Recommendations for States as They Create Medicaid Beneficiary Advisory Councils: Thoughts From People With Medicaid Experience Who Have Served on Medicaid Committees

Prepared by The Baruch College Medicaid Lived Experience Learning Team

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Introduction

When the Medicaid program began, almost 60 years ago, Medical Care Advisory Committees (MCACs) were created to provide "specialized knowledge and experience" to state Medicaid agencies. Since 1971, states have been required to include members of consumers' groups, including Medicaid recipients, on their MCACs.

Over the decades, there has been substantial variation across states in the extent of including people with Medicaid lived experience (PME) on MCACs (link, link, link, link, link). For example, a 1979 survey found that PME made up at least one-fifth of the MCAC members in 12 states, while MCACs in nine states had no PME representation. Similarly, interviews conducted in 2019 with staff from 14 state Medicaid agencies found there were still states with no PME members on their MCACs, while other states embraced PME participation, developing subcommittees composed exclusively of PME. State leaders who engaged PME reported practical benefits of doing so; "…if we're not talking to the people who are directly impacted by it, we're missing nuances, potential gaps, or inadvertent issues that we wouldn't have anticipated," explained one leader.

To address the problem that "the current MCAC requirements are insufficient in ensuring that the enrollee perspective is meaningfully represented," the federal Centers for Medicare and Medicaid Services (CMS) issued a new rule in April 2024. The rule requires that all states establish a Medicaid Beneficiary Advisory Council (BAC) by July 2025, which is comprised of Medicaid enrollees (current and former), their family members, and caregivers. CMS described the purpose as "to advise the State Medicaid agency on matters of concern related to policy development, and matters related to the effective administration of the Medicaid program." The rule reflects the understanding that the lived experience of enrollees offers policymakers and administrators insights into how programs operate (link, link, link).

The new CMS regulation includes additional requirements that aim to create more consistent structure and transparency for state BACs and Medicaid Advisory Committees (MACs)—the new name for the MCACs.[1] Notably, BAC members must initially constitute 10% of the MAC membership, and the required percentage of BAC members serving on the MAC increases to 25% within two years. State Medicaid agencies are also required to set term limits for BAC members and members cannot serve consecutive terms. The BACs are required to meet at least quarterly and ensure that meetings are accessible to people with disabilities and those with limited English proficiency. Additionally, Medicaid agency staff must provide "appropriate support and preparation…to the MAC and BAC members who are Medicaid beneficiaries to ensure meaningful participation" including "financial support, if necessary." It is not yet clear whether the new Trump administration will attempt to change the rule, delay its implementation, or limit enforcement of the rule.

Assuming that states will proceed with the creation of BACs, creating BACs will be a new and substantial undertaking for most state Medicaid agencies. Since there is a lack of research on effective ways to design and engage PME on BACs, we sought to learn directly from PME who have served on existing MACs and BACs, as well as from individuals who have supported PME on these types of committees. We wanted to understand what they feel has worked well—and what has not—about these committees and what recommendations they have for states. To do so, in the summer of 2024, we interviewed 23 people from 12 states. This included 15 PME who serve on MACs or BACs (seven on each type and one on both), three people (from nonprofit organizations or PME) who lead BACs in their states, one public member on a MAC, and five people who work at nonprofit organizations and support PME who serve on MACs and BACs.[2]

PME's experiences. PME's experiences serving on MACs and BACs varied widely. Some described the experience extremely positively: they felt heard, built connections with agency staff and other committee members, and felt empowered when committee actions resulted in Medicaid improvements.

There were, however, PME who described the experience as extremely frustrating. A woman serving on a BAC commented, "Another meeting over, they didn't actually take anything of value from us. They totally could have, there was…gold to mine from our experiences." She continued, "When you feel like you're wasting your time for three hours a month…you just want to get out."

PME felt that the committees were effective and meaningful when agency staff valued their perspectives and experiences, and when committee input led to improvements in the Medicaid program. One PME described how powerful this combination could be:

> "You build trust by giving someone real space and real time to give real feedback that's going to be used, and then showing them how it's used. And then they see like, wow, they actually care about my opinion and my experience."

