assist with managing budgets, handling payroll, paying taxes, and tracking expenses. And it's important to note that while not all individuals who self-direct utilize FMS, many individuals do.

States also have to have in place and maintain a quality assurance and improvement system to identify and address issues to ensure services delivered through self-direction are effective and appropriate.

And finally, if the individual self-directing does receive budget authority, which Gabby will discuss later, the state must obviously provide them with an individualized budget to pay for services.

Just a quick overview of nationwide enrollment. Self-direction models are available in all 50 states and the District of Columbia, and last year, there were over 1.5 million beneficiaries enrolled in self-direction, mostly through Medicaid. But it's important to note that this figure does include some other funding sources, such as the Veterans Health Administration and the Older Americans Act.

States have broad flexibility to target self-direction by geographic region, services, and populations, which Gabby will also discuss soon.

Self-direction began as the Cash and Counseling demonstration. This was launched by ASPE in 1997 using Section 1115 demonstration authority. The goal of this

Cash and Counseling demonstration was to assess the feasibility, advantages and disadvantages of self-direction in financing and delivering personal assistance services for Medicaid beneficiaries.

The pilot began in three states: Arkansas, Florida, New Jersey. And eligible Medicaid beneficiaries there volunteered to receive a cash allowance with counseling services in lieu of using a traditional agency-directed model of care. Participants hired their own workers, managed their own budgets, and designated representatives to help them control their care where necessary.

Compared to the traditional agency-delivered model of care, beneficiaries in the Cash and Counseling demonstration reported higher satisfaction with their care and quality of life as a result of participating in the pilot program.

The states that originally participated in the Cash and Counseling demonstration, those programs by 2011 had all become the modern self-direction programs, either through 1915(c) or Section 1115 demonstration authorities.

Now we'll briefly touch on statutory framework.

States have several options under Title XIX of the Social Security Act to offer self-directed services. States can use several Medicaid waivers or state plan authorities concurrently, or they can just use authorities on their own to offer self-direction. For example, Oregon utilizes every authority in this table to offer self-directed services, while Rhode Island offers self-direction solely through 1115 demonstration authority.

Each of these authorities have different requirements that dictate how the state must design and administer their self-directed programs. Elements such as eligibility, contracting, the use of family providers, and payment structures are just some of the key elements that depend on which authority states select to use. And Gabby will be touching on those elements soon.

As you can see here, Section 1915(c) is currently the most commonly used authority to deliver self-directed services. That has been the case historically because it is the oldest authority for self-direction, but states are increasingly turning to other authorities either in concurrent use or using other authorities on their own to offer these self-directed services.

There's also been some recent rulemaking. In the final access rule from May, there was, of course, the provision that 80 percent of all Medicaid payments to homemaker services, home health aide services, and personal care services must be spent on direct care worker compensation. That mandate does apply to self-directed services offered under 1915(c), (I), (j), (k), and 1115 authorities.

And the rule also requires states to report every other year on a set of nationally standardized HCBS quality measures. This is referred to as the "HCBS quality measure set." And according to CMS, CMS encourages states to use the measure set to the extent that measures are applicable to a specific HCBS program, regardless of delivery system type.

Beginning by July 2028, states must report every other year on some of these HCBS quality measure sets, regardless of the type of delivery model, therefore including self-directed services.

And now I will hand it over to Gabby.

* MS. BALLWEG: Thanks, Brian.

So now we're going to move forward into a

discussion of some of the state flexibilities in self-direction program design.

States have considerable flexibility when designing their self-directed HCBS programs within this aforementioned statutory and regulatory framework that Brian just reviewed.

One of the major flexibilities that states may leverage as they design their self-direction programs is whether to offer beneficiaries either employer authority, budget authority, or both. When a beneficiary has employer authority, that means that the beneficiary can choose who provides their HCBS. When a beneficiary has budget authority, they have an individualized service budget that's based on their functional needs. And then within that budget, they can set a wage for their HCBS worker that they will be paid.

States have also introduced additional flexibilities within budget authority that allow participants to allocate some of their service funds to goods and services that can help promote independence, such as assistive technology or home modifications.

According to the AARP's 2024 National Inventory

of Self-Directed Long-Term Services and Supports, 44 states had at least one self-direction program that included budget authority, and the top 10 states with the largest growth in their self-direction programs from 2019 through 2023 also offered budget authority.

In addition to decisions around employer and budget authority, states must also consider whether to allow a representative to self-direct services for or in coordination with a beneficiary. Most states permit the use of representatives to help self-directing individuals to manage their services and budgets.

States that allow representatives may require a formal designation, but that's not a federal requirement. If a state does allow for the election of a representative, they're generally restricted from serving as the paid caregiver as well. However, there is an exception to this rule for parents of minor children with disabilities.

States have the authority to determine who can provide HCBS under self-direction programs. CMS does not dictate qualifications for caregivers, but does require that states must establish qualifications.

To reduce opportunities for fraud, waste, and

abuse, states often implement protections such as background checks and abuse registries.

Variation in requirements for caregivers can exist across self-direction programs within a state, especially around training and certification, and these variations can often align with specialized skills required for a specific service.

In many cases, states will offer flexibility to allow family members to deliver care, generally with the condition that they are not the beneficiary's representative. States can set limits on the use of family caregivers, such as the total hours of services they may provide per week or a specific service setting in which they can provide these services.

States that permit family caregivers to provide self-directed services generally consider whether the existing provider network is able to reach beneficiaries. So this could be workforce sufficiency considerations or geography. They also consider whether the existing workforce can provide culturally competent care and adhere to the beneficiary's person-centered service plan.

According to the National Resource Center for

Participant-Directed Services, over 50 percent of self-directing individuals will hire a relative or someone they know when they have the opportunity to do so.

As Brian had mentioned, states must also have a quality assurance and continuous improvement system for their self-direction programs. These systems help ensure quality, identify potential risks to participants and employ mechanisms to mitigate these risks, such as criminal background checks for HCBS workers or checks to support financial accountability.

Regulations require that states guarantee the necessary safeguards are in place to protect the individuals receiving services and maintain financial accountability for the funds expended under a self-directed HCBS program.

Self-direction programs must balance these requirements with the need for flexibility to ensure that the participants can fully exercise their autonomy while self-directing their services and still receive the adequate supports and protections they need.

States will vary in how they design their quality assurance and continuous improvement programs to manage

risks. For example, one state disallows payments for personal assistance services while a beneficiary is hospitalized, and they do this by comparing the PAS and hospital claims for the beneficiary using the state's Medicaid management information system.

Another state requires its managed care organizations to monitor for fraud and abuse and report certain utilization anomalies, such as the underutilization of services. The state also conducts quarterly audits.

Lastly, some states can also engage in more stringent monitoring for services provided by relatives.

States have the flexibility as well to determine which populations they would like to serve through their self-directed HCBS service delivery models. Each self-direction program may have different eligibility requirements within and across states.

An analysis conducted by the AARP, which includes self-direction funded by Medicaid and other sources, found that in 2023, all states offered the self-direction HCBS delivery model for adults over the age of 65 and adults with physical disabilities. Over 90 percent of states offered self-direction for adults with I/DD and adults with

traumatic brain injury. Approximately 86 percent of states offered self-direction for children with I/DD, and just under half of states offered self-direction for adults with serious mental illness.

States have the flexibility to select which services are available for self-direction. According to Applied Self-Direction, the most commonly self-directed services include personal care, transportation, and respite services. There's no comprehensive list defining which HCBS can be self-directed, and states have considerable flexibility to identify services to self-direct.

States can vary widely in the quantity of services available for self-direction and which services they allow to be self-directed.

In a previous analysis of Section 1915(c) waivers supporting home-based services, round-the-clock services, and day services, 40 states offered self-direction for home-based services, and 22 states offered self-direction for day services in at least one of their 1915(c) waivers. No state offering round-the-clock services under a Section 1915(c) waiver offered a self-direction option for that service.

In addition to the program design flexibilities, states must also consider how they plan to administer their self-directed service delivery model. To effectively administer the self-directed HCBS delivery model and conduct monitoring and oversight, states may collaborate across state operating agencies and rely on a variety of third-party administrators.

In this section, I'm going to review select self-direction program administrators, but please note there are more, and we will be continuing to delve into these and exploring them as we continue this work.

When states administer self-directed HCBS, some choose to nest all of their self-direction programs under the state Medicaid agency, while others may delegate the administration of one or more of the state's self-directed Medicaid programs to separate state operating agencies. These operating agencies outside of the state Medicaid agency may include state departments focused on aging or I/DD populations, among others. For example, one state administers its Medicaid self-directed HCBS program across four separate operating agencies.

According to CMS, when states operationalize

self-direction programs, they should also consider the following: monitoring in a managed long-term services and supports, or MLTSS environment; identifying backup supports; maintaining workforce registries; and ensuring caregiver certification and training.

In addition to the state-operating agencies, states may also work with third-party entities to support their self-direction administration. These entities may assist the state in providing required information and assistance supports and financial management services.

When a beneficiary has budget authority, their state self-direction program must also include FMS entities as a support to perform employer-related and tax responsibilities or to assist beneficiaries in managing these budget-related tasks themselves. However, beneficiaries are not required to use an FMS entity if they don't choose to do so. FMS entities must be able to assist beneficiaries in understanding their billing and documentation responsibilities, performing payroll tax and employment benefit services, purchasing goods and services, and monitoring the beneficiary's self-directed budget.

Regarding information and assistance supports,

they must be available to beneficiaries who are self-directing their HCBS. The amount and frequency of information and assistance support provision varies at a beneficiary's choice, and the state or third-party entities contracting with the state, such as support brokers, case management agencies, and even on occasion FMS entities, among others, may furnish information and assistance supports.

Depending on the beneficiary's needs or preferences, information and assistance professionals may support the beneficiary in accessing services, they may assist in developing the service plan or service budget and monitor the provision of services and support budget management.

Next, we're going to move on to our evaluations.

Some of the most robust evaluations of self-directed programs come from the cash and counseling demonstration. In an evaluation of the original three pilot Cash and Counseling programs that Brian discussed, the demonstration was associated with a favorable impact on beneficiaries and their caregivers. For example, compared with individuals receiving agency-directed services, Cash

and Counseling beneficiaries were more satisfied with their care and quality of life.

Additionally, caregivers were about 20 percentage points more likely to be very satisfied with their care recipient's service arrangements, relative to those providing service in an agency-directed service delivery model.

They also expressed higher levels of satisfaction with their own lives, compared to caregivers providing agency-directed services.

Although caregivers and beneficiaries were broadly satisfied with Cash and Counseling, the demonstration was associated with adverse effects on Medicaid costs for demonstration-covered services. Overall, monthly HCBS costs under Cash and Counseling were higher across all three states and all age groups receiving services when compared with agency-provided services. However, researchers generally attributed the cost differential to unmet care needs among beneficiaries in the traditional system.

Furthermore, some of the increased costs in the demonstration were partially offset by savings on other

Medicaid services, like nursing facilities services and home health.

Beyond the Cash and Counseling demonstration, there are more limited empirical analyses of self-directed HCBS service delivery models, and some recent studies have assessed the effectiveness of self-direction for people with behavioral health needs, and other studies have suggested service costs and self-direction are very similar to those in the agency-directed HCBS.

Most of these studies are on a smaller scale than some of the Cash and Counseling evaluations, and they all have limitations.

I'm now going to move forward with our next steps.

For this session, we welcome the Commissioners' questions and feedback related to the elements of self-direction for HCBS that we discussed today, including state design in a self-direction program, program administration and specifically Commissioner insight into program administration, and opportunities and challenges for states and stakeholders in self-direction delivery models.

We will return at the February 2025 Commission

meeting with findings from state and stakeholder interviews, and I thank you for your attention today. We're going to be turning directly to our participant panel.

[Pause.]

CHAIR JOHNSON: So I think while we're waiting for the panelists to come on, we'll go ahead and take a couple of questions for you. I will say be brief, but maybe we'll just say one or two Commissioners or so. Any questions or thoughts?

Let's see. Heidi.

COMMISSIONER ALLEN: I'll be super quick. I had two questions that I thought were -- or things that popped up to me is, one, the risk management systems and criminal background checks and how that impacts, like, communities that have been disproportionately harmed by policing and whether or not it prohibits people from hiring a relative that might have a criminal background check -- or criminal background.

And then for the FMS entities, I'm curious about whether or not people provide benefits like health insurance and vacation time. And then what state policies,

like, you know, that you can't simultaneously have support hours at the same time as somebody is hospitalized, like, how do they do vacation time? Then are they not able to offer anything even for people who are working full-time?

So that was my two thoughts.

CHAIR JOHNSON: Thank you, Heidi.

Carolyn?

COMMISSIONER INGRAM: Thanks for all of the background work you've done. I had just a few questions to see what you found in markets.

One is what parameters states have put on in terms of controls on these types of services in order to protect beneficiaries. I think, in some cases, at least I've seen some pretty horrible harm to members and beneficiaries that resulted in death actually by people who were supposed to be their caregivers or close to the family. So I'm wondering what types of programs have been put in place to monitor that.

And then secondly, there are systems I know that have been put in place, and I'm sure Patti can talk about some of these, but the EVV vendors and those types of things which have best practices. And I'm just curious if

you saw some of those in states, but also, they can also be kind of costly and very complex in their IT administration and how it actually gets played out in the field when people have to log into systems, whether or not they have access to Wi-fi and tablets or if they're done through apps. And I'm wondering if you've seen any best practices or examples of that and then also how they report out effectiveness besides just tracking who comes in to see somebody. What are the outcomes that we're actually seeing out of that data? And I'm assuming Patti's got some of that that she can share.

So that if we are investing in these programs and spending a lot of money on them to keep people in the community, which is a good thing -- that's what we want to do -- but what type of outcomes are we actually seeing from that care? And are we ending up spending so much money developing these complicated systems that it's wasting the money instead of going to the people that need help in the community?

So thank you.

CHAIR JOHNSON: Thanks, Carolyn. I appreciate that.

Patti?

COMMISSIONER KILLINGSWORTH: I'm going to mention just a couple of things maybe for us to delve into as we continue to dig into this topic. One, I know is kind of on the agenda, which is really understanding from the state's perspective, policy or operational barriers as it relates to -- or challenges as it relates to self-direction and just making sure that we understand that as well as getting the beneficiaries' perspective.

As a Payment and Access Commission, I was a little troubled by the findings around the higher costs related to self-direction and would love to delve deeper into that and really look since so many -- well, all states offer self-direction as a model, really being able to look at average utilization of services in self-direction models versus those that are provided more in agency-directed models and see if we see increased utilization and if we kind of understand the factors that account for that.

And I think I'll leave it at that for the moment, but I'm confident I'll have more input at a later time but anxious to get on with the panel discussion.

CHAIR JOHNSON: Thank you. Thanks, Patti.

We'll just have Dennis, then, and then Mike, and then we'll go to the panel. So, Dennis?

COMMISSIONER HEAPHY: I think one of the reasons why this is important, at least from a consumer perspective, is that just as there's an institutional bias, there has traditionally been an agency bias in provision of services, and oftentimes agency workers are not able to provide all the services that an individual needs. And so there are nursing-level services that a health aide from an agency cannot do, that someone who's a consumer employer can actually have provided their service, can have nursing-level services provided for them in the home because they're the employer and not the agency. As the employee works for that individual, they're answerable to that person and not to an agency, and so the person actually has the relationship with that person. And so the relationship is not with the agency itself. I just think it's important to raise it up and why this is such an important conversation in terms of people's ability to remain in the community.

I know there's research going on right now about access to in-home care providers during COVID and comparing

folks who were in the agency versus folks who were consumer employers. So I can bring some of that information to you.

So I'd just like to contextualize this as really a means of providing choice to folks and the opportunity to live in the community the way they do, and there are things that I do as a consumer employer that I would never be able to do with an agency. And so for me, I've been on the agency model and don't know who's going to come. Folks have more complex care needs, and a lot of folks actually want to work with an individual. So just, yeah, I won't opine on it, but just to make that clear why this is so important.

CHAIR JOHNSON: Thank you, Dennis.

And then Mike?

COMMISSIONER NARDONE: I was just going comment on one of the things that I'd like to better understand is the type of supports that are provided to the worker in the self-directed setting, training.

Also, are there other supports that are provided to help, say, an individual understand like what they should do in a particular situation, emergency situation, those types of supports?

And I'm also interested in the models around EVV, because I do think it has some capability to provide some support to the workers, and I'm wondering if that's being used as of now. I mean, I know a lot of it's around fraud and abuse, but I think it also has capabilities much beyond that. And I'm just wondering the extent to which states may be employing that.

The last thing I was going to ask, just in terms of the numbers, it says 1.5 million people are in part of self-directed programs. I know that's not just Medicaid, right? Tomorrow we're going to hear some numbers around how many people are in home- and community-based services, which is like 3 million. So I guess what I'm trying to understand is, does that mean half the people are in self-directed programs? I know I'm probably not understanding that right, but I'm just trying to get a sense of the sizing because we're going to have some more information on HCBS tomorrow. So I was wondering if you could comment on that.

MS. BALLWEG: Yeah, I'm happy to respond to that. So in the work that we're doing tomorrow with the HCBS dataset, we actually were looking at that and seeing if we

could look at self-direction in there. And there's actually not a flag in T-MSIS specific to self-direction. There's one for services supporting participant direction, which does not cover the full gamut of self-direction. So we can't quantify a specific number of how many people receiving HCBS are self-directing.

In that figure, it's about 60 percent or so. A little over 60 percent of the individuals in there are funded by Medicaid, based on where that statistic came from. So that gives you a little bit better of a scope or an idea.

COMMISSIONER NARDONE: So of the 1.5 million, 60 percent of those are --

MS. BALLWEG: About, about, yeah.

COMMISSIONER NARDONE: About 60. Okay, that's helpful.

CHAIR JOHNSON: All right. Thanks, Mike.

All right. I'll turn it back over to Gabby and Brian then to introduce the panel.

PANEL ON SELF-DIRECTION FOR HOME- AND COMMUNITY-BASED SERVICES (HCBS)

* MS. BALLWEG: Thank you for that discussion.

So we are having this panel today to complement MACPAC's ongoing work to develop a foundational understanding of self-directed home- and community-based services in Medicaid, including how states -- exploring how states design and administer their self-directed HCBS models, as well as any barriers that may exist to the effective program administration of self-directed services.

Through our conversation with panelists, Brian and I plan to obtain insights on the beneficiary experience in self-directing services, including opportunities and challenges, and design considerations that states must make when establishing and administering these programs.

To this end, we have invited four panelists for today's session. We're joined by Patricia Brennan, the Director of the Office of Education on Self-Directed Services, Waiting Lists, and Special Projects with the New Jersey Division of Developmental Disabilities. We're also joined by Mark Sciegaj, a Professor of Health Policy and Administration and Professor in Charge of the Bachelor of Science Degree in Health Policy and Administration at the Pennsylvania State University. Our third panelist is Pamela Zotynia, the Service Director of Participant-

Directed Services at Values into Action, and the mother of our fourth panelist, Robert Zotynia, a Self Advocates United as One Power Coach, Artist, Changemaker, and Self-Direction Participant. Thank you all for joining us today.

And with that, my first question goes to Robert. Robert, could you please explain why you decided to self-direct your services?

* MS. ZOTYNIA: Robert uses assistive technology, so be patient with us.

You ready?

* MR. ZOTYNIA: Thanks for inviting me to speak with you today. It is truly an honor.

I was fortunate to grow up in a family who believed I should not be treated differently just because I happened to have disabilities, and they instilled this belief in me. I attended regular classes in school, not segregated special education classes. I received all of my supports in the classroom, and I made a lot of friends. I also learned a lot of things I probably would not have been exposed to in special ed classrooms.

So, when I graduated, it was a bit of a shock when I was referred to segregated adult programs. I tried

several day programs, but I found them boring most days. And sometimes they would trigger my anxiety when my peers had bad days and became loud and disruptive. I never blamed them. But being a person with mobility challenges, it can cause stress when you can't move out of the way without someone assisting.

Over time, this type of environment began to impact my health. My body became tight from constantly reacting to stress. I began exhibiting mood swings that professionals refer to as behaviors, and I developed some serious stomach issues that became life-threatening. Because I needed constant monitoring to manage my health challenges, my mom and I decided a residential setting would be best. We assumed the provider would be able to follow the medical recommendations, including closely monitoring my diet due to the damage to my stomach.

Unfortunately, this did not work out as we hoped. In the 17 months I lived in the group home, I had 12 visits to the emergency room and two inpatient hospitalizations. My mother was and is my best advocate. She demanded that the provider follow the medical orders and provide the care that I deserved.

