

[Music by Molly Joyce begins at 00:15]

Nick: Welcome to Included: The Disability Equity Podcast brought to you by the Johns Hopkins University Disability Health Research Center. This podcast challenges stereotypes of disability by sharing stories, data, and news. Each episode digs deep into topics to offer diverse perspectives and expertise to expand your view of disability.

Bonnie: We're your hosts. I'm Bonnielin Swenor, director of the Johns Hopkins Disability Health Research Center.

Nick: I'm Nick Reed, assistant professor at Johns Hopkins University Bloomberg School of Public Health. In this episode of Included we talk with MaryBeth Musumeci, associate director of the Program on Medicaid and the Uninsured at the Kaiser Family Foundation, now known as KFF. MaryBeth's work concentrates on Medicaid for people with disabilities, including issues related to people dually eligible for Medicare and Medicaid and long-term services and supports. Prior to joining KFF, she held the *[unintelligible 01:16]* Clinical Teaching Fellowship at Villanova University School of Law and spent eight years as a civil legal aid lawyer. Most recently she was the deputy legal advocacy director of the Disabilities Law Program at Community Legal Aid Society Inc. in Wilmington, Delaware, where her practice focused on Medicaid, Supplemental Security Income, other public benefits programs, and civil rights and accessibility issues. She received her B.A. with highest honors from Rutgers University and her JD from Harvard Law School.

[Pause 01:46 - 01:55]

MaryBeth, thank you so much for joining us today.

MaryBeth: Thank you so much for inviting me. I am happy to be here.

Bonnie: MaryBeth, we wanna start by having you tell our audience more about the work of the KFF Program on Medicaid and the Uninsured.

MaryBeth: Sure. As many of your listeners probably know, KFF is a non-profit, non-partisan source of facts and policy analysis, and we have a wealth of information that we make available to the media, to the health policy community, and also to the general public on our website. Then within KFF, the Program on Medicaid and the Uninsured focuses on those two key populations. We collect data;

we analyze state and federal policy on issues about health coverage and financing for people with low incomes and people who are uninsured, and with a particular emphasis on Medicaid and the children's health insurance program, CHIP.

Then within the Program on Medicaid and the Uninsured I specifically focus on issues related to people with disabilities and chronic illness. That really runs the gamut from eligibility pathways; state decisions about which benefits to cover; spending; state decisions about care delivery systems for long-term services and supports including Home & Community Based Services, as well as Medicaid's role for people who are eligible for both Medicare and Medicaid.

Nick: Oh, wow. You wear a lot of hats. We wanna focus in a little bit. Your team recently released a fact sheet earlier in December 2021 about how state policies are expanding access to behavioral healthcare. Could you share a little bit more about this, and why this effort is important?

MaryBeth: Sure. I'd also like to give a shout-out to my wonderful colleague, Madeleine, who was the lead on that paper. This draws on work that we've done over the years. We've had a long-standing interest in Medicaid's role in financing behavioral health services, and so including both services for people with mental illness as well as people with substance use disorder. Medicaid plays a very important role, of course, in covering non-elderly adults in particular with mental illness and substance use disorder. This has been a focus prior to the pandemic of ours, and of course with the opioid epidemic, it was an area of big state focus.

Then like with so many other issues, we've seen the pandemic add another layer to behavioral health needs, and so increasing needs as well as in some ways exacerbating existing barriers to accessing care. We wanted to take a closer look at state policy choices here. The paper is drawing on work that came out of our 50-state Medicaid budget survey, which is an annual survey that we do every year. We ask states specifically to highlight policy choices they were making in this area, and recognizing that many behavioral health services for adults are covered at state option.

What we heard from the states is that over half indicated interest in one of the new options in the American Rescue Plan Act, so that was the COVID relief legislation passed earlier this year. One of probably the lesser known provisions is that it creates a new option for states to provide community-based Mobile Crisis Intervention

Services. It also gives states enhanced federal funding to support them, so states could get 85 percent federal matching funds for the first three years.

As I said, over half the states expressed interest in potentially pursuing this option, which could be really exciting because the goal, as I understand it, is to increase access to services in the community and avoid institutionalization, and so having these services available in times of crisis to facilitate that. Also, just to put a side note as we're recording, the Build Back Better is still up in the air, but one thing that I believe is still in Build Back Better is it would make that new option permanent. In the rescue plan, actually it's time-limited. Then aside from that newest option we also heard a lot about states expanding behavioral health services across the care continuum, continuing to be focused on opioid treatments; mental health needs resulting from exposure to gun violence; initiatives focused on pregnant and post-partum people; and then services targeted to children with mental health needs as well. That's a few things that states have told us that they're doing.

Then the last point I'll highlight is the expansion in telehealth services, of course spurred by the pandemic, but also hearing a lot from states about considering continuing those policies after the public health emergency period eventually ends, and so thinking about what that could mean for ongoing access issues as well.