Interviewees described the following four elements as crucial for creating effective and meaningful BACs: including critical meeting components, providing supports for PME, making PME feel comfortable and valued during meetings, and using inclusive administrative approaches.

Including Critical Meeting Components

PME described three critical components of BAC meetings: Being able to provide input on issues raised by the Medicaid agency, having the opportunity to bring up issues that they believe the agency should know about, and receiving updates on how the agency responded to their prior suggestions.

Providing input on issues. PME appreciated when Medicaid agencies gave them the opportunity to "collaborate on problem solving around an issue that the Medicaid…departments are encountering." Common requests for input included reviewing drafts of agency letters and providing feedback on the agency's website. The head of one state BAC emphasized the value of dedicating half of the meeting time to "items that the [Medicaid agency] needs input on, maybe a new policy or legislation, or 'We're hearing from our hotline that people are having XYZ. What's your experience with this?'"

It was frustrating to PME when there was not time to provide feedback on issues raised by the agency because the "people coming to speak…eat up all the time talking" or because better facilitation was needed to "help herd the cats….and keep us on track." Several interviewees also highlighted the importance of Medicaid agencies seeking PME feedback early in agency processes, and not using them as a "rubber stamp" for decisions already made.

Bringing issues to the Medicaid agency's attention. PME valued the opportunity to bring issues to the Medicaid agency's attention during meetings and were frustrated when the agenda was too "rigid" to be able to do so. As a PME framed it, "I think it's the one place where we get to lead, and then we kind of drag the agency along with us to some extent."

Some BACs facilitated this by allocating specific time in each meeting for PME to raise issues. During a BAC meeting we observed, the chair said, "I always want to make time in the meetings for people to fully bring issues here." She continued, "We're kind of the informal net to pull up issues from the bottom of the ocean and then we push them up to be sorted at the fish processing plant."

Other committees incorporated PME input into the agenda-setting process by inviting PME to add items or circulating draft agendas for review. A PME described how encouraged she felt when a topic she requested to learn more about

was included in the agenda: "That was a really positive thing, because often times as a humble parent and caregiver, you go out and start trying to ask questions [on your own], and you don't get that clear…information."

Receiving updates on prior suggestions. Having a feedback loop about what happened to prior suggestions was extremely important for PME. Even if the agency could not implement the recommendation, PME appreciated explanations like, "We couldn't do exactly what you asked for but here's why we couldn't do it, and here's why we did what we did." The chair of a BAC described the positive impact on members when they were shown an updated version of the Medicaid website they had previously reviewed: "We had members with tears rolling down their face because they're like, 'Oh, my gosh! You actually listened to what I said and implemented it.'"

Several effective feedback loop approaches were described. One approach was keeping a document that tracks ideas that have been raised and the resulting changes. Another approach was starting each meeting with a report on the issues discussed in the last meeting and the actions taken in response.

PME found it frustrating if they did not learn how—or if—their feedback was being used. It raised questions about whether the council "is just kind of a performative, bureaucratic thing." One PME explained, "If people start to feel like…I'm not making a meaningful contribution, well, I'm not going to continue to participate, because I've got a million other things to do."

Providing Supports to PME

Many PME noted that the complexity of the Medicaid program sometimes made it challenging for them to participate in meetings, especially when they were new to a committee. One PME commented, "The first meeting I [felt] like, 'Oh, I'm late to class,' and this was because there are so many acronyms." Another highlighted the complexity of "policy versus regulations, versus what CMS says versus what state says, versus what an operations memo from the department indicated that the managed care organizations have to do."

To address the complexity, interviewees highlighted the importance of Medicaid agencies or nonprofit staff providing a variety of supports for PME as they serve on BACs. These supports include orientations, accessible meeting materials sent in advance, and individualized support before, during, and after meetings. As a nonprofit staff member put it, "It's great to require [PME] participation, but without the appropriate training and support…I don't know what it's worth."

BAC orientation and goal setting. Interviewees recommended that states provide an orientation for PME when they start serving on BACs. In addition to introducing PME to a range of Medicaid topics including the structure of and key staff at the state Medicaid agency, PME would appreciate learning about state Medicaid policymaking prior to serving on Medicaid committees.