Eventually, the provider issued a 30-day notice informing us they were terminating service. That's when we decided I would move back home and self-direct my services.

That was almost 10 years ago. I'm authorized for in-home and community support 24 hours per day. I hire, train, and manage my staff so they know exactly how to assist me. They help me with everything: my personal care needs, my job, accessing my technology and equipment, my household responsibilities, and navigating the community.

In addition to daily service notes, they document my moods, sleep patterns, consumption, fluid intake, and bowel movements so we can intervene if I'm experiencing an issue and to share with my doctors.

I have six staff, and all of them have worked for me between six and ten years, including during the pandemic. I haven't been to the hospital in seven years. Having control of my life through self-direction is the best decision I ever made.

I also use a supports broker to assist me, but it's a provider-managed service.

MS. ZOTYNIA: He's done.

MS. BALLWEG: Thank you, Robert.

I'm also wondering, can you share some of the examples of the services and supports that you self-direct?

MS. ZOTYNIA: So he did not program that in, if you don't mind. If Robert doesn't mind, I'll help him respond to that. Is that okay with you? Okay.

So he is authorized for and self-directs in-home and community support, which you may have heard referred to as "habilitation" in other states. He's authorized for that 24 hours per day, seven days a week. He has variances for that so that he can have more than 14 hours of service in a day. That was established when he left the group home, who established that he had a very high level of need.

He also is authorized for mileage reimbursement, although I'll be honest with you, we've never utilized it because we're just too lazy to do the paperwork. He will likely begin using that if I am ever not available and my credit card goes away with me.

He's, at times, needed nursing service. You cannot self-direct nursing service. It's a discrete service within the waiver. But in Pennsylvania, a nurse license, an LPN or RN, qualifies the support worker to

provide enhanced in-home and community support. So we have hired nurses who are paid as in-home and community support workers, but they bring the skills Robert needs.

We discontinued that a few years ago because Robert has learned to manage his health fairly well, and we didn't really feel we needed to take a nurse from someone else who's probably been waiting for a nurse for decades. There's a shortage.

Is that it? Yeah.

MS. BALLWEG: Thank you both.

My next question is going to be for Pam. As both a parent and caregiver, what has your experience been with self-direction, and how has that impacted your family?

MS. ZOTYNIA: So I have both personal and professional experience with self-direction. So I'm going to speak from my personal experience as Robert's mom.

Robert's 38. We've used probably every model of service that's been around for the past 37 years since he was diagnosed and enrolled in services. He didn't always receive services. We've used day programs. We've used group homes. We've used -- family support service was a service years ago. I don't even know if it still exists.

The majority of those are provider-managed, and although I don't like to give you the impression that we don't think providers provide good service -- they certainly do -- but it comes with some restrictions that didn't allow Robert to have the flexibility that he really was looking for.

So, when we moved towards self-directing 24 hours a day and Robert was able to have complete control while following rules and regulations because, you know, Medicaid comes with a lot of rules and regulations, which we're cool with, we really saw him begin to thrive. When we saw that happening, it began to relieve stress on me, on his sister, and on his father. So it helped us -- it helped us find a balance in our home. It helped Robert become very integrated in our community because he decides where he's going to go and when he's going to go. He decides if, you know, hey, I'm tired, I'm going to sleep late today. There's no "Hurry up. Get up. The van is here. You got to get to day program," because there's this short window that you can get in and or they close the door because of billing issues. It's really -- I understand it from a business perspective, but it doesn't really work in real

life.

It's allowed me -- although it's a lot of work -- I don't want to give anybody the impression it isn't a lot of work when you self-direct, and I tell every family we encounter, it's given me a sense of security that Robert will be okay when I'm no longer here. He's been able to build a staff complement of, ironically, all men, which is very unusual, who understand him, connect well with him. He connects well with them too, who are almost like his friends until -- they're always his friends. Let me take that back. But they're able to jump in if there's a crisis. They're able to intervene quickly, so there are very rarely crises.

Robert used to have mental health crises daily, sometimes multiple times in a day, sometimes resulting in us having to go to the ER. That hasn't happened in years because we track so many things, and the guys are amazing at tracking that after we trained them and supported them in that, that we can see that data and jump in quickly and know that something that happened today or yesterday has caused anxiety or has increased Robert's pain.

We didn't see that when he lived in the group

home. As hard as they tried, it just didn't work. He constantly was in the hospital or at the doctor. Like he mentioned, he hasn't been to an ER in seven years now, knock on wood, because I really don't want to go this weekend.

I hope that answers your question.

MS. BALLWEG: Yes, it definitely did. Thank you, and thank you both for being so open and willing to share with us.

This next question is going to be for Mark. Beyond the required person-centered planning process, the service plan, the individualized budget, information and assistance supports, states have broad flexibility in designing their self-directed HCBS delivery models. Could you please describe some of the key design considerations states typically make as they develop their self-directed HCBS programs?

* DR. SCIEGAJ: Sure. And, you know, depending on whether it's an employer authority model, which enables the participant to have control over and the choice of worker, or if it's more of a budget authority model, which enables them to have control over the worker but also to purchase

additional permissible goods and services, one design feature is whether the participant is going to be the employer or is the participant going to be a co-employer, meaning that they would refer somebody to an agency, and the agency would hire that individual to serve that participant. So that's one area.

Within budget authority, states, you know, set the parameters of what are the allowable goods and services that would be, you know, permissible in the program, so, you know, coming up with that constellation of services.

A major area, I think, design feature is before you even get into the programs, how do you convey information to potential users about the programs? How does that information get highlighted and distributed on your website? How does it actually get conveyed in the initial meeting that that individual may have with a counselor or support broker or case manager?

And oftentimes, people will come into these situations and they're not really prepared or don't feel that they're prepared for self-direction. So ensuring that there's -- in the design, that the question about self-directing or not self-directing can be revisited or as that

person becomes more comfortable in this new arrangement in their lives.

Building in staff time, because these initial discussions with, you know, new participants, they can be time-consuming, a lot of explanation. It takes more than one visit for those, that information to be processed and for them to move forward.

Another area for design consideration is the use of representatives. Most programs will allow participants to have a representative to assist them in their managing and directing of their services, so, you know, figuring out, are there going to be any restrictions to that particular role?

Another challenge -- and I think this was mentioned in the previous panel -- is that consumers who want to self-direct, it can be a challenge at times to find a reliable and appropriately skilled worker. I think it was mentioned that some states do have worker registries, and unfortunately, you know, those are a great start. But they're not the -- just because they have a registry doesn't mean that that adequately solves this particular issue. Sometimes the registries are ineffective because

they'll have lots of workers, but the workers may not be as responsive to individuals reaching out to them regarding possible employment, which leads to, you know, another design question about who -- can the participant hire a family member, and are there going to be restrictions on family members who can be employed or could be hired in this manner?

Most participants in self-directed programs do hire a family member, and that sometimes is just an artifact that they can't find workers outside of the family. A recent study showed that most participants would prefer -- you know, they don't have to rely solely on family, and they would prefer to have an opportunity to have non-family members as well.

The question was raised by one of the Commissioners, and certainly a design feature that states need to consider is how to create risk management systems. You know, how can you develop specific policies and procedures that will, you know, support staff, will support participant workers, will support the participant, you know, develop a process to identify situations that could pose potential harm and assess the likelihood of their

occurrence? So finding ways in the design process of mitigating risk and responding to potential risky situations is a key design feature, as is developing quality control measures and finding out, you know, where the program is effective, where does it need to improve and throughout this whole -- you know, that process, ensuring that the voice of those consumers are engaged and involved in that process.

So those are some of the design features that states often don't have to deal with in developing these programs.

MS. BALLWEG: That's really helpful. Thank you.

MR. O'GARA: And I think it's great, Mark, that you mentioned kind of conveying self-direction to consumers, because we actually have Tricia with us, who's from the Office of Education and Self-Directed Services in New Jersey, so that's a great segue.

Tricia, we've been talking a lot today about kind of design and administration flexibilities that are available to states. I think it'd be helpful for the Commissioners to hear some examples of what that looks like for a state. So could you just give us a quick overview of

what self-direction looks like in New Jersey, including how your state uses some of those flexibilities, what services might be available for self-direction, and maybe which populations can self-direct?

* MS. BRENNAN: Sure. So thank you all for having me join you today, and some of the things that Mark actually touched upon, I'm going to speak upon as well.

I wanted to give you a little bit of the history, though, and how some of this was established in New Jersey, because I think it's key to understand some of the way in which it was designed.

So New Jersey has been providing the option for self-directed services since the late '90s. So it's really rich in our history. Initially, it was through the Cash and Counseling, and that's the Personal Preference Program, and that's through our sister agency, the Division of Disability Services.

The Division of Developmental Disabilities began in the early phases of something called "self-determination," and that was part of a governor's initiative, and it was for people who had reached on the priority waiting list.

In the late '90s, the New Jersey Institute of Technology, NJIT, did an extensive study of people on the priority waiting list and saw that people really didn't want to go in, weren't really opting for options such as group home settings or traditional programs. And our system at that time was solely contract-based. So you had a choice of a contracted service or nothing.

What happened in 2002, we're sitting at the table, and it was actually one of my first weeks in my new role in central office, and a core group of family members came to us and said, "If you gave us the Medicaid dollars, we could do it better." So what we did is we engaged those stakeholders for an extensive period of time and built the foundation in a small -- you know, it was a governor's systems change that we were working on at the time. It was a large piece, and it was a five-year pilot program that launched self-direction for people who were on the priority waiting list for Medicaid waiver services and for those who are spending their school entitlement. So, at that time, you had a choice of self-direction or contracted services.

If you move, fast forward a few years, we also then became--offered to offer another waiver program, which

is the supports program, as we moved our whole entire system out of the contracted system into the fee-for-service system around 2014.

Again, we had the ability to -- all people on both waiver programs had the ability to self-direct. So it doesn't matter which waiver program you're on. You have the ability to self-direct.

We utilized two fiscal models for people to choose from, the vendor fiscal employer agent model and our agency with choice model.

The waiver services that people had the choice to self-direct are no different than the waiver services of people in our traditional settings, provider-based residential settings. It's community-based supports, individual supports, hourly interpreter services, respite, supports brokerage, and I might talk a little bit more about supports brokerage in one of the other questions. It's a newly launched service, but it's needed because of some of the responsibilities of self-direction. Assistive technology is available. That's through a community vendor. Goods and services, environmental modifications as well. Natural supports training, transportation in a

single passenger, and vehicle modification.

As people enter into our system through intake or some at just the end of their school entitlement, they have the opportunity to receive their support through self-direction or through a provider agency, and they have the option to do a little bit of both.

MR. O'GARA: Great. Thank you so much for giving us that detailed overview of what self-direction looks like in New Jersey.

So we've talked a lot about states obviously have kind of a lot of complex choices they can make when designing and administering these programs. So, Tricia and Mark, I was wondering if you could just both briefly describe some challenges that states face in administering these programs, and either of you can begin with that question, or I'll just pick on Mark so that we can start.

DR. SCIEGAJ: Okay. I was going to say Tricia should go first since I went first.

MR. O'GARA: Oh, sorry.

MS. BRENNAN: It doesn't matter if you want me to.

DR. SCIEGAJ: No, no. I think one of the -- you

know, if you think of the information and assistance function and you think of the financial management services functions, okay, I think one of the key considerations for states, challenges for states is whether those are going to be labor services or whether they're going to be an administrative activity. And whatever direction the state goes in will have some impact on the number of providers for those different services, will also have an impact on how the state gets reimbursed for those services. So, you know, there are pros and cons to either way, but that's certainly that -- making that decision regarding those services is a challenge.

MS. BRENNAN: So, for us, I see one of the biggest challenges as being maintaining flexibility for the individuals and the people and the families while ensuring fiscal integrity at the same time.

So, you know, there's a lot of checks and balances and guardrails that need to be put into place, you know, so that people can have that flexibility, but there are certain pieces that, you know, there is accountability for. We face challenges with that.

We also face challenges with their interaction

between our fiscal agents and the families to the point that sometimes we have a new unit, that the basis being that liaison between both of them. And one of the other challenges is the amount of responsibility, helping people understand the amount of responsibility that goes along with self-direction.

We have -- one of our self-advocates recently said to us -- and it makes -- you know, his quote, we use it all the time is, "It's not" -- and he uses communication devices to share it with us. We said, "Why are you self-directing? What would you tell anybody?" He said, "It's not easy, but it's worth it." And one of the other ones said, "I like being the CEO of my own life." So those are the pieces that, you know, you have to keep in mind, but it's the responsibility and fiscal accountability for all those pieces that may seem, you know, be a deterrent for some folks.

MR. O'GARA: Thank you both. I'm sure the Commissioners will have lots of questions about guardrails and accountability features.

I want to turn to Robert and Pam now and ask, what challenges do individuals and their families face when

self-directing home and community-based services?

MS. ZOTYNIA: Are you ready?

MR. ZOTYNIA: There are other challenges I've encountered along the way.

MS. ZOTYNIA: Hang on. Technology. Not always our friends.

Ready?

MR. ZOTYNIA: There are other challenges and I think --

MS. ZOTYNIA: Still not our friends. See if I can make this work for you.

MR. ZOTYNIA: There are other challenges --

MS. ZOTYNIA: It just wants to start at the end. Give me a second.

While I'm trying to fix this for him, I can talk from my perspective. So I agree with everything you guys just said. There is a lot of responsibility that we assume, families, self-advocates, when we make this decision. And all the rules and regulations are written by bureaucrats. No offense to anybody on this call who is a bureaucrat. I have many friends who work in bureaucracy. But they're not generally written in plain language so even

a typical family would understand, and they're extremely difficult for self-advocates to navigate and understand.

We do in Pennsylvania have supports brokers. I'm actually a certified support broker in Pennsylvania, Maryland, and I've been trained in New Jersey, although I only currently provide support in Pennsylvania and always interested in looking at what other states are doing. That is a huge benefit. If that's available, it should be always, always recommended.

My opinion, although I'm all about choice and people have the right to make decisions for themselves and decide who they want to use, what providers and what services, part of me really feels that when people start using self-direction, it should almost be mandatory that they have a support broker for maybe the first six months to get set up, to learn how to navigate the FMS, to choose if they have a choice, which FMS model they're going to use. It's very complicated.

Robert's going to talk a little bit about some of the challenges he's had. He is his own common law employer. He assumed that role this year. Prior to that, we can have -- "surrogates," they call them in

Pennsylvania. So he had selected. I was his surrogate at one point. His dad was his surrogate at one point. And then he felt he -- after a couple of years, he can do this because he has a supports broker. I don't think he would ever be able to do it without that level of support, and the supports broker is really only assisting him. They're not doing anything for him. They're --

I'm talking about it. You want me to stop talking about that because you want to talk about it? All right.

Let me see if -- I'm going to see if his app will work now.

MR. ZOTYNIA: There are other challenges I've encountered along the way. There are other challenges I've encountered along the way. But it's been --

MS. ZOTYNIA: It just wants to --

MR. ZOTYNIA: I learned about self-direction --

MS. ZOTYNIA: Got it.

MR. ZOTYNIA: -- because my mom has worked in the field for 35 years. It was not the first option offered to me by any of the numerous supports coordinators I've had over the years. We brought the information to them. I

always tell people who are interested in self-direction that it's not always easy.

One of the benefits is you can control your services and customize your day, but with this control comes great responsibility. As I'm sure you're aware, whenever a person accepts Medicaid funding, there are rules and regulations that must be followed. Understanding these rules can be difficult at times, especially if you are not familiar with bureaucratic language.

It can also be challenging to find staff. The last time I had a staff vacancy was about six years ago. It took me eight months to find the right person.

I'm lucky that I share my home with my mom, and she was able to support me while I recruited. I believe one of the barriers to finding and maintaining staff is the lack of benefits, especially health insurance. There is no mechanism within Medicaid to pay for insurance or pay time off. Staff need health insurance, and so do their families.

Another challenge is addressing performance concerns when staff are not meeting the expectations of the job. So it's very important to explain the job

responsibilities and expectations on day one and make sure everyone understands.

I use my supports broker to help me with this so there's no misunderstandings. In Pennsylvania, we have two options to choose from for financial management services. I chose the vendor fiscal employer agent model, and I am the common law employer. This means I am responsible for reviewing and approving timesheets so my staff get paid. This is done electronically using an app on my phone.

I have physical challenges. Navigating apps is difficult, but it is my responsibility, and according to our state DD office, no one else should have access to this information. I needed to write a letter explaining this challenge and requesting a reasonable accommodation so my supports broker can review the timesheets with me. After I confirm they're correct, she approves them via the app. Not many people know this is an option, although I tell everyone I can. I believe this is the reason very few people with intellectual disabilities act as the common law employer. If they and their families knew they could request reasonable accommodations, perhaps we would see more people like me choose self-direction and take control

of their lives.

There are other challenges I've encountered along the way, but it's been my experience if you work collaboratively with your team, there is no barrier that can't be resolved when you use self-direction.

MS. BALLWEG: Thank you both for those answers.

All right. We're going to be moving into the final question of today's panel before we turn it over to the Commission. As we wrap up this moderated portion of the panel, this final question is going to be for all of you. So, in 30 seconds or less, could you please share one thing that we have not yet discussed today about self-directed HCBS and Medicaid that you think would be important for the Commission to consider as we continue to work on this topic? And let's start with Mark.

DR. SCIEGAJ: Oh, okay. In 30 seconds, my recommendation would be to structure in ways to give participants a greater voice in these programs. There's no requirement that state programs have consumer engagement, but in those programs that do have consumer advisory boards, I think it can add to that program's effectiveness and efficiency, so giving greater voice to the

participants.

MS. BALLWEG: Thank you.

And let's go to Tricia next.

MS. BRENNAN: Mine is very similar. My main thing is to not have the primary focus be on the services and supports. It should really be about thinking about the services second and the person's focus on what their dreams are, so focusing on the people so that whatever it is that they want for their life and building the supports and services around them, because everybody should have the right to live, love, work, and play in their community, but they may need additional services and supports to help them achieve that good life. So, in order to achieve that success, people who are self-directing and their families and any other member of the circle of support needs to be at the center of the policy deriving. We also want to make sure that the goal is to create the infrastructure and supports and equal opportunities for all people.

So again, really changing the focus, not being of what services and supports can you get by through self-direction, what do we need to make sure is in place, what are the guardrails, but what is it that people want for

their lives, and what's going to make people successful, and then how can we support them best and build it around them?

MS. BALLWEG: Thank you.

And then we'll go to Pam next.

MS. ZOTYNIA: Robert and I are going to combine our time. We were consulting.

Robert thinks that every state should allow the person with a disability to have complete budget control. Not all states have that as an option.

We both also agree that all the planning should be -- there should be something in the language that requires it to be very person-centered, which I think is kind of what Trish and Mark were getting at there.

And financial management services, they vary state to state. Some have options. Some have only one. Some have 17. We strongly feel there should always be an option, at least two to choose from. Competition is never a bad thing. I think it improves the quality of any organization, company.

And the other thing is, at least in Pennsylvania, when we select a financial management service, they have a

contract, which I'm sure they do in each state. Those contracts expire, and every single time they expire, we're looking at a new vendor. So, it's begin again, relearn something. We would really like to see -- we understand why contracts are developed and selected by procurement the way they are, but we struggle with why change contracts when the current contractor is meeting the requirements of the contracts. We certainly understand if they're not. It creates a great deal of stress.

We just went through that in Pennsylvania this year. I work at a support brokerage. We support 10 percent of the people who use that vendor, and every one of those families was in a meltdown for months over it. And it's not just getting them enrolled, but it's training their staff on how to use a new clocking app, a new EVV app. There's a lot involved in that. So you kind of get to a point. It takes a couple of years to get to the point where things are going good, and there you go, the contract's out for a bit again. So I don't know what can ever be done about that, but we felt compelled to share that.

MS. BALLWEG: Thank you both, and thank you to

all of our panelists for participating in this moderated portion.

And with that, I will turn it back for Commissioner questions.

CHAIR JOHNSON: Thank you so much, and I just want to echo your thank-you to the panelists -- Trish, Mark, Robert, and Pamela -- for sharing your time, your expertise, your experience, and your insights. You just have no idea how much this is going to help us as we continue down this road to really understand this area and really understand exactly how we can be more helpful.

And, Robert and Pamela, hearing directly from a beneficiary truly underscores -- and I know my Commissioners, fellow Commissioners agree with me, this really underscores the work that we do and why it's so important, so we really appreciate that.