Bonnie:

Yeah. Thank you. It's so important, and I just wanna elevate for the audience that so often mental illness and substance misuse are not always linked to the disability community, but they certainly fall under the umbrella. Right? This is so critical for the work of disability advocates, disability research, and the disability community at large. Thank you so much for this work. These conversations don't always fall under that umbrella of disability, so thank you to you and your team, including your colleague who led this effort for this really important work.

Your team also has recently released a webinar and a fact sheet about new Covid-19 vaccination requirements for healthcare provider staff. Importantly this work notes, and I quote, "The new rule applies to Medicare and Medicaid providers that are directly regulated by CMS, and therefore does not reach all Medicaid providers such as certain Home & Community Based services, HCBS providers." Can you share more about this issue, and perhaps why this issue may be of particular importance to the disability community?

MaryBeth: Yeah. Thank you for that question. I think it's one permutation of an overarching issue that we've seen playing out through the course of the pandemic, and I think it's work that you have also been following in your center as well. One thing that I think the pandemic has done is bring to the forefront concerns about people who are living in institutional settings, and so that has primarily been seniors in nursing homes. Right? There has been a new attention to that, a renewed focus on that among policy makers. It's been covered in the news, so a renewed focus among the public. I think even though the challenges and concerns there predate the pandemic, they were heightened by the pandemic and have been brought into a new light. We saw this in the cases in deaths data, where people in institutional settings were disproportionately affected and have a very high share of COVID-related deaths.

I think what got less attention was the fact that this was also true in congregate community-based settings, so settings like group homes and assisted-living facilities. Across the care continuum, there are congregate-based settings in the community that shared some characteristics with the nursing homes in terms of people's needs, the services that workers were providing. You know? People had similar needs in terms of assistance with dressing, eating, that require really close contact and supervision that create those similar risks. What we saw is some states have data on some of these settings; there are a lot of gaps. There are definitely limitations, but I think generally we saw a lot. Then based on the data that we did have, we saw a lot of similarities in terms of how the pandemic is impacting folks across the care continuum.

Then we saw that issue again when states were developing their COVID vaccine priority plans. People with similar risk factors, some living in institutions, some living in the community. Many, most states were prioritizing seniors and people in nursing homes. On the other hand, very few were mentioning people in the community, whether that was people who are in group homes or people who are receiving in-home services. This most recent regulation in response to the pandemic, I think, also raises that kind of similar issue in terms of how we're responding to providers and creating policies that address the full care continuum. Initially, CMS had issued a regulation back in May of this year that was requiring nursing homes to report weekly data to the CDC about resident and staff vaccination.

Then there was a second part of that that applied not only to nursing homes, but also to intermediate care facilities for people with intellectual and developmental disabilities. Both of those

types of settings, also under the new rule, had to provide education and to offer the vaccine to residents and staff. Then other types of facilities, impatient behavioral health as well as other community-based settings, were not subject to any of that rule.

Then as the pandemic went on, CMS then revised its position in this November rule that it—you know, so where it's now saying Medicaid and Medicare provider staff must be vaccinated and set out how that would happen. This is changing from the educate and offer to a vaccination requirement. It was also broadening the types of facilities, so much more broadly across all types of Medicare and Medicaid federally certified providers, not just nursing homes. Again, importantly, omitting, as you pointed out, the HCBS settings. The policy reason that was driving this is that those settings are directly regulated by states, and so CMS explained in the rule that it was applying this rule to facilities that it regulated—or provider types, I should say—that it regulated on the federal level. That's again though, you know, creating this ongoing gap and uncertainty about how folks across the care continuum will—you know, pandemic response, how that worked.

Then I'm not sure if you want me to get into this, but there's actually been quite a lot that's been going on with the ruling in the last couple of weeks since we put out that paper: a number of states, about the half states have filed law suits challenging the Biden administration's ability to impose that requirement. There are four cases. Right now we have the rule temporarily blocked in about half of the states in the country. There are two courts of appeals who have said, yes, the rules should not be implemented while this case is being litigated. Then we have another case out of Florida where the appeal's court said the rule should be allowed to go forward while the case is being litigated.

Then the most recent development is that—I believe it was just yesterday, quite recently—the federal government has asked the Supreme Court to weigh in on the two cases from the Fifth Circuit and the Eighth Circuit, where the courts had blocked the rule. The federal government is now asking the Supreme Court to lift those preliminary injunctions while the appeals go forward. Quite a lot of uncertainty, not only, potentially disparate treatment at least in the states where the rule is now going into effect across the care continuum, but also we're thinking about Medicare- and Medicaid-certified providers being subject to different requirements depending upon where they live right now.

Nick: Do you have a comment, Bonnie? Sorry.

Bonnie: Yeah. Yeah.

Nick: You looked like you wanted to talk.