As part of the orientation, PME also thought it would be helpful to learn about the goals and limits of the BAC, as well as what is expected of committee members. "So what is this BAC going to do?…If it's going to be about changing the system, what does that change look like? Put some fences around it right? Like, be real, be honest, be clear about it," a PME commented.

Additionally, another PME highlighted the value of being oriented to meeting norms and practices. Her state meetings follow *Robert's Rules of Order,* and she explained, "While that may be commonplace, for me it wasn't, so I was like, 'Wait, what's going on?'"[3] Relatedly, several staff who support PME thought that orientation and training should help PME learn to advocate for themselves and encourage them to feel "empowered to say, 'I need you to slow down, or I don't understand that'" during meetings.

Accessible meeting materials sent in advance. Receiving meeting materials well ahead of meetings is highly valued by PME because it gives them time to review and process the topics. One PME explained, "Usually two weeks before [the meeting] we'll get the agenda and the slides so that we can review everything…And it's great, because we can always go back to [the materials] and reference [them], which has been really helpful…and we can ask questions [and] feel really well informed."

Additionally, it is important to PME that meeting materials are clearly written and made available in accessible formats such as Spanish, braille, and large print. A PME emphasized the importance of accessible materials commenting:

> "It's very important if you want a person with a disability [serving on a BAC] that has a hard time reading—and I'm guilty. I have a hard time reading. So, I'm gonna let you know up front, so you can break it down where I can understand it and don't use every alphabet acronym."

Meeting support for PME. The importance of offering personalized support for PME before, during, and after committee meetings was emphasized repeatedly during our interviews. Depending on the state, these supports were offered either by state staff or staff of a nonprofit organization contracting with the state. A nonprofit staff member who supports PME on a state committee explained, "I feel like everybody needs a different level of support…for some people you have to really do a ton of conversation ahead of time."

We heard many examples of effective ways that staff provided support to PME on committees. For example, one nonprofit staff member called PME to discuss the meeting agenda with them in advance. Staff from another organization used what they called the "post-it note strategy," where staff would "put post-it notes on different [parts of the meeting materials] to help remind folks, 'Oh, that's right. I had a question about this.'"

Another highly valued strategy was having a BAC pre-meeting facilitated by nonprofit staff prior to the formal BAC meeting.[4] A PME whose state contracts with a nonprofit to host pre-meetings explained, "We just review the issues and get background knowledge and information so that when we actually participate in the state meeting we're up to speed. We understand the context of the topics that we're talking about."

During committee meetings, nonprofit staff described supporting some PME by sitting next to them to "whisper to [the PME] or point to something." For remote meetings, nonprofit staff described texting with PME "so that when stuff comes up, they can ask [a] question and I can quickly explain it." One PME, whose health condition makes it difficult to type, said it was important for him to have someone he could text, using talk-to-text, and the person could post his comments in the chat.

After the meetings, a nonprofit staff member described holding debrief calls where she asks the PME she supports, "Did you understand all the things? Was there anything that came up that you wanted to talk more about? [Are there] other ideas that you have that work to respond to this?"

A PME who missed several BAC meetings explained that the state staff who facilitated the meetings reached out to her to check in. This made her feel valued because the state staff "was very aware and involved with all of the people in the program" and was able to help her solve a personal issue so that she could continue participating on the BAC. Several PME suggested that it would be useful for state or nonprofit staff to hold standing office hours to answer questions about committee issues.

Making PME Feel Comfortable and Valued During Medicaid Meetings

PME described feeling comfortable and valued during meetings when they had positive relationships with other attendees and when meeting facilitators created a supportive meeting environment, encouraged PME to share their perspectives, and ensured that PME felt heard.

Building relationships. Many PME described the benefits of developing relationships with meeting facilitators, Medicaid agency staff who regularly attended, and other committee members. One PME shared, "the stronger my relationship….the more I'll feel comfortable participating." Another PME explained the value of connections with agency staff: "We have an established rapport with the [Medicaid agency staff]. Overall, I think that there's a level of respect and understanding about where each entity is coming from."