So, at this time, I'd like to open the floor to my fellow Commissioners for some questions and comments for our panelists. So, anyone is first up?

All right. Let's go with Sonja and then Angelo.

COMMISSIONER BJORK: Hi. Thanks for the great panel.

I'm wondering if our consumer folks and your mom can talk a little bit about the procurement support services. I'm not really familiar with how that works. So what kind of business is that, or how do you help folks connect with good providers?

MS. ZOTYNIA: You're talking about the support broker service?

COMMISSIONER BJORK: Yeah, yeah. The support broker.

MS. ZOTYNIA: Okay, okay.

COMMISSIONER BJORK: I don't really know that term.

MS. ZOTYNIA: Okay. So, it varies by state. In Pennsylvania, it's called a "supports broker." In many states, it is.

COMMISSIONER BJORK: Okay.

MS. ZOTYNIA: It's separate from the service coordinator. So, everyone who has services and has an individual support plan is required to have a supports coordinator.

The supports broker is different. They are only available to people who self-direct. In Pennsylvania,

that's called "participant-directed services," and the service definition defines the tasks that we are allowed to do.

It's a pretty long list, but it basically falls into three buckets" assisting with employer-related duties, so things like recruiting, hiring, managing, helping you develop those tools in your home and learning that; increasing your knowledge so that you understand compliance rules and you remain in compliance; and navigating natural supports, helping people connect to non-paid supports in the community.

A good example that I often use is Robert happens to be an artist, and when he said years ago, hey, I'm really interested in connecting with other artists, a very well-meaning supports coordinator referred him to a specialized program for people with disabilities that was an artist's apprenticeship that's waiver-funded. And we go there and we buy artwork, and it's amazing, but it wasn't what he was looking for. He wants to connect with typical people in the community who may or may not have disabilities. So that's what we do, is help you sort of create that everyday life.

MS. BRENNAN: And can I -- I'm going to just add a couple things. Yeah, exactly.

So, we launch supports brokerage in New Jersey, but as a lot of people were saying, it is a lot of responsibility as the -- you know, "Maybe I want to self-direct, but there's so much responsibility that goes along with it. If someone could help me with those pieces, that'd be a great service."

New Jersey, we did work closely with some of the folks in Pennsylvania with looking at it, and we launched the service, probably the worst time to launch a service, 2019 in the fall, so right before COVID. So we, you know, are struggling with enhancing it as a service and, you know, different pieces of it, but it is an option for people who are saying exactly that, you know, your supports coordinator is going to help you find, you know, a service provider, but they're not going to help you connect to find that class in that community that you may be looking for. And maybe you're looking for -- you've got a parent who says, you know, my person or the -- I want to find a class that -- you know, I want to find a cooking class in the community. You know, the parent is trying to help somebody

self-direct or the person who is -- they'll have time to check all those different places out. They're going to do some of that background research of this, you go here for this type of thing, here for that type of thing. They're going to connect you to your community and figure those pieces out and help you also hire self-directed employees, help recruit staff, figure those extra pieces, but not the support coordinator role.

And a lot of times, there are families who are like, "I can do that. I got it on my own," and others who say, "I really need someone to help me do that." And it's a service they can choose from their waiver of service.

COMMISSIONER BJORK: Great. Thank you so much for clarifying.

CHAIR JOHNSON: Thank you.

Angelo?

COMMISSIONER GIARDINO: I too wanted to thank all the panelists.

And particularly for Pamela and Robert, again, being self-directed sounds like it's been so transformational. Do you have thoughts about when and how we should introduce the option of self-direction, and what

would be useful to start preparing someone for what sounds like is a really heavy lift but worth it?

MS. ZOTYNIA: Self-direction should be the first thing offered to anyone who walks in a door to enroll for services. It should always be the first conversation.

It wasn't always -- it's supposed to be in Pennsylvania. I think it's actually mandatory. It doesn't always happen that way, but years ago -- Robert is 38. So, years ago, it didn't even really -- it was around, but not like it is today.

But having that conversation first, because my experience -- and I come from the advocacy world. Prior to where I am today, I worked in advocacy for decades. Families are often led to believe they must depend on providers. That's the only solution they have, even if they don't necessarily want that.

And this new generation is growing up in a very different educational setting than 40-, 50-year-olds did. Robert was one of the first people in our school district who was included in school and went with typical students, graduated cap and gown with his peers, received services, but in a regular classroom. He didn't envision a life of

segregation where I hear from people now who are like, "What do you mean you're referring me to a day program? Like, why would I want to go there? I want a job. I want a girlfriend or a boyfriend. I want a life."

So, my recommendation is it always, always, always should be the very first conversation, but with the understanding that people are given the information and understand it's not always easy. There are supports available to help you, but there are times where it's been stressful for us in our house when we were sort of building it. And it's much better now than it was back then, because we kind of got in a groove, and we found good staff. But I was not -- and I work at home now too. So, if staff calls off, I'm here. I didn't always do that. I used to have to go to an office like everybody else was doing, and it was so stressful for me, that without a supports broker, this never would have happened, because I would come home tired and not be able to do that.

And I'm sorry, Trish. I keep --

MS. BRENNAN: No, I just wanted to add that the reason our new office is that we've only been around for three years, three years in February has come about, is to

educate people on the option of self-direction. So, as you heard me mention that our system moved from contracted-based with option of self-directing, so anybody had choice of provider-managed or self-direction. But to really -- so people can be empowered to make that their own decision if they want to self-direct or go the provider-managed route, because not everybody really understands what it truly means and the options that are available to them. So, our goal is to do that.

And also, we've been having sessions with families statewide to facilitate networking sessions, and we have peer-to-peer networking sessions so that families -- so it's not so alone.

So, one of the things we heard from families is self-direction can be isolating because it's us trying to do it ourselves. What we've done now is we've been building together, in-person and virtually, sessions for people who are self-directing and for families who are self-directing locally. So, like to say, hey, how did this work out for you when you were trying this? Or hey, do you know if there's somebody in your community? And the people with the lived experience share it the best, but we're just

there to facilitate it. That's the role of our educational piece, the Office of Education and Self-Directed Services, to help people do those next steps.

DR. SCIEGAJ: I just wanted to add one last little point of having the staff be fully cognizant of what self-direction can add to that individual's life. Not often are these folks entering into these occupations fully aware of what self-direction is and how it functions.

And when you're working with somebody who's coming into the system, I totally agree with Pam, self-direction should be that one of the first things that is discussed. Not everybody is going to be prepared to take that option at that point in time. But again, if you design in to have that conversation at regular intervals, I think we'd have more people selecting the option at some point.

MS. ZOTYNIA: I just want to add one more thing, because Mark mentioned staff, and I had forgotten about this. So, Robert has a couple of staff who work with him now who also worked with him in a group home when he lived there years ago. And I remember -- I mean, we are documenting everything we need to document. He has daily

service notes. We go over and above, even our state TD office, who we share it all with, are like, "Who's making you document all this?" And I'm like, "I am, because we need to. And you are too." But I remember them coming here and saying, "Where's the book?" because they were expecting this giant book of paperwork that they were so used to having to complete in provider-managed programs because of licensing requirements. And I'm like, "There's no book. This is our home. It's not a facility." So, we have Google Docs. You're going to spend 15 minutes documenting. If you're spending more than that in your 10 hours that you're here, you're over-documenting. And we'll help you figure out how to kind of minimize that.

So, it's a different culture. It's just a different culture. The same service, but it's a different way of delivering it.

CHAIR JOHNSON: Thank you.

Jami and then Dennis.

COMMISSIONER SNYDER: Thanks so much for joining us today.

I had the opportunity to work in two states, both of which offered self-directed care. A large percentage of

individuals who are eligible took advantage of self-directed care in one state, and it wasn't used really at all in the other state that I worked in. And so, I'm kind of curious to hear from you what you think sort of those barriers might be that kept individuals from taking advantage of this option.

And I know you've alluded to many of them, and for instance, just making sure it's the first option that's offered to individuals that are eligible. But I'm curious to know, do you think it's more about system design, or is it about individual awareness of the option, or is it about the lack of training or educational resources? Or maybe it's all of those things, but just curious based on your experience, what the kind of primary barriers might be to individuals really taking advantage of self-directed care as an option, viable option.

MS. ZOTYNIA: I'm going to jump in on that one. I think everything you just said, but I would add to that for families and for self-advocates, it can be -- fear can be a part of it, fear of the unknown. I'm on my own. There's no provider I can call. There's no staff coming in because there's a snowstorm or they're sick. Tag, I'm it.

There's no one to help us navigate any of the other parts of Robert's life, and there's a lot of parts. He has a lot of technology. He uses a power chair. His power chair broke a couple of months ago. I'm trying to find a vendor to fix it. There's no one for me to pick up the phone and call to help with that.

If he had a provider, it's kind of their responsibility to do all those things for him, even Medicaid, making sure he has no lapse in Medicaid. A provider is never going to let his Medicaid lapse. They're going to do everything in their power to keep him authorized, but that's kind of on us right now. And we manage it well, but I do think about that when I'm not here. Hopefully, somebody opens the mail when he starts getting letters from Social Security and Medicaid and responds to those things. So, who is going to do those pieces?

So, I think it's really helping people see that there are resources out there, and I have also found and have done this. Robert and I both do this, talking to someone who uses the model. So, we've done that individually. Robert has done presentations. He has a

whole PowerPoint that he does and talks to self-advocates about, you know, here's how you can build this life that you deserve and desire, and there's help out there, and we are happy to be part of your circle of support as you get there. That has been very helpful to families.

MS. BRENNAN: And I just want to add, I think a lot of it is the education piece, because as folks are exiting the school system, they may not be aware of all the options that are out there. And making sure that everybody, when they come through our doors and intake, really understands and they're empowered to make that choice of if I want a self-director, I want to go provider-managed, what is it that I want for my life, and going those next steps.

And it's also connecting people. So, what we've seen at some of our early phases of where we throw stuff out in different counties, hey, we're having a family networking session. It's for people who are self-directing, who have a vested interest in self-direction, and it's facilitated by the division of our Office of Education and Self-Directed Services. We see people who have been self-directing for about 20 years getting

together and sharing things. And at the same time, there are people who just want to know new pieces, and they connect with each other. And these great bonds are formed of, hey, do you want to hear what I'm doing? And then it starts to sound like, well, maybe it's something that I would like to do, or saying, hey, I've been through something similar, so making those connections and providing those opportunities for education, especially from people with lived experience.

We have similar peer-to-peer sessions, same thing. If you're interested in self-direction, you can come to these as well, but they're only for -- they're not for providers. They're only for people who are self-directing or who have an interest in it. And then that's where some of the other educational pieces come through in the connections. It's a lot of really understanding what it means and understanding the responsibilities and not being worried that you don't have the support. So, it's needing to have that support of potentially having the ability to hire a support broker, having the support of your support coordinator, and your whole building that good circle of support as well.

CHAIR JOHNSON: Thank you.

Dennis.

COMMISSIONER HEAPHY: Thanks.

First, kudos to you, Robert and Pamela, for making this work because it is very challenging to do this.

As a matter of fact, years ago in Massachusetts, Robert, you wouldn't have been able to be eligible for the self-directed because your family is involved. And back in the day, it was really only if you could do it yourself, direct everything individually as a person. That's the only way -- that's the only way folks were actually eligible to do this. So, the program has advanced since then, and now we have lots of folks that self-direct. But that's the way it started, very individualistic and not at all interpersonal.

And so, my question, I guess, is for Mark and Tricia, and that's -- what other models have you seen in other states that you would look to that would have best practices and for folks who are self-directing services? And I mean, not just -- when I say services, I mean all services. So, the Cash and Counseling would cover all services, not just direct services provided in the home.

MS. BRENNAN: So, when you say what other models, do you mean other states and how they're doing something? There are some other states that we have been researching as we talked a little bit about support brokers and trying to enhance it and figuring out those different ways. That's definitely something that New Jersey is definitely trying to make sure we can enhance supports for people who are self-directing.

And there are a couple other states who are doing other ways that are working in certain pockets a little better, but we're trying to implement it statewide. So that's a different way as well.

We've been working to implement it statewide. We do definitely find challenges with accountability. We find challenges with different aspects of implementation and barriers that we hit with some of the things that are written in our waiver. So that's definitely a challenge.

DR. SCIEGAJ: Yeah, I think that there are -- you look at the growth of self-direction in states, obviously California has almost half the total number of folks self-directing. New York has grown significantly over the last 10 years. So, I think in terms of best practices, I'm -- I

don't know if I could point to a particular state, because I think they're -- you know, each state probably has things that it does really, really well.

This goes back to one of the previous questions: Why did it grow so much in one state versus the other state? And I think part of answer to that is, is self-direction part of the culture within that, you know, the overall Office of Medical Assistance in that state? And if it is, I think that has an impact on how the program gets presented. Is it presented first, as Pam would suggest it should be, or is it just presented as one of the options? I think that people, you know, staff education and training around this as an option, because I think people enter into those occupations from academic programs that are a little bit more biased towards agency approaches, and to empower somebody to self-direct their own services or manage their own services is a bit of a paradigm shift. And I think states that are successful in this area have from the leadership down integrated the principles of person-centered approaches and empowering of individuals.

COMMISSIONER HEAPHY: Yeah. I have other questions, but I don't want to dominate the conversation.

So, I'll let Tricia go.

CHAIR JOHNSON: Tricia, yeah.

COMMISSIONER BROOKS: Thanks, Dennis, and thank you all.

Robert, that is just so powerful to hear directly from beneficiaries. I really, really appreciate you taking the time to do this.

I have two questions. I'm going to get them both out quickly. I've heard education and training. So, in terms of someone moving from, you know, point A to being self-directed, is there a playbook? Is there a step-by-step transition, here's how you take this responsibility on, and then here's how you take the next responsibility on and so on and so forth? So that's my first question.

And the second question is, it sounds like it's a lot of work for Robert. Does Robert get paid for his time in managing his care

MS. ZOTYNIA: So, I'm going to help Robert answer that.

No. So, the person receiving service would not get paid because they're getting service, but Robert also holds the role of common law employer. I previously did.

His dad previously did. That role cannot be paid. Our understanding is that's a Medicaid rule.

I've never really researched it to see if that's true or not, because it didn't really matter to us, but whoever is -- sits in either the managing or common law employer role, that is an unpaid position. I will say it never bothered us, but I will tell you many families are a bit upset about that because it can take a lot of time. And it takes, you know, time away from either their workday or their, you know, whatever.

So, if I'm not here and Robert was not common law employer and he had to go find like a friend or an extended relative to do it, it's a big ask.

I forgot what your first question was.

COMMISSIONER BROOKS: Oh, sorry. It's about step-by-step training so that you can transition to independence as your own self-directed care manager.

MS. ZOTYNIA: Go ahead, Trish.

MS. BRENNAN: I was going to just say that, you know, we don't have -- we're still developing because we're a newer unit, a whole new office from almost three years developing the different pieces of the training that need

to go into place. But we do honor the fact that everybody is individual. So, it's going to be based upon the person, right? And what works for one person is not going to work for somebody else.

But what we've seen -- and we've been helping families to share some of the things that have worked for them. So, we have a couple of 00 we have a mom who put together this amazing spreadsheet and shares her template of how she tracks her staff and time and everything. And we've done webinars with those families to share to other families, and we've learned from them as well, some really great tools that, you know, we wouldn't have even thought to come up with, that families have come up with, and we're working on getting people to share, you know, the different pieces that work for them.

We've had some webinars, some, you know, just web chats with where families that have been really successful and will work with how they train their staff, give presentations. There've been even a small -- couple of small conferences that do the same thing.

When it comes to play-by-play playbook, each FI does their own, does their own exact what you need to do,

how you enroll, how you onboard, all those pieces for their staff, depending upon whether you choose the fiscal agent, employment model. or the agency with choice model. So, it would depend upon each model that we have.

But we are actively working on more educational tools for families, and for people under services, we're working on a couple of different ones that our peer-to-peer group is putting together, because those are people who are self-directing and we have, like, really great conversations with them when we meet with them about what they do and they don't like when they're interviewing a staff and they don't want to hire that staff, and maybe their mom likes the staff and they don't like the staff. We have some really great conversations.

So again, we're still developing some of those pieces, but it's key to listen to those with lived experience and who have been doing it for some time. The families that came to me in 2002 are the families we call upon the most because they've really, you know -- the one mom who talks about what it was like to have to fire a staff that she loved that her son didn't like because it was somebody like her, and he wasn't fun to hang out with

and figuring out all those different pieces and sharing that and how you have to take that into consideration.

MS. ZOTYNIA: So, in Pennsylvania, we are also refining our tools. But we've spent -- I sit on a work group with our PDS point person in our DD office and a bunch of other folks, and I think we spent about two and a half years writing a participant-directed services, which is self-direction in Pennsylvania, manual, which has now been moved -- like, it has to go through legal and all these steps before anybody ever said it would be, you know, 15 years from now before they publish it. But -- so we've worked on that.

We are constantly working on training tools. The brokerage that I work for, we have a whole kit that we use that we developed and are willing to share that, you know, with others. They just have to be, you know, willing to accept it, but you would think people would want to do that, but that doesn't always work that way.

But we do a lot of webinars, a lot of trainings, not only with families, but also with supports coordinators, because there's turnover.

MS. BRENNAN: Yeah.

MS. ZOTYNIA: You know, there's a lot of turnover, and they have a lot to learn. It's not just self-direction. So, you know, we go in and we do some webinars with them, partly to try to increase our referrals, because, you know, we're a business, but also to help them understand the service, so they're accurately referring people and people are able to make informed decisions. And that's very important to me as a family member. Even if I do a referral meeting, I always go over these things and say to people like, "You know, we've been there. We've selected a service and then figured out next week, oh, we don't really want that." And now, you know, that poor provider is out of luck because we're ended service with them. So, people really need that knowledge to make an informed decision, but they still can change their mind because, you know, that's their right to do that.

MS. BRENNAN: And we've recently added -- support coordination competencies is something that's in the works, and we just recorded a piece about self-direction. And that's something that they're going to have to, you know, complete that section. It was a webinar that my colleague

and I and my assistant director and I did for about self-direction 101 so that all support coordinators have to really have a good understanding of what it is as they're moving forward, because that's the key piece. Sometimes you can have a family really knows they want to self-direct, but if it's a brand-new support coordinator who is newly hired by the agency and they don't quite understand that piece, that can put up a barrier. So, we're making sure that that's mandated for support coordinators. We just recorded it. It hasn't completely come up yet, but they already did as a broad one, but it wasn't mandated before. It was something they could choose to go to. Now we're saying you have to do it, and one of your core competencies is you have to understand what self-direction is and explain it to all your families.

CHAIR JOHNSON: Thank you.

And it looks like we have Mike and Heidi with questions.

COMMISSIONER NARDONE: Thank you for this panel. I feel I'd be remiss if I didn't just thank you. Given my many years that I spent in state government in Pennsylvania, I like the heavy focus on Pennsylvania. So,

it's good to see you.

Tricia and Pam may have already answered this, but I just wanted to kind of maybe see if there were other things that would be helpful to workers in terms of providing supports for them as they're conducting their working in the field.

I think you mentioned some more training, education, but I'm wondering if -- Pam, the thing that really struck me when you said when you had to deal with the wheelchair, power wheelchair, you kind of felt like you were on your own, right? And I just was wondering if there are things that you would like to see built into the program to help with self-direction and provide support to folks who are self-directing. Are there other things other than some of the things you mentioned as well as Trish mentioned to help this?

And the other comment I want to make is -- and maybe this is more a question for Mark. My recollection is, in Pennsylvania, that although self-direction is very much part of the I/DD waiver, it's really been a struggle in the elderly and disabled waivers to implement self-direction or to introduce self-direction. I'm wondering if

it's a cultural thing, if it's an education thing, because I think that the state has had -- the commonwealth has had much less success in terms of introducing this concept to the aging waiver. And I wonder if that's true in other states as well.

MS. BRENNAN: I want to add -- I just want to add something to that piece, just kind of show some of the things that we're doing with aging, because it's kind of exciting for me as well.

New Jersey is one of the first five states awarded the ACL grant to bridge the gap between aging and disability services, and what we've been able to do is start to -- we've worked in so many silos, and then what we're doing now is really working together with our agency with aging. So that is so cool because -- and we say this all the time. So, my colleague, Andrea, who I never would have known -- I work directly for the assistant commissioner. She works directly for the assistant commissioner. They all work for the commissioner at DHS. But we never would have known each other if it weren't for this grant to bridge the gap between aging and disability services. We never would have worked together.