A PME on a BAC described how the committee facilitator went "above and beyond" and built a "relationship with each person" outside of committee meetings. A staff member who supported PME on the MAC recommended that any Medicaid agency staff who regularly attend BAC meetings "interact individually" with PME and "[get] to know every single member of that BAC." Interviewees highlighted that having informal "chats" before and after meetings, as well as during breaks, when "people are just gathering and visiting," is an effective way to build relationships, particularly when meetings are in-person.

A few PME appreciated the importance of creating "community spirit," but felt that their BAC meetings sometimes spent too much time on building relationships. "We would have more time for what I feel like we're really there for, which is talking to these people about Medicaid policies and things," one PME explained.

Creating a supportive meeting environment. PME were thankful when meetings were facilitated in a caring and supportive way. For example, one PME appreciated that her BAC began each meeting with a brief personal opener: "You know it's kind of validating to know that you're not the only one that's being pulled in a million directions….Then, more people feel comfortable sharing…their perspective." Another PME valued that his meeting facilitator gave "people a soft landing for a lot of really serious topics" by ending the meeting with an "activity where everybody kind of gives their feedback and there's some closure to it."

Several PME mentioned the importance of facilitating meetings in a way that is "trauma informed" because "the trauma that is in this population is so high."[5] As a PME explained, "I think the trauma informed model needs to be front and center, and I think [my state] does a pretty good job of that…[but] you occasionally get people coming from more bureaucratic angles that might not quite get it."

Encouraging PME to share their perspectives. Interviewees stressed the importance of facilitators actively encouraging PME participation during meetings. A nonprofit staff member described asking committee members about when and how they prefer to share during meetings so that during a meeting she can facilitate their participation in the way and at the time that works best for them. "That's helpful for me, because I get the best information out of folks if they're feeling prepared and comfortable with the timing of what they're gonna be sharing," she explained.

Another approach we observed, which sparked interesting dialog, was a facilitator inviting people to contribute. "I want to encourage our new people here to speak up and speak out," said the facilitator, "Do any of our new people have something that they brought to the meeting that you want to talk about?"

Helping PME feel empowered to ask questions or to help set the pace of the meeting was another component of encouraging PME to share. A nonprofit staff member recounted telling a PME she supports on a committee, "Your lived experience is all of the expertise you need, and…if you have a question about something, ask that question because

you are likely not the only person who has that question." Interviewees also recommended that facilitators actively encourage PME to indicate when they need the presenter to slow down—either using an icon on Zoom or holding up a small card during in-person meetings.

Ensuring PME feel heard. Many PME highlighted the importance of feeling heard when they spoke in meetings. "Just…making people feel heard makes a big difference," explained a PME. A PME described how the facilitator of her BAC effectively achieved this: "She would just kind of listen and take things down and say, you know, we're going to handle it or look into it, and I think she followed up enough, and she was consistent behind the scenes." Another PME praised the leader of her committee: "She's very quick to say, 'That's a really good point…She's very respectful of the contributions that people make.'"

PME particularly appreciated when the Medicaid director was present. "It made me feel like our input was actually being taken seriously," one PME commented. In contrast, however, it was very frustrating to PME when agency staff did not show their videos or were not actively participating. One PME explained that in some meetings "there are other Medicaid employees joining in, but not saying anything…'Why are you on the call if you're not going to say anything?' It's like they're not even listening."

Interviewees also reported that agency staff did not always respect when they shared their Medicaid experiences. "There's sometimes when staff…when you're sharing a lived experience, they'll try to either shut you down or kind of diminish that, as being, 'Well, that doesn't happen to everyone,'" explained a PME, who countered, "Well, how do you know it doesn't happen to everyone?"

Using Inclusive Administrative Approaches

Interviewees highlighted the importance of using inclusive administrative approaches, specifically having a diverse BAC membership, having multi-year membership terms, offering a variety of meeting formats, collaborating with PME to determine meeting times and frequency, scheduling breaks during meetings, explaining acronyms and technical language, and compensating members for their participation.

Diverse membership. Almost all of the PME we interviewed stressed the importance of a diverse committee membership to ensure that issues faced by all types of PME are heard. One PME explained that the diverse membership of his BAC "adds a lot to the richness of the discussion that we have…If you have a more representative set of members on any given committee, then you have a better chance of capturing a truly representative sample of how we're all working through this system."