And now we have done trainings. So, her staff has done some trainings for all of DDD. We've done -- we've brought the area agencies on aging into our family networking sessions for people who are self-directing because it's -- you know, share what resources are available out there and really, you know, educate the agencies on aging and what self-direction is as well.

So, we're starting to bridge those gaps and cross, you know, braid the services together and intertwine so they're no longer working in our single-lane silos.

DR. SCIEGAJ: And also, I think historically, younger populations have been better advocates for themselves, and so that's why you might see larger numbers or more acceptance of self-direction in those populations. But I feel that we are, you know, beginning to turn a corner with older adults, with elders and self-direction.

I think there has been historically sort of a bias that somehow you turn, you know, 70- or 80-years-old, you're no longer able to manage your life anymore. And I think that kind of perception has shifted over the last decade. But certainly, younger populations have been much better advocates and wanting of this particular option.

CHAIR JOHNSON: All right. Heidi.

COMMISSIONER ALLEN: Thank you all so much for being here. Really enjoyed this panel.

I want to follow up on something that Robert said about sick leave -- well, specifically like vacation time is what was mentioned. But I was thinking about other benefits that people really rely on like sick leave, paternal leave, retirement savings, vacation time, and wanted to follow up on this health insurance because, I mean, it seems like ideally you want somebody to stay, and yet people are going to have natural transitions. You know, women might give birth. Fathers might want to be home with the baby. Somebody might themselves get sick. And it seems really challenging to ask people to give up that protection for this kind of job, which we all feel like is such an important job.

And so, I'm wondering like what Medicaid could do to help people, help employers be able to support their employees in a long-term way so that they'll both be able to recruit, but also keep people in these positions. That's my first question, and then I have a second question.

MS. ZOTYNIA: Okay. So, I'm going to help Robert answer that.

What is available -- so there's no benefits because it's a fee-for-service. You must provide a service in order for Medicaid to reimburse. So, you can't pay people when they're not here at work. You can't pay for health care. You can't do any of that.

But what we can do is offer what's called a "benefit allowance," and I think it's like $2 an hour or something. So, if I'm paying you $20 an hour, I can give you this benefit allowance. So, you actually see $22 in your paycheck, with the assumption that you're using that to buy health care or compensate you when you take off a week to go to the beach or whatever.

And Robert does offer that. All of his employees are receiving that.

But the reality is health care is really, really expensive. So even on the exchange in Pennsylvania, we have our own -- it's called "Pennie" or something. And they're telling me they're paying a real lot of money for health care, almost to the point where they don't even want to buy it. They want to just hope they live through the

year, and they'll take the hit on their taxes when time rolls around. But it's just not right.

If there was a way -- and I don't know that there is a way -- that even if there could be some sort of a coalition that you could purchase -- I'm thinking back to my days where I worked for another company and we purchased -- we were a small company. We purchased through our chamber of commerce. So, we got a group rate, even though we only had three employees. If they could build something like that in the state so that the support workers could purchase their insurance, that way they would at least get a better rate and better health care.

I don't know what the solution is. All I know is it's a struggle. People need health care, and the best workers leave jobs because -- even if they really enjoy working with the person, because they have to take care of their families.

We are fortunate that most of the guys that work for Robert, their spouses have health care through their jobs. So at least they're covered, but not all of them. We have one guy right now who's told us, as much as he loves being here, he's getting married. He's got to

provide for his new wife, and he's got to find something with health care. He's part-time here in the evening, so he's hoping it doesn't impact him. But we will be sad to see him go, but we'll certainly understand that. We can't pay for it. I can barely pay for my own health care. I'll buy them dinner, but I won't buy them health care.

MS. BRENNAN: With our agency with choice model, so if you choose to go that route, there is additional dollars that come out of the person's budget if you use that model. And if the person works over a certain amount of hours in a week and they meet the certain criteria, they can purchase health care, but it comes out of the person's budget. So that's the different model.

And people have to make that choice, and that's a hard choice when you're becoming -- so many families are like, well, which choice, which fiscal agent do I use? It's their preference. Weighing that is a lot of responsibility, trying to figure out which type of fiscal model do I want to use, because we have two of them. And then the one does have the option of benefits, but additional dollars come out of your budget. So, you have to figure those pieces out.

MS. ZOTYNIA: And in addition to that, some of the -- I know one AWC in Pennsylvania that limits the worker to 29 hours a week so that they're not obligated under the ACA to provide employer health care, which is wrong in my opinion.

COMMISSIONER ALLEN: That seems like a really significant issue and something that we could continue to think about.

My second question is that in earlier session today, we've been talking about transitions to care for youth with special health care needs. And when you age into adulthood, which we know when a lot of education service is also in, if that was a particular challenge -- I know it was a long time ago. Robert, you're fully an adult now, but if you remember that transition and if there's anything that you would add to us to think about it as we're working on that issue as well.

MS. ZOTYNIA: So, Robert has always had physical challenges. He has cerebral palsy. So, he's had a lot of surgeries, orthopedic-related surgeries throughout his life. He didn't really develop his significant health issues till he was in his mid-20s. So, we managed at home.

We had really good health care, for one. And there's some great pediatric facilities in Pennsylvania and in Delaware that we access. So, he had great health care and got through those years.

It was when he left school, became an adult, entitlements are over, even insurances are over. He couldn't even get PT and OT anymore like he once did. He went to rehabs as a child for years and got PT and OT and speech every single week, and then you become an adult and it's like everything ends. And we'll give you 10 speech therapy visits in a year, but you better have, like, 27 doctors signing something that says you need this.

So, the challenge really became in adult life and also finding medical professionals who have the necessary skills for whatever your medical issue is, who are trained to work with people with intellectual disabilities and people who don't communicate in a traditional way. That's been a challenge.

When Robert was 19 years old, he had surgery. It was sort of minor. He had some digits on his feet amputated, and when we were at that appointment discussing it and decided that's the route he wanted to take as

opposed to a more invasive surgery, the nurse came in and handed me the paperwork. And I said, "I can't sign that. I'm not his guardian. He is a competent adult. He has to sign his own paperwork." And they argued with me about that and were like, well, he can't do that. He has a disability and he can't talk and blah, blah, blah. They had three doctors come in who talked to Robert for 15 minutes, and every one of them said he's clearly telling us to throw them in the garbage. Like, he is consenting to this, and he can make his mark. So that's a challenge for adults.

I mean, I've gotten calls frequently from people who -- adults with disabilities who are at the hospital, in the ER, and doctors who are afraid to provide medical care because they're not sure they're able to consent to it, even though we know they are. So, they're looking for someone else to come in and sign off on that, and they don't really care who it is. And that's a problem. So, educating the medical community would go a really long way.

I'm not sure if I actually answered your question because I tend to go down rabbit holes.

COMMISSIONER ALLEN: No, it was very helpful.

Thank you.

MS. ZOTYNIA: Okay.

CHAIR JOHNSON: That's very, very helpful.

All right. Any other comments or questions from the Commissioners?

[No response.]

CHAIR JOHNSON: Hearing none.

So, I just have to say this really was a great way to kick off this work. Great background that you all both shared with us. And then also this panel was very exceptional. I really appreciate the time that you all took to come out and talk with us.

So, I'll look at Gabby and Brian. Anything else that you all want to do in terms of closing out with the panel? Are we okay?

MS. BALLWEG: I don't think so. Just thank you all for joining us today. We really appreciate your time.

CHAIR JOHNSON: Thank you so much. We do.

MS. BRENNAN: Thank you for having us.

MS. ZOTYNIA: Thank you.

CHAIR JOHNSON: Take care.

MS. ZOTYNIA: Bye.

CHAIR JOHNSON: All right. So, Commissioners, we do have a couple more minutes, then, for additional conversation and discussion if you'd like. So, if there are any themes that you wanted to highlight or other areas of investigation based on the conversation with the panel and the earlier conversation, then we have Gabby and Brian here to help us walk us through that.

All right. So, Patti.

COMMISSIONER KILLINGSWORTH: So just kind of following up on some of the remarks really from all the panelists, but particularly from Patricia and Mark around some of the ways to really improve access to self-directed programs, I think we talked about information requirements, which could come in a number of ways. And I'm just sort of thinking about my own experience as a state leader in Tennessee and really trying to get these programs really accessible to people, making them a part of welcome letters to home- and community-based services, making sure that they are a part of member handbooks for managed care programs, that there are special handbooks I believe were talked about that are specific to self-direction.

We actually made -- developed materials that had

to be reviewed with every single person at their initial person-centered planning meeting and annually thereafter, and that they were -- the health plan was required to get a signature from the person saying I do or I don't want to direct my own services. And it was language that the state developed.

Even with all of that, we learned very quickly that service coordinators just weren't quite comfortable having these conversations with people, you know, and there's a way to ask a question to get a no. And so, we had to do specialized training really with coordinators and make sure that was a required part of their training so that they would really understand how to have a good neutral conversation that was informative and allowed an informed decision, obviously good training for the person or any authorized representative in terms of the expectations and requirements and then for their workers as well.

And then maybe one of the things that we did that was most important was that we measured utilization on an ongoing basis. So, we wanted to know health plan to health plan like how are you doing getting people enrolled into

self-directed programs, and we looked at that on a very regular basis.

And then ultimately through our Money Follows the Person rebalancing demonstration offered financial incentives to health plans based on the percentage that they were increased, that they were able to achieve over time.

So, I just think there's a lot of things that can be done to make sure that people have an opportunity to avail themselves of the options that are there within their states.

And then I would continue to just say, as we look into this -- Patricia, in particular, mentioned kind of the accountability challenges and some of those pieces. And so really understanding what those guardrails are, how to ensure accountability, a look at cost relative to provider-delivered services and just kind of balancing the payment and access issue as we go along.

Thank you.

CHAIR JOHNSON: Thank you, Patti.

Dennis.

COMMISSIONER HEAPHY: Thank you.

I knew I was wrestling with part of the presentation. That's because it was a very IDD-focused model of care, and when you have different populations of folks who are receiving -- who are actually coordinating their services with a personal care attending, consumer employer -- that's a model, we call it "consumer employer." Different people have different needs, and so it's about choice.

And so, in Massachusetts, at least people can choose to have a CORI, and if they do, the mechanism is there for them to, you know, have their PCA CORI checked. For those who don't want to require a CORI, they don't have to. There are folks that if they want more intensive training, they can get that. And folks who don't want to do it and they want to make sure they're training the PCA to do it their way, then they can do that.

And so, I think for me, it's better understanding the different models, I think, and Massachusetts at least would be a revolution if you asked or required notes to be taken on what the PCA did during the day with the individual. But there might be people who might want that, and so if they do, they should have the right to have that.

But it's really about the flexibility and ensuring that it's about supporting the people's right to live in the community in the least-restrictive setting possible.

And, you know, with EVV, making sure that the PCA is there, is actually showing up doing it, like -- and leaving when they say they're leaving. That's all fine and good. It's just when they're there, it's what they're doing. It's ensuring the person can live in the community in the way that they want to and giving each -- like, a parent or a child or an older person, they want to know that information, let them have it.

Thanks.

CHAIR JOHNSON: Thank you so much. Appreciate that.

Heidi.

COMMISSIONER ALLEN: Thank you. This is a great panel.

I realize, though, that I'm missing some fundamental information on this topic. Like, how does this intersect with dual eligibility and Medicare? And I was curious about how, like, Money Follows the Person, which I thought was something similar -- is this different money?

So, I don't know if there's materials that you just want to send me personally that get me caught up. But I came into the conversation a little bit like -- so this is home- and community-based services, and this is available as part of home- and community-based services. Who all is eligible for it, and for how long? And what are the exclusion criteria? I think it would just be helpful to have, like, more basic understanding of that.

CHAIR JOHNSON: Any other comments or questions?

Oh, Jami.

COMMISSIONER SNYDER: I was just going to note, again, something that Pamela mentioned when I'd asked about access to self-directed care. She said one of the barriers is really around fear, and then a couple of the panel participants talked about the importance of peer education and peer support in overcoming some of that fear. I just wanted to make note of that again, because I think that is a really important piece of the equation in terms of ensuring that individuals understand the availability of the service and really want to take advantage of it as an option.

CHAIR JOHNSON: Great call-out. Thank you.

And then, Tricia, I think I saw your hand up.

COMMISSIONER BROOKS: Yeah. I want to understand better the different roles that they talked about, and in particular, they talk about the support coordinator. It sounded like the support coordinator sort of fills gaps in what you self-direct. But just understanding those roles more explicitly would be helpful.

CHAIR JOHNSON: No, that's great. That was one of my questions, too, so I appreciate that, Tricia.

COMMISSIONER BJORK: There's the broker, too. Remember, it's two roles.

CHAIR JOHNSON: Right. And the broker, right, that Sonja mentioned. Right.

Any other?

Oh, Dennis.

COMMISSIONER HEAPHY: I guess and how that role differs in different states and what type of program. They're all very different in how they run the program, and also what type of program the state has.

COMMISSIONER BROWN: Well, it could also be different waivers in the same state.

COMMISSIONER HEAPHY: Yeah.

COMMISSIONER BROWN: I don't think the support broker is a thing in the elder waivers. So, I think it could be a variation within the state as well.

COMMISSIONER HEAPHY: It may be population-based.

CHAIR JOHNSON: Any other ones?

[No response.]

CHAIR JOHNSON: Okay. So, Gabby and Brian, this was, again, great. We really appreciate your efforts, and you got a lot of feedback from us. And I know we'll have more questions to you, but really appreciate where you started with this, and I can see it really ending in a great place. So, we really appreciate your efforts. Thank you.

All right. So, with that, we are going to go to our final public comment, and so it's open now for public comment. We do invite you all in the audience to raise your hand if you'd like to offer any comments. Please make sure you're introducing yourself and the organization that you represent, and as always, we ask that you keep your comments to three minutes or less.

Let's see. We have one. Camille?

PUBLIC COMMENT

* MS. DOBSON: Good afternoon, Commissioners. Camille Dobson, Deputy Executive Director at Advancing States. We represent the aging and disability agencies that deliver public and community services for older adults and people with disabilities. And this was such an amazing afternoon. Appreciate you so much taking on this issue. It's shrouded in lots of mystery and, I think, confusion, so different in every state.

And a lot of the comments I was going to make, Patti has already made, perhaps not surprisingly.

But I wanted to -- in particular, around older adults, I think Mike's point also about it being different based on population. You know, we continue our support to states, really, to understand the critical role of the labor case manager, the support coordinator, the service coordinator, whatever you call them. You know, they are -- they're the linchpin in starting a person's journey to self-direction.

It is harder for them than it is to direct people to agencies and services. There's a tremendous amount of turnover in case management. Our members are complaining not just about the direct care workforce but also about

their case management rosters and the difficulty of retaining case managers.

We have been in more than one state where the case manager is making the decision themselves about whether they think the person can self-direct, particularly in aging waivers. And so I think that this is a really -- again, the need for support brokers, CMS doesn't require every state. They recommend that every state have a support broker or a function to support the person who's self-directing, separate from the FMS and separate from the provider, and not every state has it. And I think that's also a deterrent.

So there are lots of opportunities, I think, for you to make recommendations for ways to strengthen self-direction, because it has -- the satisfaction is very, very high from our members who survey their folks and ask if they've been self-directing.

Dennis is a living example, I know. But I guess we're very appreciative that you're diving into this topic because it is filled with confusion, mystery. Not every state does it. California has got more than half. Between California and New York, they have probably three-quarters

of the people self-directing in the country, which makes the rest of the programs across the country very, very small and unique and many times hard to manage for our state members.

So thank you.

CHAIR JOHNSON: Thank you, Camille. We appreciate that comment.

Any other comments?

[No response.]

CHAIR JOHNSON: Okay. In the absence of none, if you do have additional comments later, feel free to visit our website, and you can submit your written comments there anytime. And then also on the screen, you'll see that we have our MACPAC presentations are available for downloading for this meeting on our website as well.

So, with that, we will adjourn this meeting today. Thank you so much for such a great day, great conversations, a lot for us to think about, and we will see you all tomorrow at 9:30 a.m. for our public session.

* [Whereupon, at 4:47 p.m., the meeting was recessed, to reconvene at 9:30 a.m., Friday, September 13, 2024.]

PUBLIC MEETING

Ronald Reagan Building and International Trade Center
Hemisphere Room
1300 Pennsylvania Avenue, NW
Washington, D.C. 20004

Friday, December 13, 2024
9:33 a.m.

COMMISSIONERS PRESENT:

VERLON JOHNSON, MPA, Chair
ROBERT DUNCAN, MBA, Vice Chair
HEIDI L. ALLEN, PHD, MSW
SONJA L. BJORK, JD
TRICIA BROOKS, MBA
DOUG BROWN, RPH, MBA
JENNIFER L. GERSTORFF, FSA, MAAA
ANGELO P. GIARDINO, MD, PHD, MPH
DENNIS HEAPHY, MPH, MED, MDIV
TIMOTHY HILL, MPA
CAROLYN INGRAM, MBA
PATTI KILLINGSWORTH
JOHN B. McCARTHY, MPA
ADRIENNE McFADDEN, MD, JD
MICHAEL NARDONE, MPA
JAMI SNYDER, MA

KATHERINE MASSEY, MPA, Executive Director

AGENDA PAGE

P R O C E E D I N G S

[9:33 a.m.]

CHAIR JOHNSON: Good morning. Happy Friday, and thank you for joining us for our second day of our MACPAC Commission meeting.

We're looking forward to this morning's conversation, and we will be continuing our discussion on HCBS. So with that, we have Tamara Huson, our Senior Analyst and Contracting Officer, joining us as we return to our discussion on provisional plans of care for HCBS and potential policy options for ensuring timely access to services.

So, Tamara, over to you.

TIMELY ACCESS TO HOME- AND COMMMUNITY-BASED SERVICES: POLICY OPTION ON PROVISIONAL PLANS OF CARE

* MS. HUSON: All right. Thank you. Good morning, Commissioners.

So I'm back again to talk about provisional plans of care, specifically to present for your consideration a policy option directing CMS to issue guidance.

I'm just going to start with some quick background. First, just a reminder that today, when

looking at this graphic, we're focused on Step 3 in the eligibility and enrollment process for individuals that are seeking HCBS, which is the development of a person-centered service plan, or a PCSP. And a PCSP is a document that describes the services and supports an individual requires to meet their needs and their individual preferences, and statute dictates that HCBS can only be provided pursuant to a written plan of care.

So one way that states can expedite delivery of Section 1915(c) home- and community-based services is to use a provisional plan of care, which is a type of preliminary service plan that identifies the essential Medicaid services that can be provided in the person's first 60 days of waiver eligibility. And states may call provisional plans of care by other names, such as "interim service plans," "temporary service plans," or "initial plans of care."

Provisional plans of care have been allowed since 2000, when it was described in the state Medicaid director letter, known as Olmstead Letter No. 3, which was issued in response to the 1999 *Olmstead v. L.C.* decision.

And states document in Appendix D-1 of their

Section 1915(c) waivers if they allow the use of a provisional plan of care and their procedures for developing such plans.

So I want to recap the review of our -- or the results of our waiver review. We received a few questions about our waiver review. So I want to provide a few more details on our process for some additional clarification.

So, as you recall, we contracted with The Lewin Group to conduct an environmental scan, and one item in that scan was a review of Appendix D-1-d of states' Section 1915(c) waivers to see if the waiver had language allowing for the use of provisional plans of care. And so Lewin found such language in 17 states.

Then we also received a list of waivers by state from CMS that had language on provisional, interim, or temporary service plans. And so after cross-referencing and combining these two data sources, we found that 24 states allow for the use of provisional plans of care across 59 Section 1915(c) waiver programs.

So this table here shows that data. It is slightly updated from the table that was included in our October presentation. We received some feedback after that

presentation that led us to make a few changes and re-verify all of this information.

I would also just like to emphasize the data here is a count of waivers by state in which those Section 1915(c) waivers have language authorizing the use of provisional plans of care. So it does not necessarily mean that the state is currently using the provisional plan of care authority, and we don't have a good count of what that is.

I also want to recap the themes from our stakeholder interviews and provide some new information. So I shared the findings from our stakeholder interviews that we conducted over the summer with you in October, but since then we've gone back to a few people to gain additional insights on the reasons for low state uptake of provisional plans of care and on the need for guidance on this topic.

But first, again, I just want to recap what we shared in October. So we heard from state officials and national experts that provisional plans of care were most often used for emergency situations, such as natural disasters or hospitalizations. However, our interviews

also indicated that few states are actually using provisional plans.

So of the four national organizations that we spoke with, none of them were aware of any states using provisional plans of care. And then we spoke with five states, and of those five states, one said that they are not currently using this flexibility, two states shared that they do use provisional plans but not very often, and then two states were actually unsure.

And then finally, since the larger scope of this project on timely access also includes presumptive eligibility for non-MAGI populations, we also heard from a number of states that are using Section 1115 demonstrations that they use what is essentially a provisional plan of care and provide a limited benefit package for those individuals that are found presumptively eligible.

So this slide is some new information and is informed by both our original round of interviews as well as the additional ones that we conducted since October.

So one of the most prominent reasons that we heard that can contribute to low state uptake of this policy is a lack of awareness. So the feedback from

experts in three states that we spoke with indicates that states are not operationalizing this flexibility. A couple of interviewees noted that waiver approvals can contain legacy language and hypothesized that states had not fully implemented the authority. Another contributing factor may be state staff turnover, which can lead to a loss of programmatic knowledge and the ability to update operating procedures quickly. Two interviewees also talked about how there may be a lack of awareness in the hospital discharge planning process about how to use provisional plans of care for Medicaid beneficiaries.

A few interviewees also cited limited state capacity, administrative complexity, and competing priorities as a reason why states may not be using provisional plans of care.

So CMS advises that states that want to implement this policy should submit a waiver amendment, which can be a resource-intensive and administratively burdensome process. Changes to waiver programs require state staff resources and time to develop new policy, identify operational changes, for example, changes to case management systems, as well as time to educate both state

staff and HCBS providers.

Finally, among many competing priorities, implementing provisional plans of care may not always be at the top of the list. For example, states and CMS officials noted that the volume of recent regulatory action that states have been working to come into compliance with, such as the final rule on ensuring access to Medicaid and also other regulatory action around person-centered planning from the past few years.

Then we also heard that in some states, their operational processes affect decisions to use or not use provisional plans of care. In particular, three states shared with us that they complete the level of care assessment and develop the PCSP together in the same meeting, thus, kind of negating the need for an interim service plan.

And then finally, provisional plans of care may not be feasible or may not be appropriate for all individuals. So for example, interviewees noted that a provisional plan of care may not be appropriate for somebody who needs the full array of services to safely discharge from the hospital back to the community.

Then this slide on guidance has mostly the same information as my last presentation, but I want to recap a little bit. So the guidance and provisional plans of care, again, comes from the 2000 Olmstead Letter No. 3, and nothing more recent has been published.

There is a brief mention in the section 1915(c) technical guide about how states should describe in Appendix D-1 on service plan development the procedures the state will use to develop interim service plans and the duration of said plans.

I'll also note that just on Wednesday, CMS held a webinar detailing revisions to the Section 1915(c) waiver application and the technical guide, and those changes will be rolled out on Monday. And in that webinar, they noted some very small revisions to the technical guide on provisional plans of care.

In our interviews, we also got mixed responses on the need for additional guidance on the use of provisional plans. So again, two states that are rarely using this authority shared that it's a long-standing flexibility that they've used, and they didn't feel they needed additional guidance.

National experts, however, all pointed to the fact that so few states are using provisional plans of care, and they expressed desire for additional guidance, as it could encourage more states to use this flexibility.

When we spoke with CMS, they again pointed to Olmstead Letter No. 3 and the long-standing ability that states have had to use provisional plans, saying that there's no new policy that warrants additional guidance.

They also noted that they've not received any recent technical assistance requests. Instead, CMS highlighted for us how they've been trying to promote the use of provisional plans, such as in recent webinars, the preamble to the access rule, a Center for Medicaid and CHIP Services Information Bulletin titled "Ensuring Continuity of Coverage for Individuals Receiving Home and Community-Based Services," and at recent ADvancing States HCBS conferences. And in each of these instances, CMS has reiterated that the authority is already provided in that Olmstead letter.

So to move on to our policy option, our policy option reads that the Centers for Medicare & Medicaid Services should issue guidance to outline the Medicaid

authority, either state plan or waiver, that states can use to adopt provisional plans of care and to identify policy and operational issues that states should consider in the course of implementation.

So again, as I just stated, interviewees were really mixed on the need for guidance. National experts as well as one state agreed that guidance would be helpful. Two states, again, that have operationalized the use of interim service plans said they did not need additional guidance.

But the apparent lack of awareness and the limited use of provisional plans of care indicates that there might be a need for additional guidance.

Interviewees noted that CMS could better describe the intent of the policy and how provisional plans of care could be used, including state examples and how to operationalize the policy.

Interviewees also noted that specific guidance on this topic would provide reassurance to states that they're operating their programs in accordance with the statutory and regulatory rules that govern HCBS. And one expert also noted that provisional plans of care could help states meet

the new timeliness requirements in the access rule.

This policy option also proposes that CMS clarify for states that provisional plans can be used for all HCBS authorities, including Section 1915 state plan options and Section 1115 demonstrations. Olmsted Letter No. 3 is specific to 1915(c) waivers because it predates the other 1915 state plan options, and while we have identified one state that uses provisional plans of care in its Section 1915(i) SPA and its 1115 demonstration, there's no guidance expressly stating that this flexibility is allowed for these other authorities.

When we spoke with CMS, officials there said that there's nothing prohibiting the use of provisional plans in these other authorities, and they noted that the regulatory language on person-centered planning is fairly consistent across all the Section 1915 authorities.

In particular, CMS officials noted that the requirement for Section 1915(i) generally follows that of Section 1915(c), and this is consistent with the findings from our work on 1915 authorities.

Finally, one expert hypothesized that interim service plans might be a useful tool for Section 1915(i)

programs but may be less so for 1915(k) since those usually have a smaller benefit package, but they ultimately supported the clarification that this policy option would provide.

Then finally to talk through some of the potential effects of this policy option. So state Medicaid agencies and operating agencies for HCBS programs may benefit from greater clarity on how to authorize and implement the use of provisional plans of care.

If guidance leads to more states using provisional plans, the number of new enrollees who have a provisional plan could increase, potentially leading to more timely access of services. In emergency situations, this more immediate access to services could enable individuals to remain in or return to the community as opposed to going into an institutional setting.

An increase in the number of provisional care plans can affect the entities responsible for providing them as well. So in states where plans are responsible for developing PCSPs, the staff, such as caseworkers, would need to be trained on how and when to operationalize the use of provisional service plans. And use of provisional

plans of care may allow enrollees to more quickly be connected with HCBS providers.

Providers would also need to be educated on the difference between a provisional plan and a regular PCSP and how services authorized could differ between the two versions. A decrease in services could negatively affect providers, although many stakeholders noted that there are typically more services authorized in a full PCSP than a provisional plan of care.

And finally to finish with some next steps. Today it would be most helpful to know if Commissioners have any feedback on the proposed policy option. I'm also happy to answer any additional questions. And if you are supportive of the policy option, then I'll return in January with the recommendation language and draft chapter for our March 2025 report to Congress.

And with that, I turn it back to you. Thank you.

CHAIR JOHNSON: Thank you, Tamara. That was very helpful.

All right. So I'll open the floor to Commissioners. So again, just so we level set, really want to get your feedback on the policy option, if that's what

you want to pursue, but also to any clarifying questions that will be helpful to the conversation will be great. So with that, I'll open the floor.

All right, Mike.

COMMISSIONER NARDONE: Thank you, Tamara. That's very helpful. I'm generally supportive of the policy option.

I wanted to ask, though, in the previous month, we also had a presentation about presumptive eligibility, and I'm just wondering, there was also some -- it seemed to be some misunderstandings around when presumptive eligibility could be used, who could be an agent to do the presumptive eligibility, what some of the fiscal potential liabilities were around presumptive eligibility. And I was wondering, did you consider -- or in talking to states, is that also potential, something we could marry into this recommendation as all part of kind of the effort to level the playing field in terms of institutional versus HCBS care?

MS. HUSON: Sure. So maybe just a quick recap of what we heard when we spoke with folks about presumptive eligibility. So one is just a reminder that presumptive

eligibility for non-MAGI populations can be done through two different authorities, so through Section 1115 demonstrations or by expanding hospital PE using a SPA. And so there is a lot of guidance around that second avenue of using hospital PE through a SPA, even though only one state that we know of has done that for the non-MAGI populations specifically.

But then thinking about the Section 1115 demonstrations, similarly, there was no consensus among the interviewees about whether guidance was or was not needed for that avenue. So again, we spoke with five states that have PE programs for their non-MAGI folks, and of the state officials we spoke with, one state strongly supported the need for guidance, while two other states did not. And then the other states really just talked about how TA with CMS was the most important thing for them in developing their programs.

Again, among experts, similar to this, there's kind of a general feeling that guidance is always helpful. But one expert noted that since much of this work is being done through the 1115 demonstrations, which really does rely heavily on that technical assistance, that back-and-

forth, that what we're kind of seeing is policymaking through waiver applications. And they wanted to kind of consider the tradeoff of formal guidance for an 1115 and about how you may lose some flexibility and the ability for states to really tailor programs to their state environment versus if CMS were to issue formal guidance with some parameters around how states could do that.

And then we also did ask CMS again about guidance for presumptive eligibility, and they indicated at that time that they were not planning to issue any guidance around how to do it in 1115 waivers.

So I hope that's a helpful recap of kind of what we heard and why we didn't move forward with a policy option at that time around presumptive eligibility.

CHAIR JOHNSON: Thank you, Tamara.

Dennis.

COMMISSIONER HEAPHY: Thank you. Could you go up to the Olmstead Letter No. 3 slide? Thank you.

When I look at this letter, I look at the timing of it, and it comes right after the Olmstead Agreement in 1999. It's really about ensuring that states are upholding their obligation to the civil rights of folks who live in a

community in the least restrictive setting possible.

So when I look at this, I see that Medicaid -- or CMS, rather, is providing states the ability to use a means of preventing people from being institutionalized unnecessarily. And so I think it's really important for us to support the proposal in the sense that states should be taking advantage of any means possible to ensure people's civil rights are being upheld and that they're reducing people from unnecessarily being institutionalized when they could be in a community setting.

CHAIR JOHNSON: Thank you, Dennis.

Patti?

COMMISSIONER KILLINGSWORTH: Continuing on with the comments that Dennis made, I do think the timing is really, really important and that it signals access to services for people who are otherwise institutionalized or at risk of institutionalization. And I really do think that this is an issue which sort of strikes at the heart of access to home- and community-based services and the fundamental institutional bias that continues to be in the law.

So if you want to go into an institution, you may

do so without delay, and you may have your services retroactively covered, notwithstanding some plan of care that has to be developed by the state or the state's delegated entity after you are determined eligible for those services, as is the case with home- and community-based services. So we've replaced a hurdle, an obstacle to services in the community that doesn't exist for services in an institution, and we've placed an obstacle to reimbursement for those services.

And it seems to me that when you're talking about someone who is at risk of institutionalization, we should make it easier for them to be able to access at least the urgently or immediately needed services that are required to keep them in the community and not have them be institutionalized, as opposed to requiring yet another administrative hurdle for those services to be made available to them, an administrative hurdle both for them in terms of the plan of care but also an administrative hurdle for the state in terms of "Oh, no, if you want to do this thing, which will make sure that people can actually access the services that they need in a timely manner, you need to go get special authority for that."

Should we just expect that states can make those services available to people when they are immediately needed, including through the use of interim service plans, initial service plans, whatever in the heck we want to call them? Our goal should always be to ensure that people have timely access to the supports they need when and where they need them in a way that, as Dennis said, protects their civil rights to receive those services in the most integrated setting appropriate for their needs.

And so I think this is one where not just -- I mean, the guidance -- my fear is that the guidance will be written and it will be written in a way that makes it harder for states to do what they may, in fact, already be doing. And I'll give you an example of that, and I'll just apologize in advance if this messes anything up, which I always worry about.

So, in Tennessee, there are three 1915(c) waivers, which since right after that Olmstead letter have allowed for initial plans of care.

When we created our 1115 demonstrations, our managed long-term services and supports programs, we identified the need for immediately needed services to be

provided right away, right? Not 90 days from now, but right away when people need them while that person -- that more sort of comprehensive person-centered support plan is being developed.

We didn't put that in our waiver, by the way. It's in our contracts, which CMS also approves. But it wasn't sort of a waiver amendment or a waiver authority. It's just something that we do because it's the right thing to do for people, and it is specified in contract language approved by CMS. So there may be easier ways for states to do some of these things short of "I got to go through a public comment process. I've got" -- who in their right mind is going to say, "No, I don't think you should make services available to people when they need them. I think you should make them wait"? So we should make that process easier for people.

And I would hope that any guidance that would be issued would try to make that as easy for states as possible in order to improve access to services and keep people out of institutions.

CHAIR JOHNSON: Thank you, Patti.

So from your remarks, then, when we look at the

recommendation as written, as we're suggesting, are there things in there that you think we want to make sure that we're considering? I'm just trying to get a sense of where we would go from your remarks that you have. Patti?

COMMISSIONER KILLINGSWORTH: There we go. Sorry. I was struggling.

I would like to see us maybe add some language about an expectation that the language is crafted in a way so as to make it -- I don't know what the right word to say is -- at least administratively burdensome as possible, right? So the most expeditious or efficient ways for states to be able to do that.

What I wouldn't want to see is, oh, you have to go get a waiver amendment in order to be able to make services available to people more quickly.

CHAIR JOHNSON: Okay. And then also another point is that we can also put more description in the chapter as written, too, as well, to indicate that. All right. That's very helpful.

COMMISSIONER KILLINGSWORTH: Thank you.

CHAIR JOHNSON: Dennis?

COMMISSIONER HEAPHY: Yeah, I think it's also

going to be helpful in the chapter to really contextualize this within Olmstead and do a much deeper explanation of why it's there and both to support the state's obligation, but that this is actually means of supporting the state's ability to implement Olmstead.

CHAIR JOHNSON: Thank you, Dennis.

Any other thoughts or comments from the Commissioners?

[No response.]

CHAIR JOHNSON: Is there general support, then, for this potential recommendation policy? I see a shake of hands. All right.

Tamara, is there anything else that you would need from us? I think we all are in agreement that additional guidance is always helpful. I just want to make sure that CMS understands the intent and some other options in terms of how they can make sure they're providing that for states.

MS. HUSON: Yep. That's great. Thank you. That's everything I need to move forward.

CHAIR JOHNSON: All right. Thank you so much.

[Pause.]

CHAIR JOHNSON: All right. We're going to have Gabby and Janice join us next to talk about HCBS spending and utilization that represents findings from our investigation into HCBS spending and utilization over the last couple of months.

[Pause.]

HCBS SPENDING AND UTILIZATION

* MS. BALLWEG: Hello, and good morning, Commissioners.

Today Janice and I are going to share high-level results from a two-year analysis investigating Medicaid home- and community-based services spending and utilization between 2019 and 2021 using data from the Transformed Medicaid Statistical Information System, or T-MSIS.

This project expands on MACPAC's 2017 HCBS claims analysis chart book which analyzed HCBS use and spending patterns from 2010 through 2013 among fee-for-service Medicaid beneficiaries using the Medicaid Analytic eXtract files, or MAX files.

The purpose of this analysis is to develop a baseline of data from which we can analyze Medicaid spending and utilization among LTSS subpopulations.

I'm going to begin this presentation with some background on utilization and spending patterns in HCBS and how this analysis fits into the Commission's HCBS access framework.

Next, I'll discuss the analysis itself, and then I'll turn it over to Janice who will provide an overview of our methods followed by a review of high-level findings from the T-MSIS data.

Janice will then dig into the 2021 dataset to discuss variations in demography among Medicaid HCBS users and to detail HCBS utilization and spending patterns across an array of stratifications.

Lastly, Janice will highlight some key takeaways from today's presentation and conclude with our next steps.

As a reminder, Medicaid beneficiaries who use long-term services and supports, or LTSS, are a diverse group spanning a range of ages with different types of physical and cognitive disabilities and various services and supports needs.

HCBS are an optional benefit that all states provide, and they're designated to allow people -- they're designed to allow people with LTSS needs to live in their

home or a home-like setting in the community.

In 2021, over 2.5 million individuals used HCBS. The total number of HCBS users in a year can vary based on the methodology used to identify HCBS users, and please note that this total excludes HCBS users from one state due to some data quality concerns.

States will vary in the types of services they offer to HCBS users, and they also can vary in their service definitions, with over 60 different specific services available to HCBS users, such as case management or day services.

To facilitate national analyses of HCBS users and expenditures by service type, researchers have classified these services into categories which we call the "HCBS taxonomy." Some of these HCBS taxonomy categories include round-the-clock services, supported employment, and day services.

The Centers for Medicare and Medicaid Services provides a list of 12 subpopulations from which states can choose their target HCBS populations for Section 1915(c) waivers.

In our review of waivers, we found that many

serve more than one of these subpopulations so we can we consolidated the subpopulations into six groupings.

This organization also mirrors other studies that use similar groupings, and it will allow for easier comparison across similar populations.

The subpopulations are as follows: individuals with intellectual or developmental disabilities or autism spectrum disorder, those under age 65 with potentially disabling conditions, older adults which includes people over age 65, people with brain injuries, individuals with mental illness, serious emotional disturbance or substance use disorder, and those with HIV/AIDS.

You may notice that we usually say in our work the phrase "individuals under age 65 with a disability," but here we're using the term "potentially disabling conditions." We do this because there's no disease severity or functional assessment data in the T-MSIS analytic files, or TAF, which we use for this work. So, we have to rely on diagnosis codes to identify possible disabilities for this LTSS subpopulation. So that's why we're using the phrase "potentially disabling conditions" in order to indicate that these beneficiaries in the

subpopulation have at least one condition that could be the basis of a disability.

The services HCBS users require will vary both across and within subpopulations by type intensity and cost, depending on the recipient's health and functional status. This also depends on the nature and severity of their disability, the setting in which they reside, and the availability of formal and informal supports.

These beneficiaries often receive services and supports for many years or even decades. As a component of LTSS, Medicaid spending on HCBS has outpaced spending on institutional care since 2013.

In 2021, Medicaid programs spent approximately $82 billion on HCBS compared to about $67 billion on institutional care. Also, please note that the total HCBS expenditures do exclude spending from one state due to some data quality concerns.

Spending also varies by HCBS authority. On average, Section 1915(c) waiver services as opposed to state plan services accounted for the majority of HCBS expenditures. However, it's also important to remember that Section 1915(c) waiver authority has been available

for longer than some of the state plan authorities.

Lastly, spending on LTSS varies by subpopulation, and some beneficiary populations account for a disproportionate share of LTSS expenditures relative to their share of LTSS users.

However, limited research on spending and utilization across LTSS subpopulations has prevented us from identifying the extent of these differences and stratifying these findings by factors that could influence access to HCBS.

As we continue with this presentation, I would like to note that all of the Medicaid expenditures that Janice and I discussed today comprise both the state and federal share of all the LTSS expenditures.

This analysis also ties into the Commission's HCBS access framework. As a reminder, the Commission established this framework in 2022 and recognizing that we can't fully identify disparities in HCBS access without accounting for differences in states' eligibility criteria for HCBS and the other domains of access, this work is only examining one of the four domains, which is the use of services domain.

Moving on to the analysis. While research exists on use and spending in Medicaid LTSS, there's relatively little detailed information across demographic characteristics, LTSS subpopulations, HCBS taxonomy categories, and delivery systems. Absent this additional research, it's challenging to identify the extent to which some of these differences in use and spending in Medicaid LTSS occur across these different groups.

Through previous MACPAC work, we heard from state and federal officials, as well as national experts, that more effort is necessary to explore the causes of existing health disparities, but data are lacking. Stakeholders emphasize the importance of stratifying data, and one expert noted that these data would allow policymakers to monitor and ensure populations are adequately served.

In 2017, MACPAC, in collaboration with Mathematica, analyzed HCBS use and spending patterns for Medicaid fee-for-service HCBS users and beneficiary subgroups from 2010 through 2013 using the MAX data, which is a predecessor to T-MSIS. However, due to some data quality concerns with the MAX data, the study did not include managed care, nor did it classify state plan

services to the HCBS taxonomy categories.

We built off of this 2017 study to conduct this preliminary analysis of the T-MSIS analytic files, or TAF data, on HCBS spending and utilization and categorized our data by demographic characteristics, HCBS taxonomy categories, and LTSS subpopulations.

This analysis will establish a baseline of data from which to better understand some of the differences in use and spending across these groups. The data include both HCBS and institutional LTSS utilization and expenditures. However, our primary area of interest for this project is HCBS, which will be the focus of our presentation today.