Interviewees felt it was important to define diversity broadly and include members of different races, ethnicities, ages, health status, and types of Medicaid eligibility. Additionally, interviewees thought it was essential to have representation from people who were Medicaid recipients themselves, as well as those who were caregivers of Medicaid recipients. The value of including members from rural, urban, and suburban areas was also emphasized repeatedly.

Multi-year membership terms. Many PME expressed that it took time to get comfortable and participate effectively on MACs and BACs. One PME explained, "You're just learning for the first two years…It probably took me almost three years…just to even be able to understand the massively complex systems that you're supposed to be advocating to improve. You really need that time to just learn."

Given Medicaid's complexity, several PME emphasized the importance of serving for several years, especially since the CMS final rule does not allow consecutive terms. "I can't stress enough how important it is for people to have some years to serve on a committee like this in order to be an effective advocate," one PME shared. Another PME added, "As long as someone's willing, and actually committing to participating, I think they should be able to stay on the [committee]."

Collaboratively determining meeting times and frequency. A PME highlighted that it is important to have meetings at times that work for most PME. One PME explained, "[At] 10 or 11 a.m. on a Tuesday morning, most people who are on Medicaid are going to be working, or they're going to be caregiving, or they're going to be doing something that doesn't involve sitting in a state meeting."

Interviewees recommended that meeting times, as well as meeting frequency, be collaboratively determined with PME. This was the approach used by the facilitator of a BAC that meets on Saturdays. "We asked the families, 'When can you come?'...Certain ones could have done it during the week, but to get all of them we had to do it on Saturday." Interviewees recommended that facilitators be flexible and change approaches based on member feedback.

Offering a variety of meeting formats. Some of the PME we spoke with preferred in-person meetings, others preferred virtual meetings, and still others liked hybrid meetings best, lending support to the requirement in the CMS final rule to use a variety of meeting attendance options.

PME described the benefits of in-person meetings as they "make you more comfortable," provide "a unique opportunity for relationship building," enable "those side conversations," and let you "see each other's faces and read each other's responses in a more personal way." However, in-person meetings are less accessible for PME who live far from the meeting location, are caregivers, or who have a disability. One PME who preferred in-person meetings, commented that it would be too "difficult [to attend] just logistically because of the medical needs of my son." Another explained, "If [meetings] go back to being in person, I can't attend. I'm too disabled."

PME appreciated meetings with both in-person and virtual options because they ensure that "members who cannot be there in person…can still participate, and their voice is still heard." One PME described another accessible approach used by his state, which addresses the problem of emergency health issues experienced by PME or their children. The Medicaid meetings are recorded, and if members cannot attend the meeting, members can watch them afterward and provide comments within a week.

Scheduling breaks in the meetings. Interviewees, particularly those with disabilities or who work with people with disabilities, emphasized the importance of scheduling breaks during the meetings. A PME emphasized the importance of having the breaks scheduled at specific times: "Because there's predictability in the schedule. You know when the breaks are happening. If you have needs you need to take care of, you know when you can do that."

Another staff member mentioned that breaks can be valuable for helping PME participate more fully in meetings because they provide an opportunity to catch up if something is unclear: "When you take that break the individual can say to their supporter or another member in the room, "Hey, can you tell me what this means? I'm struggling with that."

Explaining acronyms and technical language. Many PME highlighted how confusing the Medicaid-related acronyms and other technical language were during committee meetings. Beyond ensuring that meeting materials defined acronyms, they suggested that agency staff and presenters remember that they are speaking to people on committees "who don't do this for a living." One PME explained, "You can use acronyms, but can you break those acronyms down where we can understand it?" One state uses the Zoom chat during BAC meetings to provide definitions of any acronyms used during the meeting.

Compensating members. PME overwhelmingly viewed compensation for serving on advisory councils as important because "it shows how much they appreciate what we're doing" and "that your time is of value." Additionally, a PME commented, "They might be able to get a broader voice by offering some kind of compensation."