And with that, I'm going to turn it over to Janice to discuss the methodology and some of our findings.

* MS. LLANOS-VELAZAQUEZ: Thanks, Gabby.

So to measure HCBS spending and utilization, we partnered with Mathematica to analyze TAF data from calendar years 2019 to 2021. Just a note here that our analytic period does include data that cover the COVID-19 public health emergency in 2020, which had a major impact on the utilization of all health care services, including

LTSS. And we didn't make any adjustments to our data to address changes that may be attributable to the public health emergency.

For our analysis, we first identified LTSS claims, both HCBS and institutional care, by using several data elements on a claim. To identify institutional LTSS and HCBS covered under Section 1915 waivers, we adapted our methodology from CMS's LTSS expenditures and users report. And to identify HCBS covered under Section 1115 demonstrations, we adapted the methodology from KFF's state health facts.

Next, once we've identified the LTSS claims, we linked them to the eligibility file to identify certain beneficiary characteristics of interest, such as age, gender, and eligibility group, and to classify beneficiaries into the six subpopulations that Gabby listed earlier. Please note that the subpopulations are not mutually exclusive, and beneficiaries are counted in each subpopulation for which they met the criteria.

And lastly, we stratified the results by beneficiary characteristics and the six LTSS subpopulations for granular-level analysis.

As shown on this table, from 2019 through 2021, the total number of Medicaid beneficiaries and the number of HCBS users increased, while the number of institutional LTSS users decreased. The number of Medicaid beneficiaries increased from 91.6 million in 2019 to 97.7 million in 2021, which represents a 6.7 percent increase. The number of HCBS users increased by 15.4 percent over that same time period, which outpaced the growth in Medicaid enrollment.

From 2019 to 2021, the number of institutional LTSS users decreased from 1.8 million to 1.5 million in 2021, which represents a 17.5 percent decrease.

Before we review the rest of the data in this presentation, I just wanted to note a couple things. One, the table on this slide and the graph on the following slide, they exclude data from at least one state due to data quality concerns. However, for the remaining figures in this presentation, we include all states and D.C. for completeness.

And also, while our analysis did include data from 2019 to 2021, we found that the data remained fairly consistent for all three years. So, for the purposes of this presentation, we're just focusing on 2021.

On this graph, we're showing the state distribution of HCBS and institutional LTSS users as a share of all Medicaid beneficiaries in 2021. The dark blue bar on the bottom represents HCBS users, and the light blue bar on the top represents institutional LTSS users. Nationally, 3 percent of beneficiaries use HCBS, and 1 percent use institutional LTSS. And this is shown in that bar in the middle labeled United States.

In the majority of states, the percentage of HCBS users was higher than the percentage of institutional LTSS users, which ranged -- the users -- HCBS users ranged between 1 and 9 percent of Medicaid beneficiaries. And the percentage of institutional LTSS users ranged between 1 and 3 percent of Medicaid beneficiaries.

Next, we'll compare demographic characteristics of Medicaid beneficiaries and HCBS users as a whole and across the six subpopulations.

So, first, we'll take a look at age. For two subpopulations, age was part of the criteria used to classify beneficiaries into these groupings, which ends up being borne out in the age composition of these groups. So, among beneficiaries under 65 with potentially disabling

conditions, we only see beneficiaries under 65, and among older adults, we only see beneficiaries over 65.

Compared to the overall Medicaid population, HCBS users were older, with over 30 percent of users aged 65 or older, compared to just under 10 percent of the Medicaid beneficiaries.

Across the HCBS user subpopulations that include children, we found that the share of children was smaller compared to the overall Medicaid population. Beneficiaries with I/DD or ASD and mental illness, SED, or SUD had the highest percentage of beneficiaries aged 18 and younger, with 22 percent among I/DD or ASD and about 21 percent among beneficiaries with mental illness, SED, or SUD.

Next, we'll compare the distribution of race and ethnicity across groups.

In MACPAC's previous work, we've highlighted the state variation in the quality of race and ethnicity data as reported to T-MSIS. So, for this analysis, we supplemented state-reported data with the TAF race and ethnicity imputation file to estimate the proportion of race and ethnicity among beneficiaries.

HCBS users were less likely than the overall

Medicaid population to identify as Hispanic and more likely to identify as white.

In 2021, 14 percent of HCBS users identified as Hispanic, compared to 26.8 percent of all Medicaid beneficiaries.

In four of the six subpopulations, over half of the beneficiaries identified as white, and that is among the I/DD or ASD subpopulation, individuals under 65 with potentially disabling conditions, individuals with brain injuries, and those with mental illness, SED, or SUD.

The HIV/AIDS subpopulation had the largest share of beneficiaries that identified as Black and non-Hispanic with 56.3 percent and the largest share that identified as Hispanic with 17.7 percent.

And older adults had the largest share of beneficiaries that identified as Asian or Pacific Islander with 13.2 percent.

Next, we'll take a look at the distribution of eligibility groups. The majority of HCBS users were in the aged or blind or disabled eligibility group, comprising almost 73 percent of beneficiaries, compared to 19 percent in the overall Medicaid population. Among four

subpopulations, I/DD or ASD, individuals under 65 with potentially disabling conditions, and those with brain injuries, and HIV AIDS were in the blind or disabled eligibility group. And the largest -- and older adults by definition were almost exclusively in the aged eligibility group, and the largest share of beneficiaries in the children eligibility group was among beneficiaries with mental illness, SED, or SUD with 15.1 percent beneficiaries.

Taking a look at beneficiaries' dual eligibility status, that is, that they're eligible for both Medicare and Medicaid, the data show that full-benefit dually eligible beneficiaries were more prevalent among HCBS users with 49.3 percent compared to the overall Medicaid population with just 10.3 percent. Older adults had the largest share of full-benefit dually eligible beneficiaries with 92.6 percent, followed by individuals with brain injuries with 62.2 percent.

There are three subpopulations where over 50 percent of their population was enrolled in Medicaid only, and that is beneficiaries with I/DD or ASD, individuals under 65 with potentially disabling conditions, and

individuals with mental illness, SED, or SUD.

On this graph, we're showing the distribution of gender across Medicaid and HCBS users, which was fairly similar across all groups, with the exception of older adults where females account for the largest share compared to other subpopulations.

Finally, we're taking a look at the distribution of geographic location, which was also fairly similar across all subpopulations, with the majority of beneficiaries residing in urban areas.

We'll now review some high-level findings related to HCBS spending and utilization stratified by taxonomy and by subpopulation.

In 2021, there were about 3.3 million HCBS users and $84 billion in HCBS spending when including data from all 50 states and D.C. Round-the-clock services was one of the most commonly used HCBS taxonomies, with 33.5 percent of users, and it also accounted for the largest share of total HCBS spending, with 44.6 percent.

Case management was another taxonomy that was commonly used but comprised a much smaller share of total HCBS spending, with just 2.2 percent.

Looking at HCBS spending and utilization by subpopulation, the data show that the largest subpopulations among HCBS users were individuals with mental illness, SED, or SUD, with about 1.4 million beneficiaries; older adults with about 1 million beneficiaries; beneficiaries with I/DD or ASD with about 814,000 users; and individuals under 65 with potentially disabling conditions, with about 593,000.

The subpopulations with the highest total HCBS spending were beneficiaries with I/DD or ASD, with almost $44 billion in 2021, and beneficiaries with mental illness, SED, or SUD, with almost $40 billion.

The distribution of HCBS users and expenditures varied by subpopulation. The dark blue bar represents users, and the green bar represents expenditures.

As shown on this graph, the I/DD or ASD subpopulation comprised 24.5 percent of users but accounted for the largest share of spending at 52.1 percent, and beneficiaries with mental illness, SED, or SUD, accounted for the second largest share of spending at 47.4 percent.

On the next several slides, we will highlight spending and utilization among the four largest LTSS

subpopulations for the five most commonly used taxonomies within each subpopulation.

On this graph and the following graphs, the dark blue bar represents users, and the light blue bar represents expenditures.

Among beneficiaries with mental illness, SED, or SUD, the most commonly used HCBS taxonomy was mental health services and behavioral health services, with 35.7 percent of users. However, the largest share of expenditures was for round-the-clock services at 42.5 percent.

Among older adults, the data show that just over half of older adults, at 51.6 percent, used round-the-clock services, which also accounted for the largest share of their expenditures.

Compared to other subpopulations, older adults used round-the-clock services and home-based services at a higher rate.

Among beneficiaries with I/DD or ASD, similar to other subpopulations, round-the-clock services again was the most commonly used taxonomy, with 36.6 percent of users, and had the highest share of expenditures. Compared to other subpopulations, the I/DD or ASD subpopulation used

case management at a higher rate with 32.6 percent of users.

And finally, among beneficiaries with potentially disabling conditions, we see that round-the-clock services, again, was the most commonly used taxonomy and accounted for the largest share of spending. Compared to other subpopulations, this group used equipment, technology, and modifications at a higher rate, but this taxonomy accounted for the smallest share of their HCBS expenditures at under 1 percent.

So, to recap the high-level findings we reviewed today, compared to the overall Medicaid population, HCBS users were older, less likely to identify as Hispanic, more likely to be in the blind or disabled eligibility group, and more likely to be dually eligible for Medicare and Medicaid.

And we covered a few specific findings among subpopulations. We discussed their age, race, ethnicity, eligibility groups, and dual eligibility status.

In addition, we also discussed how the distribution of HCBS spending and utilization varied by subpopulation, where we found that beneficiaries with I/DD

or ASD accounted for the highest share of total HCBS expenditures. And each subpopulation varied in their HCBS taxonomy category utilization, likely reflecting each subpopulation's unique needs. Among most subpopulations, round-the-clock services was the most commonly used taxonomy and accounted for the largest share of expenditures, and case management was another commonly used service but accounted for a small percentage of expenditures.

As for our next steps, we welcome Commissioner feedback on the areas of interest based on the data we've presented today. We will develop an issue brief with the high-level findings, and we intend to use the new HCBS dataset for future analyses and publications.

And with that, I'll pass it back to you. Thank you.

CHAIR JOHNSON: Thank you so much. That was great. I mean, anytime we can get more information about data, we're excited about it. I see the folks over here very happy about it, for sure.

So, let me turn it over to the Commissioners. Again, if you all could provide your insights or your

thoughts around what's presented and any things we want to go a little bit deeper on as well. So, I'll open the floor.

All right, John.

COMMISSIONER McCARTHY: One observation and one question. Heidi and I both had the same reaction when we saw that chart where you showed the dual eligibles and using HCBS services, and I think you had something like 90 -- was it 92 percent or 99 percent on that chart for older adults? Yeah. I mean, it just goes to show you that work that we've looked at, why it's so important on duals. And you've got a program that basically is paying for all these services, and it's a completely separate program paying for those services. So, I just need to point that out. It's like the work that we do on duals is so important because of that chart there. Also, kind of, in my opinion, calls into question which program should be paying for those services, but we'll talk about that another day.

The other one is, if you go back to the charts where you looked at utilization by type and their case management was in there -- so for, like, the I/DD population and the aged population -- keep going. It's the

graphs. If I was reading it right, it was only like 32 percent of the population was using case management. And I was just wondering if there was something with our data on that that's not being captured or if -- I don't know if Patti might have greater insight into this. Because if you're on an I/DD waiver or in most aged waivers, every year your plan of care needs to be re-looked at. And so usually, there's case management that goes with that. And so, I was just wondering.

The dollar amount seems maybe right because states don't pay a lot for that, but the utilization of it seems relatively low in comparison, but what utilization you would think on an annual basis would be. So that would just be a question I would have on our data on that one. Not saying that data's wrong. I was wondering if people are enrolled, for instance, in managed care, if the case management is not being captured because it might be in a cap payment or something like that.

CHAIR JOHNSON: Thanks, John.

Mike?

COMMISSIONER NARDONE: So, I wanted to start with a question. First of all, this is great data. We could

spend lots of time on this.

I was wondering, can you just help me understand the difference between round-the-clock and home-based services? Are they the same services in terms of, like, personal care or attendant services, but one is continuous around-the-clock versus maybe four hours a day? Is that the main difference? I just want to understand that.

MS. BALLWEG: I think we can go back to the HCBS taxonomy and clarify that for you. There are differences, and CMS has a really nice chart that lists them out. So, we can go back and give you a good answer for that.

COMMISSIONER NARDONE: Great. Thank you.

So, I had a couple of thoughts, too. John, I was wondering -- and I might have missed this when you talked about it -- is there could be -- one of the things I'd like to, if we can explore -- is the difference between the data from MCOs versus fee-for-service, like the distinctions there. I think you raised that in your memo, and I guess I wanted to reinforce that I think that would be very helpful to be able to look at. That might be one of the reasons why you're not picking up case management for people who are in a capitation program.

I just wanted to be clear, too. I think it'd be interesting to look at, and I just want to make sure I'm understanding the way your -- the methodology is. When you're looking at the different populations, for the most part, I think those populations would line up into waiver categories. Like, they would be fairly lined up with waiver categories, with the one exception -- and I might be wrong, right? -- being the SMI SED, that those might be actually expenditures that are more across waivers, because you're looking at actual claims, right, in terms of -- so I think it'd be interesting to maybe look at that in terms of the waivers. In other words, where are the SMI expenditures in terms of specific waivers? I think it would be interesting to track that over time, because I assume this is -- and particularly as we look at the aging waivers, is that number increasing? I just think it would be helpful to look at that in terms of the data that you are putting together.

And just on the duals point, I think that the one takeaway that I had was just, you know, in addition to John's point, is that the variation in the duals population. We kind of always think -- you know, I think

MACPAC has done a good job in the past of, like, recognizing the different subpopulations that are part of that, and I think this data really helps to drive that home. So, thank you.

CHAIR JOHNSON: Thank you, Mike.

Tricia?

COMMISSIONER BROOKS: Just a couple of things. We love data, so thank you for this.

Can you go to the graph that was the state distribution, I think? We don't see state names, and I'm really curious here. I mean, my gut reaction is that this might reflect the average median income in a state, you know, for elders or something, that states that have higher income, you know, would have fewer beneficiaries as a share. But do we plan to label the states if we do a brief and include this?

MS. LLANOS-VELAZQUEZ: So, I mean, we do have state-level data, but for the purposes of this one, we wanted it to keep it high-level and, like, not focus in on specific states, but for future analyses, that's something we could consider.

COMMISSIONER BROOKS: Yeah, I think it would be

helpful to have it in the brief.

The other thing I think that would be helpful is to understand the average annual cost of beneficiaries compared to who's in HCBS versus institutional care.

Thank you.

CHAIR JOHNSON: Thank you, Tricia. Great points.

Patti?

COMMISSIONER KILLINGSWORTH: So, can we go to slide 21? I just want to be sure that I understand the data, because what my brain always tries to do is to total everything up. So, I would expect that these are -- we talk about it being a percent of the total, right? So, I would expect that each of the HCBS users is a proportion of total users and expenditures is a proportion of total expenditures, but the math doesn't work for me, right? So, can you just explain to me what this slide -- how this slide is depicting this information?

In the first example, 24.5 percent of what and 52.1 percent of what?

MS. LLANOS-VELAZQUEZ: Right. So, the subpopulations aren't mutually exclusive. So, when you sum the percentages, it's going to be greater than 100 percent.

And so, it's 24.5 percent of all HCBS users for I/DD or ASD. And, you know, for example, like, those beneficiaries could also be in the mental illness, SED, or SUD, so that 24.5 percent and the 41.2 percent have overlap. So, they're not mutually exclusive groups, which is why we kind of presented them as separate bars. Does that make sense?

COMMISSIONER KILLINGSWORTH: Kind of. It's just really hard to get a sense of what it really looks like then, right? Because I've got 52.1 percent of expenditures being I/DD and 47.4 percent being in the mental illness category. I have no idea sort of what percentage of that is kind of overlap. It just I'm struggling to kind of make sense of it in terms of what it actually means.

Maybe I can have an offline conversation with you about that to see if there's a different way, maybe, that we could sort of tease out the details.

John, I do think you're right on the administrative services kind of being the explanation on case management. I think especially under managed care, we don't see those services. Case management typically provided as a waiver or HCBS benefit, it's provided as administrative function of the health plans. Sometimes

that happens outside of managed care as well.

And then, Mike, I think you were also right that the round-the-clock is more like residential kinds of benefits, whereas in-home services are personal care services in the taxonomy code.

So many places that we could go with this data, and I want to understand it, make sure that I understand it better before I offer some thoughts about that.

CHAIR JOHNSON: Thanks, Patty.

Heidi?

COMMISSIONER ALLEN: I'm super excited about this. I know it takes a lot of effort to work with the files and make them suitable for rigorous analysis, and I'm just so glad that that investment in time and energy has been made, and then now I think we're going to benefit from it for the next several years.

I was really interested. I mean, one of the things that I always notice when I look at data like this is that Medicaid really is serving people who have great disadvantage, and the money is being spent exactly where you would expect it to be spent. So that to me is reflective of Medicaid doing its job, and in particular, I

think of the rights of people to not live in institutions and moving from institutional care to the community environment, the least restrictive environment. You see that in the round-the-clock care that people need and are using, and so I think that that's a really interesting subpopulation for comparison, because if you require round-the-clock home- and community-based services, that means without that you would be living in an institution.

And so, I think it would be really interesting to see for that population, looking at kind of all the services that they're receiving and comparing that to the cost of people who are in institutional care, because if the numbers are even close, then obviously, the benefit is the least restrictive environment. I mean that's in law.

I'd like to understand the mental health, substance use disorder, and SED population more. I'm curious, is this like group homes? What kind of care are these folks receiving in home- and community-based services? I think that's just really kind of something that would be great to understand more since it's such a significant amount of expenditures and participation.

I'm wondering if we can observe PACE in this

data, because I think that was one of the things when we had the PACE conversation. It was such a beneficiary, beloved program that families and consumers seemed to really love. But there were some questions. Like, nobody really knew what the economics of it were, and so if we can look under the hood of that, that would be great.

Then I'm just reflecting on the race-ethnicity slide, and kind of two things come forward to me, a story of advantage and disadvantage, advantage in that you see that whites are disproportionately receiving home- and community-based services and disadvantage that you see the impact of HIV/AIDS on the Black non-Hispanic population.

I think that when we collect data on race/ethnicity, it's important for us to kind of think how we can take that further to interpret why it is that you see disproportionality.

Some things, we know from epidemiology of who has what disease burden and plays out here, but some of it is not as clear, like why whites would be disproportionately more likely to be receiving home- and community-based services.

So that's my thoughts. I'm very excited about

this data source and the work that you guys are doing.

CHAIR JOHNSON: Thank you, Heidi.

Dennis?

COMMISSIONER HEAPHY: Thank you. This is great, really great data, but it raised more questions for me.

Michael asked about the round-the-clock. I actually looked online to try to find out. It still confused me. What does this mean?

And I also was, as I looked at the data, trying to better understand by state, the level of HCBS provided to folks, because we know the distribution of access to HCBS varies by state. And so, what is that variation across the states? Is the data available for that, or is that just beyond the scope of what you're able to do?

MS. LLANOS-VELAZQUEZ: Yeah, we have state-level data.

COMMISSIONER HEAPHY: Right.

MS. LLANOS-VELAZQUEZ: Yeah. So, when you're saying the level of HCBS, are you -- like, can you define that a little more?

COMMISSIONER HEAPHY: Sure. So, in one state, personal care kind of services might be 20 hours a week,

when in another state, it might be 60 hours a week. And so, when we're looking at distribution of access to HCBS, what does that actually look like? Is that helpful? Can you get down that deep?

MS. LLANOS-VELAZQUEZ: Yeah, that's helpful. Thank you.

COMMISSIONER HEAPHY: Okay.

And one other question. I just can't remember it right now, but I'll get back to the question. It's more about, like, going down to the data to, like, what does all this mean? And that's what I'm trying to figure out.

Also, with the race and ethnicity data, what does that actually mean in terms of why aren't folks getting access to these services, especially in light of COVID. We saw what happened there.

CHAIR JOHNSON: Yeah. Thanks, Dennis.

Any other thoughts or questions?

[No response.]

CHAIR JOHNSON: All right. Anytime we get more information, we want more information. We have more questions. But I think you have some good questions and some good thoughts to kind of move us forward a little bit

more on this, and I'm just excited that we have this dataset to help us with our future projects. So, thank you both for all you're doing to make sure this is happening. We appreciate it.

All right. So next up, we're going to have findings from our technical expert panel on HCBS payment policies. This is going to be our last session this morning focused on HCBS, and so Katherine Rogers, our Deputy Director, and Emma Liebman, our Senior Analyst, will be making their way up to talk to us about the findings that they have.

[Pause.]

FINDINGS FROM A TECHNICAL EXPERT PANEL ON MEDICAID PAYMENT POLICIES TO SUPPORT THE HOME- AND COMMUNITY-BASED SERVICES (HCBS) WORKFORCE

* MS. LIEBMAN: Hi, everyone. It's great to be here. This is both mine and Katherine's first time presenting, so we're excited. Well, I'll speak for myself, but I think we're both excited.

Today Katherine and I will be presenting the latest installment of our work on payment approaches to promote the HCBS workforce. This presentation builds off

work that kicked off during the November 2023 Commission meeting, and our former colleagues Rob Nelb and Asmaa Albaroudi last spoke to the Commission on this topic in March of this year.

And then this fall, Katherine and I held a technical expert panel, or TEP, on HCBS payment, and we'll use this session to share the findings from the TEP and trace the through line in terms of the findings from our previous work as well.

Our goal for the conversation today is to discuss next steps for this work, including potential policy options, and we're really looking forward to hearing from the Commissioners about our findings and where they may lead us.

So, with that, I'll pass it over to Katherine.

* MS. ROGERS: Thanks, Emma.

So, to start, just a quick overview of what we'll go over today. We'll provide some policy background on the foundation for this work, including discussion of the HCBS workforce, how Medicaid HCBS is authorized and paid for, and how Medicaid programs set HCBS payment rates. After that, I will turn it back over to Emma, who will go through

all that prior work that MACPAC has completed in HCBS payment, which was presented in last year's analytic cycle, and we'll cover the policy issues examined and discussed in that TEP in September. At the end, we'll facilitate some discussion with all of you about the best path forward, next steps.

So we'll start with the HCBS workforce. As you all know, Medicaid is the primary payer of formal LTSS in the nation. According to a 2024 MACPAC analysis, some of which you just saw, in calendar year 2021, total federal and state Medicaid spending on HCBS was $84 billion, as they mentioned, accounting for 55 percent of all Medicaid spending on LTSS and about 18 percent of Medicaid expenditures.

The workforce supporting HCBS programs is diverse, serving people across all those LTSS subpopulations and assisting Medicaid beneficiaries with a wide range of services and supports, also as discussed in the last presentation. This includes performance of activities of daily living and including a growing number of independent providers working in self-directed models, like you heard about yesterday.

HCBS workers also work in a range of settings, including group homes, assisted living facilities, individuals' homes, and more.

All states have reported shortages in some corner or multiple corners of their HCBS program. And while HCBS workforce challenges predated the COVID-19 public health emergency, there's widespread evidence that significantly exacerbated these challenges.

HCBS is, of course, delivered differently in different states. There are a number of different authorities under which state Medicaid programs can design, deliver, and pay for LTSS in home- and community-based settings. These authorities all intersect with states' use of Medicaid managed care as well, since HCBS is delivered through both fee-for-service and managed care delivery systems, depending on the state jurisdiction.

The intersection of delivery systems, HCBS authorities, self-direction, provider types, and payment rates means payment for HCBS may look different state to state, and it is fairly complex.

A note that our focus here today is primarily on fee-for-service payment policy, as that is set by states

and providers are paid directly by states, but it's important to understand that fee-for-service payment policy has downstream effects to both managed care provider payments and self-directed provider payments, through budget-setting processes, for example.

States also feel the effects of cross-program shifts; for example, workforce shifting from an agency model to a self-directed model. So we can't ignore the entire HCBS payment ecosystem as we go here.

While payment rate models and rates themselves vary across service types, for example, day programs versus personal care aides, those models generally, like other Medicaid services, rely on several key components of the service model and data on those inputs. Many LTSS or labor-driven service delivery, and so worker salaries or wages, often comprise usually the largest share of payment rates. These may also be governed by local or other laws regarding minimum wages overall or within a sector.

Other employee-related expenses, such as training or benefits, comprise another component, and these may vary based on the provider, provider type, or setting.

HCBS providers have program-wide expenditures,

such as transportation, program support, administrative support, including medical records management, compliance, incident reporting, and more.

Providers obviously make independent decisions about their own agency policy, though the May 2024 Medicaid access rule established a reporting requirement and a standard for certain HCBS to ensure at least 80 percent of Medicaid payment rates were directed to worker wages and compensation.

From a policy perspective, the requirements for formal rate reviews vary. Only 1915(c) actually specifies the periodicity required for the rate review from the federal side. There are no requirements specified for the type of rate review, the content of the rate review, for any HCBS authority.

Throughout today's presentation and this work, we'll use a few terms we'd like to clarify here that fall under that umbrella of rate review. When we talk about rate studies, we are talking about comprehensive data-driven evaluations of the payment rate that may result in changes to the fundamental method used to pay for that service or group of services. This may look like the

comprehensive work that's conducted at the very outset of implementing a new service and setting a payment rate method in the first instance.

States also employ methods for updating rates without fundamentally changing the methodology through indexing or rebasing, and in indexing, we're talking about linking the payment rate to some trend factor, such as a wage standard. In rebasing, we're talking about periodically recalculating the rate without changing the methodology but using new data, such as cost reports or new wage data.

Before we zoom in a bit more on the work that we've done across this project, a brief refresher on MACPAC's Provider Payment Framework. This framework is a starting point for assessing how Medicaid payment policies, including here in this project for HCBS, can be used to address the goals of the Medicaid program. In this context, we are focused specifically on how payment can impact access to HCBS.

Medicaid statutory objectives for provider payments include economy, a measure of what is spent, efficiency, how what is spent drives what is achieved among

the goals of care, and access and quality are measures of what we can obtain from those provider payments.

In order to promote access and quality, states can improve payment rates or find ways to achieve more efficiency; that is, obtain more value for the expenditure.

Now I'll turn it back over to Emma to continue with the background on MACPAC's prior work and the findings from our TEP.

MS. LIEBMAN: Great. Thank you, Katherine.

So I will begin with the study approaches and then get into the findings from our past work.

During our last Commission cycle, our colleagues contracted with Milliman to develop a compendium of payment policies for HCBS provided under the Section 1915(c) waiver authority, which was then published in January of this year. And then, in an effort to better understand payment strategies that states are pursuing to improve HCBS rate setting, our colleagues also worked with Milliman to conduct interviews with national experts as well as stakeholders in five states.

Through the Section 1915(c) compendium, we learned that states have flexibility to define HCBS

services, and as a result, service definitions vary significantly across programs and states. For example, our colleagues investigated three broad HCBS taxonomy categories that account for the majority of HCBS spending. Those include home-based services, day services, and round-the-clock care. And the compendium identified 253 unique state-defined services that fit into these three taxonomy categories.

We also learned that many states use rate studies to develop and update rates, but there's significant variation in the way that states use this tool. For example, states vary in how comprehensive their rate studies are, so whether they're reviewing services from one waiver or state plan or looking across the board, and how frequently they take on these studies.

As we know, there's no CMS requirement around rate studies and few requirements around rate reviews or updates more broadly. So many states don't use rate studies at all or regularly review and update their HCBS rates.

States also vary in the extent to which they publicly document their rate study process or results, with

some states publishing formal rate study reports and others having very little external documentation.

The compendium also shows that even when states do conduct rate studies, they do not always implement the study recommendations.

And then the final key takeaway from the compendium was that HCBS worker wages tend to make up the largest component of the HCBS payment rate, and states tend to rely on several data sources to develop wage assumptions, most notably Bureau of Labor Statistics Data, or BLS data. However, BLS data does not have a classification for HCBS workers. So states use other BLS categories as proxies for HCBS workers.

Moving on to our interview findings, our colleagues found that rate setting is the primary strategy that states use to address HCBS workforce challenges. When designing and updating rates, the national and state stakeholders we interviewed stressed the importance of comprehensive data-driven and aligned rate assumptions and regularly updating rates to account for a changing policy environment using tools like rate studies, indexing, and rebasing.

In particular, the interviewees discussed the fact that there is significant variability in rate assumptions that can incentivize workers to switch to higher-paying services, which can create access challenges.

Interviewees identified rate studies as an important mechanism for ensuring that rates are designed in an aligned manner and include all of the relevant inputs to promote adequate workforce participation. However, the interviewees also identified some of the drawbacks of rate studies, including how resource-intensive they can be.

They also resurfaced the point that rate study recommendations are not always implemented, largely due to budget constraints.

Finally, the interviews also covered potential non-financial strategies for promoting the HCBS workforce, such as workforce training and credentialing programs, public campaigns to encourage workforce participation, and promoting the use of family caregivers to supplement the HCBS workforce.

Overall, though, the interviewees did not share much evidence regarding the effectiveness of these strategies.

Moving on to our most recent phase of work on this topic, I'll now run through the approach and findings from our technical expert panel.

Similar to our previous work, we contracted with Milliman to help us home in on some of the most promising payment strategies that states may consider when setting HCBS rates and how those rates may be developed and updated over time. We also carved out some space to consider payment strategies beyond rate setting.

We held our TEP in September with participation from CMS officials, plan associations, actuaries, and consumer representatives, and overall, as was mentioned earlier, many of our findings corroborated and built upon what we learned from our previous work on this topic.

Over the course of the next few slides, I'll review the key findings from the TEP.

Our first key finding was the importance of comprehensive rate assumptions. Today HCBS wage assumptions and rates may not reflect the full range of inputs necessary to provide care to beneficiaries. For example, the rates may not include the professional skills and responsibilities that one type of HCBS worker provides

versus another. They may also not reflect the time that HCBS workers spend conducting program activities beyond the direct provision of care, such as completing incident reports or progress notes. And rates may also not reflect variations in patient acuity or additional costs associated with providing care to certain beneficiaries, such as translation services or travel needed to reach rural beneficiaries.

The TEP participants identified several strategies that states may use to ensure that these inputs are included in the rates, such as productivity adjustments, local payment rate adjustments, or code modifiers.

The next key finding, which mirrors findings from our previous work, is the importance of aligned rate assumptions. There is significant variation in payment rates across HCBS delivery models, programs, and geographic regions, meaning that rates for the same or similar services may differ from one model to the next.

Wages may also differ due to underlying rate differences or minimum wage variations across states and counties.

As we discussed earlier, these rate variations can lead HCBS workers to participate in models or programs that offer the highest wage, which can create access challenges.

TEP participants also noted that incentives based on rate variations extend beyond HCBS into the LTSS system more broadly and emphasized the importance of considering rebalancing efforts in the rate-setting approach.

TEP participants, like our previous interviewees, encourage states to use alignment and variation strategically to incentivize adequate workforce participation according to beneficiary need.

In considering how to achieve comprehensive and aligned rates, TEP participants identified the importance of strong data. As we discussed earlier today, HCBS service definitions and the way that these services are reported varies across states and HCBS programs. Without clarity about what each service entails and how services differ from one another, it's really challenging to build or fund appropriate rates.

TEP participants also discussed the lack of a single reliable data source for HCBS worker wages across

states and HCBS programs, which surfaced during the compendium findings as well.

Again, without timely and accurate base data from CMS or at the state level, it's challenging to build appropriate wage components into the payment rates.

The 2024 Medicaid access rule, among several relevant provisions, requires public reporting of direct care worker compensation and hourly rates for key HCBS services. So this rule may improve HCBS data transparency and standardization. However, the impact of the rule is yet to be seen, and there may be further opportunities for CMS to improve data, including around service definitions and wage assumptions.

Moving to the next finding, consistent with our earlier findings, the TEP participants emphasized rate studies as an effective tool for building rates, as well as identified some of the challenges associated with this tool. Namely, rate studies require significant time and energy inputs from a variety of stakeholders, including providers, legislators, Medicaid agency staff, et cetera, which can create a real administrative burden.

As we discussed before, budget constraints may

also mean that even when rate studies are conducted, their recommendations may not be implemented. And then on the flip side, tight budgets might mean that implementing rate recommendations leads to unintended consequences, such as implementing utilization limits or program wait lists.

With all of that in mind, TEP participants encouraged CMS or states to identify the right cadence for rate studies that balances their benefits and drawbacks. For example, some participants suggested staggering the use of rate studies across HCBS services to reduce administrative and financial burdens. However, other participants emphasized that rates should be updated in tandem, given the interconnectedness of the HCBS system.

TEP participants pointed to indexing and rebasing as less burdensome tools for ensuring that HCBS rates are updated over time but noted that budget constraints may still affect the ability to implement rate updates.

Additionally, because indexing and rebasing do not update the rate methodology, they run the risk of locking in outdated rate structures. For that reason, TEP participants agreed that indexing and rebasing are tools that CMS could require or states could opt to use in tandem

with or in the interim between rate studies rather than instead of rate studies.

Finally, the TEP discussed payment strategies beyond rate-setting approaches, such as wage add-ons, covering technology to promote remote care, value-based payment approaches, and state-directed payments. Generally, the strategies that states have adopted to date have relied on enhanced funding through the American Rescue Plan Act, which is running out in the next few months. So we'll have to monitor to determine whether these strategies will continue to be funded out of state budgets. Additionally, states offered mixed opinions when it came to success of these strategies.

So having discussed our key findings, we'll now move on to the next steps for this work.

Overall, we'd like to use the rest of the time to hear from the Commissioners about how we may use TEP findings to inform MACPAC's future work in this area, including potential policy options. We've laid out five specific questions for the Commissioners' consideration today.

For the first and second question, as we

discussed, only HCBS programs operated through Section 1915(c) waiver authority are required to review their rates, and as a result, many states do not regularly review or update their HCBS rates.

Additionally, even where rate reviews are required, there are few specifications regarding what constitutes an adequate rate review.

With that in mind, we'd like to discuss whether more HCBS authorities should be required to conduct rate reviews with some baseline frequency and what rate review requirements might look like, including what could be made public in terms of rate review methodology and outcomes. For example, given the various benefits and challenges of rate studies, indexing, and rebasing, how should these mechanisms fit into rate requirements?

Moving to the third question, we discussed that HCBS payment rates and wage components may not reflect the full extent of HCBS worker contributions, which has implications in terms of workforce participation. We'd appreciate Commissioner input on whether there's a role for CMS to support states to ensure comprehensive wage assumptions.

Next, for question 4, lack of alignment across rates can lead HCBS workers to be paid different rates for the same or similar services, and lack of consistent service definitions across HCBS programs complicates this issue. We're hoping to discuss the role of CMS or states to improve rate alignment where appropriate, including potentially by supporting more consistent service definitions across programs.

And finally, we've heard repeatedly that states lack clear and consistent wage data on which to build HCBS payment rates. We'd like to discuss the role for CMS, Congress, or states in promoting and maintaining sufficient wage data.

As we move forward on these main findings, there are also a couple of areas that we're planning to continue to monitor, namely whether states continue to finance payment strategies adopted through ARPA funding, any further evidence on the impact of non-rate-setting strategies to promote the HCBS workforce, and finally, the effects of payment adequacy and reporting requirements included in the access rule on HCBS data transparency and standardization.

So, with that, I will turn it back to our Chair and look forward to hearing the Commission's thoughts on our findings as well as the five questions posed here.

CHAIR JOHNSON: Thank you so much, Katherine and Emma. Great job for your first time up for sure.

All right. So let's keep it on the slide, and let's see if we have any feedback from the Commissioners, obviously on the entire presentation, but also on these five questions that they're asking us.

Heidi.

COMMISSIONER ALLEN: So thank you for this work, and I am looking forward to discussing potential policy options.

We've been talking about this issue for multiple years, and the thing that always just rises to the top to me is this is not a career that people would counsel their children into. And as long as that's the case, we're always going to have a workforce issue for the rates that people are paid, the wages that they're paid. They could do jobs that are just so much less physically and emotionally demanding and require less skill.

And so why would you lift somebody up and down

multiple times a day versus be a greeter at Walmart? It's just if you're making the same money, and I think that we constantly struggle with that. So I think of other difficult jobs that we've invested in as a society to make them worthy of people wanting to do that, like teachers. Teaching is a job that people want to encourage their kids to, but it comes with really good benefits. So the salaries are not as high as you would get if you're a physician or a lawyer, but you're going to have a really good middle-class, stable career. And I think that this is a difficult middle-class, stable career for people.

And just listening to Robert testify yesterday about the people who work for him and who have worked with him for years can't take sick leave, they don't have vacation time, they can't take family leave or paternity or maternity leave, they don't get retirement benefits, they don't get vacations, they don't have health insurance. And I just feel like we could continue to kind of demand that home- and community-based service agencies try to funnel more money to employees, and that definitely seems worth doing.

But I wonder if there's any other way that the

state would want to say we need to invest in this workforce by giving them a career pathway and thinking about that. I mean, I know it's a total wild idea, but thinking of the potential pathway for public employees, for people to go into it as a long-time career. You know, it does feel like sometimes we just have to do big thinking, and with the aging of the population and more people wanting to stay home -- and we certainly don't want the aging of the population to mean that more people have to spend down to go into institutional care -- we have to figure out a way to make this a career that people would want to go into and that would be sustainable for an American family.

And so I know we're working around the margins here of like what exists, but I do think that framing to Congress, you know, that it is time for big-picture thinking. It is time for us to think about, you know, the fact that we need this workforce in place more and more every year, and it's going to require some definite action.

CHAIR JOHNSON: Thank you, Heidi.

Patti?

COMMISSIONER KILLINGSWORTH: This is a challenging topic, and I agree that it's a really, really

important topic, probably one of the, if not the, most significant challenge facing states in delivering home- and community-based services.

I want us to be careful that we stay in our lane and that we -- you know, our role is to think about recommendations that would help to ensure the adequacy of funding and payment for the services, including the payment to the direct care workforce, without kind of becoming overly prescriptive and, you know, starting to suggest, for example, that services should -- that states should use the same service definitions and they should all pay the same way. And I think that may be stepping beyond the scope of our statutory responsibility.

Completely agree that we need a -- that we need more transparent, accountable reporting of both payments and costs for these services that can help to enable a complete understanding of whether Medicaid payment is adequate for these services. I think that needs to be a data-informed approach that just currently doesn't exist, right, because we don't know what the workforce is paid, and so some sort of way of gathering that information, I believe, at a state level, because it is states that are

responsible, you know, for setting the rates or for informing that process when we're talking about managed care reimbursement. I just think that has to happen at a state level.

I do think it's important that there is a consistent approach across long-term services and supports broadly as it relates to nursing facilities as well as HCBS programs, providers, and populations because they share a common workforce. They share common workforce challenges, and the last thing that we would want to do is sort of favor one over the other and create access issues in another area of the Medicaid program.

Completely agree that we -- so Heidi talked about sort of this, you know, kind of the challenge of this, the nature of the work and kind of the way that it's set up, but there's a bigger problem we haven't talked about. And it's sort of like it's the reality of the demographics of an aging population, where if you look at the population of people projected to turn 65, projected to turn 85, those numbers are going up, up, up. Those are the people most likely to need long-term services and supports. By the way, people with disabilities living longer and longer, all

good things, but then if you look at the demographics of the workforce age population, the age of people who would be most likely to deliver these services, it's kind of flat, right? So we have this practical issue of we don't have enough people, and it doesn't matter what you pay them. We don't have enough people to deliver all of the supports that individuals need. We don't have enough people to staff restaurants. We don't have enough people, right?

I mean, we're seeing it kind of everywhere, but I think it's acute because of the nature of these particular services that are provided and how critically important they are for people's needs to be met on a day-to-day basis.

I agree with Heidi that the notion of career pathways is really, really important for this workforce so that it's not a dead-end job, if you will. We have the ability to sort of draw people into the field and help them feel like it is something that allows them promotional kinds of opportunities.

I do think there's opportunities for expanded scope of practice for the direct care workforce to really

encompass things like medication administration and the performance of routine health care tasks, things that sort of elevate that role and then would come with, hopefully, commensurate increases in pay because it would be a more cost-effective way of meeting those kind of routine needs when they're in the home.

But I think as a practical matter, we do also have to look beyond workforce solutions to alternative ways of ensuring that people have access to the supports they need. We talked a little bit about remote supports. There are all kinds of assistive technologies, but we cannot -- no matter how we set reimbursement for this workforce, we are not going to solve what is a fundamental demographic challenge in this country.

We are going to have to look to alternative ways in addition to, right? So we need to look at the adequacy of payment, but we also need to recognize this is not a solution -- or this is not a problem that will be solved through a single solution related to paying the workforce more. It's much bigger than that.

CHAIR JOHNSON: Thanks, Patti.

It seems like a lot of forums we talk; we hear a

lot about the career pathways, and I'm just curious too. Have we seen that work? Have we seen examples of how states have utilized that tool to get more people involved in the series? Just things to think about.