PME thought that compensation should include all costs associated with attending a meeting, including "compensation for people's time, personal assistance, interpreters," as well as travel costs such as hotels, gas mileage, and food. Several interviewees highlighted the challenge for PME of paying travel costs out-of-pocket. One nonprofit staff member described that her organization initially paid for a PME's travel costs to attend an in-person meeting "because he didn't have the money to put up front, so getting reimbursed didn't really work."

Several PME highlighted that they would appreciate quick and straightforward compensation systems that did not require printing, scanning, or waiting weeks for payment. The facilitator of one BAC described creating an efficient approach for payment. At the end of each committee meeting, PME use a QR code to indicate on a Google form what type of gift card they would like and whether they prefer it to be electronic or mailed, and the gift cards are promptly distributed.

Conclusion

For the first time in the history of the Medicaid program, federal regulation requires states to convene a council exclusively made up of PME so that agency leaders have a direct pathway to learning about PME's experiences seeking Medicaid coverage and healthcare. The requirement is scheduled to go into effect in July 2025, though it is unclear at this time whether changes will be made under the new Trump administration. The findings from these interviews are relevant regardless of the regulatory landscape, as states are already required to have PME on their existing advisory committees and a number of states already have a BAC.

What we learned from these interviews is that for BACs to be effective and meaningful, agency staff need to value their perspectives and experiences, and BAC input needs to lead to improvements in the Medicaid program.

Interestingly, many of the recommendations that we heard from PME and nonprofit staff for structuring BACs were consistent with what Medicaid leaders shared with Zhu and colleagues about successful approaches for engaging PME on Medicaid committees. These approaches include providing training for PME, investing time and staffing to effectively support PME, providing PME with compensation, holding meetings at times that accommodate PME's availability, building in a feedback loop, and partnering with nonprofit organizations that work closely with PME. The recommendations are also consistent with prior research on federally required consumer advisory boards for Ryan White funded HIV/AIDS Bureaus and University Centers for Excellence in Developmental Disabilities.

The leadership of each state Medicaid agency will need to take thoughtful actions to create an effective BAC. Leadership will need to commit staff to running the BAC who understand how to connect with, support, and work collaboratively with PME. Medicaid leaders themselves will also need to attend BAC meetings and listen carefully to BAC members. Many decisions will need to be made in the coming months ranging from the frequency and timing of meetings to the selection of topics for the BAC to address. Creating and running a BAC will require agency flexibility. A Medicaid agency staff member described her state's experience creating a BAC as a "long…and winding journey."

The PME we interviewed valued the Medicaid program and were honored to participate in Medicaid committees to "give back and pay it forward." They applauded the new BAC rule and the possibilities it provides for PME to influence Medicaid administration. They repeatedly expressed the hope that there will be buy-in from Medicaid agency leadership and that states will not treat the BAC as "checking a box."

Notably, states that have already created BACs have found value in them. A Medicaid staff member who chaired a BAC offered an explanation why: "We have all of our best minds and intentions to design our programs, but we don't really know how it's really going for members. The only way we can find out, is to listen." BACs provide an important opportunity for Medicaid agencies to ask questions, listen, and then act to improve the Medicaid program.

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ABOUT THE MEDICAID LIVED EXPERIENCE LEARNING TEAM

This issue brief was prepared by Jessica Greene, Diane Gibson, Nancy Aries, and Kori Mascheck, of the Medicaid Lived Experience Learning Team. The Learning Team, which is a grantee of the Robert Wood Johnson Foundation, studies best practices for gathering lived experience and using it in Medicaid advocacy and conducts research that uses lived experience as the basis for suggested improvements in Medicaid. The Learning Team members are affiliated with the Marxe School of Public and International Affairs at Baruch College of the City University of New York.

ENDNOTES

1. For simplicity, we use the new term MAC throughout this article, and we refer to existing BAC-like committees as BACs.
2. Semi-structured interviews were conducted over Zoom and lasted between 30 and 60 minutes. Audio recordings were transcribed. The authors coded the transcripts and identified key theme and subthemes.
3. States may want to consider forgoing formal meeting procedures for the BAC or using simplified versions of Robert's Rules of Order, such as this.
4. Those considering this option are encouraged to consult their state's open meeting laws to determine whether this approach complies with the requirements.
5. GUIDE: Trauma-Informed Meetings, Discussions & Conversations.