Dennis?

COMMISSIONER HEAPHY: Thank you.

I agree with much of what Patti said and also Heidi, but I do think we need some standard definitions across states of what it means to be a direct service worker. There's a person, like a personal care attendant, providing direct services in the home versus a homemaker versus -- I don't know -- and versus someone who's working in a day hab. So, like, having definitions, I think, would be really helpful. So there's some standardization at least for the collection of data.

I also think that it would be helpful to have some data on the variation in wages across the state -- across the country, because we get some sense of what the variation looks like, understanding that, you know, there are variations in income across different states as well. But I think I would love to see more data on what people are actually getting paid.

And the third thing is Medicaid. A lot of the folks that either don't have insurance or they're on Medicaid, and actually increasing the income would cause harm to those folks. And so how do -- you can capture some of that data and say, you know, where might it be -- how are we going to make sure that those folks don't get harmed and they're not going to lose their medical insurance because their payment rate is going to go over what Medicaid allows? So those are a couple of thoughts I had.

Thank you. That was really great.

It's a crisis. I know that Patti talked about it. We really are in a crisis. So we should find every way to address this.

And states are really overburdened, and so is there a role for others to help states with their payments?

Thanks.

CHAIR JOHNSON: Thank you, Dennis.

Tricia?

COMMISSIONER BROOKS: Building on what Dennis was saying about variation by state of payment rates, I'd be interested to compare that to the penetration of HCBS services compared to institutional to see if we can

illustrate the correlation between payment and how far you can get in serving your population in the community.

The other thing that was the first thought I wanted to share; I know that Pam is a caregiver herself. She's obviously very sophisticated and experienced in that work, but I would love to hear from a panel of caregivers themselves. I'd like to hear the challenges and the hopes that they would have in doing that work and what the barriers are. I think that would be very interesting.

Thank you.

CHAIR JOHNSON: Thank you. That's a great suggestion, Tricia.

Jami?

COMMISSIONER SNYDER: Thanks so much for this work.

I had a question actually on slide 18. You talked a little bit about some of the payment strategies that states have employed using Rescue Plan Act dollars. It sounds like the TEP had a bit of discussion around state efforts to extend some of those strategies or financing efforts. Can you provide any more detail? I'm just curious because we are coming to that, sort of that end

point on March 31st of 2025 when the funds either need to be used or they're no longer available to states, what states are doing to make those payment strategies and financing efforts available beyond that time.

MS. LIEBMAN: Anecdotally, we heard from some states that there is an interest in continuing, and we heard that from some CMS leadership as well. But we don't have any specifics in terms of what states will be capable of.

I think there is some data about state intentions to continue some of the strategies adopted during ARPA. I don't have that in front of me at this moment, but I can get back to you on that.

However, I think it's still kind of yet to be determined in terms of whether states will really be able to follow through on those intentions.

COMMISSIONER SNYDER: Yeah, I guess given that the deadline is looming, I think that's something that might be interesting for a panel presentation over the course of the next couple of months, looking not only at what states are doing to extend some of the financing and payment strategies, but also how states used Rescue Plan

Act funding to extend non-financial strategies to address the kind of workforce concerns. Have we sponsored that type of panel?

EXECUTIVE DIRECTOR MASSEY: Just as a reminder, we have HCBS ARPA monitoring as an ongoing activity. We did have the panel last analytic cycle where we reviewed what efforts were being done at a federal and a state level about evaluating the investments made. We are still monitoring those activities, and we do plan on wrapping up the monitoring once states complete the run out of those funds, but we can take it under advisement.

COMMISSIONER SNYDER: Okay, great. Thank you.

CHAIR JOHNSON: Thank you.

Carolyn?

COMMISSIONER INGRAM: Thank you.

Thanks for continuing to put this together and bring it to us.

A couple of questions I had, just back to comments that I think my colleagues have had around, you know, states are very strapped. The system is very strapped. Are there other ideas or things that we can look at, a little bit to what Jami was talking about, to remove

barriers or other tools that are used besides just the rates and the financial reimbursement?

And I don't know if that fits under the scope of this, but I'm thinking of things like scholarship programs or some of the items our colleagues brought up about, you know, further training or things like that that help make it easier for people rather than just the financial rate discussion about can we keep just reviewing rates and then find out they're not adequate, but then what is going to happen with that? Are there other tools that can be employed?

CHAIR JOHNSON: Thank you, Carolyn.

John and then Angelo.

COMMISSIONER McCARTHY: A couple of things. One, great work, and this is a super complicated subject. Having been one of the consultants who set rates way before I was Medicaid director and then doing these things and building them from the ground up, it is always difficult to do those and try to hit on those. So I think you hit on almost every topic I would have brought up.

There's just a couple, though, that I also wanted to bring up, and that is, one, when designing rates, you

can design rates that hit all of those topics that you talked about, right, which you had the different issues around travel or experience, things like that. The issue then becomes the rates become so complex that providers get upset because you'll have a rate chart of like a thousand different rates that you'd have to bill for each person.

So just little things, like when a person starts, they might be making -- I'll make it up. I don't know what the numbers are, but they could be making $12 an hour, but if they're in the job for five years, they might be making $18 an hour. So how do you have a rate that takes all of that into consideration?

There's also the issues you run into around when you're rate setting. As it was talked about, you're setting rates for the I/DD waiver, but the aged waiver isn't doing rate updates, especially around nursing services. Nurses can go to hospitals. Those are really hard rates to set because of all the different places and the fact that you've got more commercial payers in hospitals and some other places. So you're competing with the commercial market also, which we're also starting to see competition for commercial market in just home- and

community-based services, right, because many people, as we're aging, are getting HCBS services not through Medicaid, just through private pay.

One of the last things is I know a couple of people brought up, they want to see what people are actually paid or cost reports. Cost reports are also a little bit dangerous to work with from the standpoint of you're looking at costs. If you're setting rates off of costs, then there's the incentive to continue to just raise costs. You might say, well, wait a second, the rates don't cover it.

But I'll just give you examples of when I was doing this, and you would have two entities. One is a nonprofit who can do fundraising. So when we were looking at cost reports, we couldn't figure it out. Their costs were twice that of other entities, and we were like, how can they be staying in business? Well, it's because they did fundraising, and so do you take those costs that are twice as high and average it into the rates, but then you're underpaying them but overpaying other people? So again, it's very complicated in some of these things.

I think the questions you have are good questions

for us to take a look at, but it is a very complex subject when we get into some of these, and it will be interesting to see what our recommendations are.

COMMISSIONER GIARDINO: Again, thank you for the work.

I wonder if -- you know, looking at some of your questions, you've talked about CMS and Congress. I wonder if we can also look at other entities in the federal government that may be commenting on some of this. Like, this workforce issue is certainly related to Medicaid, but it's a much bigger issue than Medicaid, and I think Patti was referencing some of that.

I don't know. I assume it's the Department of Labor, the Department of Commerce. I mean, there's other entities that I think are looking at workforce issues, and I wonder what the key drivers are to Heidi's point of making this a middle-class career.

There are experts in how the workforce works, and I don't think that's a domain of Medicaid. So can the federal government help us so that we could be efficient here? So what are the three, five, seven things that you have to do to make a career pathway?

And we might have a little role in Medicaid to suggest something related to the rates, but there are many, many other domains related to the workforce. I'm sure you're aware in mental health, for example, many of the states are coming up with different pathways for licensure and approving people to work in mental health because there's such a crisis there.

But I would just encourage us to look to the federal government, which you're part of and we're part of, and see what else they're doing because I suspect there's like a 30-page report from the Department of Labor in how to fix one of these frontline positions. So if you could just look at that, that would be helpful.

CHAIR JOHNSON: Thank you, Angelo.

Dennis?

COMMISSIONER HEAPHY: Thanks.

I'd also like to see what percentage of folks are full-time versus part-time. I don't know if you can access that data or not, but I think that makes a difference. And I think that's it.

CHAIR JOHNSON: All right. Thank you.

All right. Any other follow-up questions from

anyone else?

[No response.]

CHAIR JOHNSON: Okay. All right. Well, thank you both again for this great session. We appreciate it.

MS. ROGERS: Thank you.

MS. LIEBMAN: Thank you.

CHAIR JOHNSON: Okay. So you know the holidays are upon us when you get your MACStats. So really looking forward to Asher and Chris walking us through some of the highlights.

HIGHLIGHTS FROM THE 2024 EDITION OF MACSTATS

* MR. WANG: Hi. Good morning, Commissioners.

Today I'll be presenting on our key findings from the 2024 edition of MACStats, our Medicaid and CHIP data book. This year's MACStats is scheduled for release next Wednesday, December 18th, and for members of the public, we will have MACStats both compiled as the published book and separated into individual tables on our websites. Most of the tables will have both Excel and PDF versions for your convenience.

MACStats is our regularly updated end-of-the-year publication that compiles a broad range of Medicaid and

CHIP statistics from multiple data sources, including census, enrollment, survey, and national- and state-level administrative data.

Listed on the slide above are the six sections of MACStats. Key statistics of this year's MACStats show similar results to last year. These key statistics focus on Medicaid and CHIP enrollment spending compared to other payers, Medicaid's share of state budgets and more.

In fiscal year 2023, over 32 percent of the U.S. population was enrolled in Medicaid or CHIP at some point during the year. Looking at the state-funded portion of state budgets, Medicaid was a smaller proportion compared to elementary and secondary school education. Medicaid and CHIP combined were a smaller share of national health expenditures when compared with Medicare as well.

And moving on to the trends in Medicaid and CHIP enrollment over time, we can see the impact of policy responses and the unwinding. Compared to July 2013, Medicaid and CHIP enrollment was around 38 percent higher in July 2024. Most of this increase happened during the initial years after the bulk of the ACA expansion.

Enrollment in Medicaid and CHIP had peaked during

the continuous coverage requirement, and most recently, as states began to redetermine eligibility for beneficiaries following the end of the continuous enrollment requirement, the number of Medicaid and CHIP enrollees have significantly declined.

From July 2023 to July 2024, enrollment in Medicaid and CHIP decreased by around 14 percent, or 12.5 million enrollees. This follows a 2 percent increase in Medicaid and CHIP enrollment from July 2022 to July 2023.

Looking further into growth trends, this graph shows growth trends in Medicaid enrollment and spending. Overall, spending and enrollment have had complementary trends, both rising and falling in tandem. The trends reflect policy changes and economic conditions, such as economic recessions and policies to expand and preserve Medicaid coverage.

In this graph, spending for health programs are compared with spending for other components of the federal budget for fiscal years 1965 through 2023. In general, the share of the federal budget devoted to Medicaid and Medicare has grown steadily since the programs were enacted in 1965, and Medicaid spending continues to account for a

smaller share of the federal budget than Medicare.

In fiscal year 2023, the share of federal spending on Medicaid and CHIP increased from the prior fiscal year. This recent growth reflects an increase in federal Medicaid spending from greater enrollment and the provisions of the Families First Coronavirus Response Act, as well as a large decrease in other federal spending related to pandemic relief.

We also looked at various characteristics of program enrollment and spending. As of July 2022, nearly three-quarters of enrollees were enrolled in comprehensive managed care, and this accounted for over 50 percent of Medicaid benefit spending.

LTSS users accounted for only 4.8 percent of Medicaid enrollees but almost 30 percent of all Medicaid spending. That is, $219 billion was spent on services for these 4.5 million enrollees. I will note that this estimate only includes enrollees using LTSS services under fee-for-service arrangements and does not include those receiving LTSS under a managed care arrangement.

In fiscal year 2022, the new adult group, which applies to states that have expanded Medicaid, accounted

for about 26 percent of Medicaid enrollees and 23 percent of spending.

In fiscal year 2023, drug rebates reduced gross spending by about 51 percent. We also saw that in fiscal year 2023, DSH upper payment limit and other types of supplemental payments, such as those made under Section 1115 waivers, accounted for over half of fee-for-service payments to hospitals.

Total spending for full-year equivalent enrollees across all service categories ranged from $3,786 for children to $25,483 for the disabled eligibility group. Spending for managed care capitation payments was the largest service category across all eligibility groups.

In 2023, we saw that 35 percent of Medicaid enrollees had annual incomes less than 100 percent of the federal poverty level, and 50 percent had incomes below 138 percent of the federal poverty level.

As of July 2024, 40 states and D.C. have expanded Medicaid and now cover the new adult group, which is one more state than last year.

MACStats also reports on beneficiary health, service use, and access to care using survey data from the

National Health Interview Survey and the Medical Expenditure Panel Survey.

In 2023, children and adults with Medicaid or CHIP coverage were less likely to be in excellent or very good health than those who have private coverage. Children with Medicaid or CHIP coverage were as likely to report seeing a doctor or having a wellness visit within the past year as those with private coverage and more likely than those who were uninsured. And while most children with Medicaid or CHIP had coverage had a usual source of care, they were less likely to have one compared to children with private insurance.

Children and adults with Medicaid or CHIP coverage, we also saw were as likely to report no difficulty reaching their usual medical provider by phone during business hours as those covered by private insurance.

And this is our figure notes and sources. Thank you.

CHAIR JOHNSON: All right. Thank you very much.

All right. Any questions or insights from the Commissioners?

Yes.

COMMISSIONER GIARDINO: I just want to thank you for MACStats. Many of the people I work with really look forward to the publication of the statistics, and they use it in both their advocacy and academic work. So it's really become an authority in the field. So your effort is really very much appreciated. Thank you.

CHAIR JOHNSON: Thanks, Angelo.

Patti?

COMMISSIONER KILLINGSWORTH: I certainly echo that.

I have a quick question about managed care data since in one of the bullets you talked about it not reflecting managed care expenditures. So tell me a little bit about what to expect related to that.

MR. WANG: Yeah. So, the LTSS number that we reported was only for fee-for-service. But now that we've done the HCBS data run, we're planning to include the identification of LTSS managed care in our spending. And in the future, we may consider also breaking down the spending distribution of managed care. But it can become difficult when we're accounting for things like directed

payments and supplemental payments in managed care. But it's definitely something that we're considering for the future.

COMMISSIONER KILLINGSWORTH: Okay. Good. Thank you.

CHAIR JOHNSON: That's great. Thank you.

Jennifer. Jenny.

COMMISSIONER GERSTOFF: I may not be remembering right, but I don't think that MACStats in the past has had information on third-party liability coverage. Is that right?

MR. PARK: Yeah, that's right. We haven't broken out third-party liability.

COMMISSIONER GERSTOFF: Okay. So I was just thinking now that we have T-MSIS data, it gets better all the time, it might be useful to evaluate T-MSIS to see if it's worthwhile to try to summarize that information into charts for MACStats in future years.

CHAIR JOHNSON: Thanks, Jenny. Good call-out.

Heidi?

COMMISSIONER ALLEN: Thank you, Asher and Chris. I love MACStats.

Could you in future years consider in that chart that shows the spending in the services over time, have a separate category for duals? I just think that it's important with the aging of the population and the trends of more people receiving long-term services and supports in Medicaid to make clear that that is a shared relationship with the Medicare program. I think that there's a misconception among the public that Medicaid spending is growing so much because of the non-categorically eligible adult population or expansions to children or expansive to postpartum people.

But I think it's, as we know, the dual population is a considerable amount of expenditures for the Medicaid budget, and I just feel like if that’s reflected -- not that one. It was the -- it was the line graph, that one, yeah -- or the other one, the one that has -- that one right there.

Because you can see that like CHIP is so cheap. Look how cheap CHIP is in there, and I think that if you could see Medicaid, that what you would see probably is that relationship.

If you said duals there, had Medicare, CHIP, and

duals as part of the Medicaid, I think that would be really interesting to see.

MR. PARK: I would just want to point out Exhibit 21 in MACStats does have like total spending broken out by eligibility group, and it does show it for the dually eligible beneficiaries and would also put a plug in for the Duals Data Book that we publish in conjunction with MedPAC.

CHAIR JOHNSON: Tricia?

COMMISSIONER BROOKS: I just want to add my kudos. We love MACStats, and I'm just curious if we're going to have a Christmas present in the mail with a hard copy.

CHAIR JOHNSON: That's what I heard. It's available next Wednesday, right?

[Laughter.]

COMMISSIONER BROOKS: Thank you.

CHAIR JOHNSON: Okay. Thank you.

All right. So with that, Asher, do you want to remind us again how people can access the MACStats?

MR. WANG: Yeah. So it's available on our website as both Excel and PDF versions.

CHAIR JOHNSON: Very exciting. Thank you again

for a great holiday gift.

Anyone else before we close it out?

[No response.]

CHAIR JOHNSON: Okay. Thank you both again. Again, this is obviously very exciting for all of us. So it's a great way to end our meeting today. We appreciate it.

So with that, let's go to our public comments. We will open it up. We invite you in the audience to raise your hand if you have any comments to offer. We do ask that you introduce yourself and the organization that you represent, and we also ask that you keep your comments to three minutes or less.

So, with that, any comments? We do. We have one from Lindsay Jones.

PUBLIC COMMENT

* MS. JONES: Hello. Yes. My name is Lindsay Jones. I am a co-chair of the Federal Advocacy Committee with the National Academy of Elder Law Attorneys, also known as NAELA. I am a practicing elder law attorney from just outside Cleveland, Ohio.

My comments pertain to the session on timely

access to home- and community-based services.

So NAELA strongly supports MACPAC's efforts to improve timely access to HCBS, and we want to express appreciation for the great work you're doing on this subject. Improving access to HCBS is one of our core policy priorities, and speeding up the receipt of services is particularly important as part of the overall issue.

While we would support a potential recommendation around CMS guidance for provisional plans of care, NAELA's view is that conversations around improving timely access should focus not on the take-up of any specific authority, but rather by addressing the operational and procedural difficulties associated with aligning the financial assessment, functional assessment, and person-centered services plan development.

So I'd like to offer Ohio as an example. So we have presumptive eligibility involved with our PASSPORT home- and community-based services program. PASSPORT is a program that offers a maximum of four to six hours of daily in-home care services. So that's the amount of assistance that people can qualify for if they receive those services.

Presumptive eligibility as part of that program

can offer up to 90 days of those services to be provided to an applicant while their financial eligibility is being determined. However, the applicant must first be determined eligible for all non-financial requirements. So that means that they have to jump through all of the hoops involved of the functional assessment process and the development of a person-centered services plan before any services can actually kick in.

The unfortunate reality of that situation is that it can take weeks to complete the non-financial eligibility portion, at which point the financial eligibility determination has typically been completed, and that negates the need for presumptive eligibility in the first place.

So what we see in Ohio is often that despite having presumptive eligibility with PASSPORT, it's almost never used. It simply doesn't come into consideration because of the timing concerns involved. So the applicant does not receive services at an earlier point in that process, despite the availability of presumptive eligibility. That means that the gap in service is not addressed for them, and it leaves them in a vulnerable

situation, which often results in a period of short-term hospitalization or even long-term institutionalization because they have a period of four to six weeks typically where they have no supports, despite the fact that they were eligible for the same and in need of them.

The idea of using provisional plans of care would better address this gap in services by shortening the approval of presumptive eligibility services, typically by two to four weeks. That would allow services to offer that support to allow the applicant to remain in the community while their financial eligibility is determined and a formal person-centered services plan is established. In our view, that short but critical amount of time would assist in avoiding unnecessary institutionalizations and other adverse outcomes.

In addition, as some Commissioners and stakeholders have shared, the financial eligibility determination can also be a primary source of delay. Regarding that concern, educating state agencies as to the requirements and state options, allowing for self-attestation by applicants, ex parte reviews and renewals via electronic asset verification systems and electronic

service may also be effective.

CMS guidance would be a helpful starting point and would lead the way on this issue, but ultimately to make progress, we will require a long-term effort to understand and respond to specific operational considerations and challenges in each state as HCBS programs are incredibly state-specific.

Again, we appreciate the opportunity to speak and will be submitting written comments in the coming days. We stand ready to be a resource or connect MACPAC with legal professionals who are on the ground in various states and are assisting HCBS applicants every day.

Thank you.

CHAIR JOHNSON: Thank you for your comment.

Do we have any additional comments?

[No response.]

CHAIR JOHNSON: All right. Seeing none, I do want to remind you that if you do have additional comments later, you can definitely feel free to submit them to our MACPAC website.

And with that, I want to thank you all for attending today's meeting and yesterday's meeting as well.

Hope you have a great weekend, and we wish you all a wonderful holiday season. We'll see you in the new year.

* [Whereupon, at 11:40 a.m., the meeting was concluded.]