Bonnie: [Laughter] I do. I do.

MaryBeth: Oh, okay. Sorry if that was a little too weedy. Like if you want me to—[laughter]

Bonnie: No, no.

Nick: No.

Bonnie: This is so important. As you know, I am acutely interested in this area. I have so many questions. I'm just trying to filter through and ask the most pressing one. You know? Gosh. This is complicated, right, and complex, and striking to me that we are again in a scenario where the disability community [laughter] is impacted differentially by these policies or these gaps in policy. Right? You know? You don't say, "Oh. I'm gonna not have my HCBS, my Home & Community Based Services providers come in my home right now because there's not this vaccination mandate. It's not an option. Right?"

You don't have options in these scenarios, and it's just, it's complicated. That kind of mentality has continued. Right? It's, yeah, it's complicated on top of the fact that these decisions at state levels, and I know that's how this country is run, and you know it is the democratic process. Again, it's what we've seen across the whole pandemic is the leadership, the values of the leadership on disability inclusion and equity play into these decisions. Right? It's at the peril of the disabled population. Right? It's depressing to me to see this continue still.

MaryBeth: [Distorted audio 16:12]

Bonnie: That's all, I guess, I can say. [Laughter]

MaryBeth: Yeah. I mean, I guess just to, if you are interested in, I pulled a couple of quotes from the cases and I really think this maybe puts it [unintelligible 16:24] the two sides for folks. Right? When you said the cases from Missouri and Louisiana, which are the ones that blocked the rule temporarily, and then the case from Florida that said, "no." You know? The litigation can go forward, but the rule should not be blocked during that process. You know? This

sort of difference in ideas about state power; federal power; what's in the public interest just really become very starkly clear.

CMS was relying on its ability to—it has a general ability to regulate for health and safety of Medicare- and Medicaid-certified providers to protect the people who are getting those services. Courts had just very disparate ideas about what that meant.

According to the Eleventh Circuit, of course, requiring vaccination would further that goal of protecting folks who were getting healthcare services. We certainly don't want people to be getting needed healthcare for some other non-COVID-related reason, and then end up being infected with COVID, as the court in that case points out, is entirely preventable because now we have vaccines.

Then the courts who came out on the other side saying this is, in their view, way beyond the power that Congress gave the agency to regulate here, and they would need specific authority to do that. Then just thinking about how they conceived of the public interest. The Missouri court said, "Yes. We agree that the public does have an interest in stopping the spread of COVID, but...," it concluded, "the public will suffer little if any harm if the rule is blocked." Louisiana court said, "The public interest is served by maintaining the liberty of individuals who do not want to take the vaccine."

Then on the other side, the Florida court, which was affirmed by the Eleventh Circuit, talked about the public interest in slowing COVID spread, protecting patients from infliction of a potentially deadly virus by those who are supposed to be taking care of them. That, to me, it just really drives home starkly different views about not only the issues in this case, but the larger policy issues that have been swirling throughout the pandemic.

Nick:

[Laughter] You know? For the audience, just like the context of this conversation too is like we're recording this right now as the new Omicron variant data is coming out. It just feels like we're hitting another major wave. It doesn't feel like we; I guess we are. Like the data's telling us we are. It just feels like one of those things that it feels like the community is just helpless at the arms of policy makers who don't seem to have interest of the people in mind necessarily that would align with what many people would consider to be their health interests.

Bonnie:

I just wanna add.

Nick:

Yeah.

Bonnie: I'm sorry. It's hard for me to be quiet on this issue admittedly. I'm intrigued by it. Right? There's lots of conversations, MaryBeth, around what you're talking about. Around fostering democracy and a healthy democracy in conversation. What concerns me is at its core is how the disability community hasn't been allowed, or democracy hasn't been accessible to them, and so their voices haven't been included in these kind of policy decisions. They haven't had equitable access to the democratic process. What concerns me most is that right at its core. It is the impact of that on these types of decisions that then directly impact their safety, their human rights, their opportunities. Anyway I know that's a big discussion, but it's an interesting one, so just thank you for those quotes. It's important.

MaryBeth: Yeah. I mean, you really see how the pandemic is almost moving faster than policy is able to respond right now. This rule came out on November 5th. At that point CMS set it up and said, "Okay. We have been encouraging vaccination. We still see a lot of variation by region and by state, and so we've come to the conclusion that we now need to move to a requirement." The way they set that up was they cited the Delta variant; they cited the what was then an upcoming flu season. You know? As Nick alluded to, like just in little over a month, the pandemic context has changed again, and so now in the filings with the Supreme Court they are saying, "And now we're facing the Omicron variant..."

It's like another layer, another permutation of the pandemic, and policy is still trying to catch up. With the rule being blocked, and at least some states not being able to try out the response that the federal government is proposing would hopefully help bring this more under control. You know? It remains to be seen if it can even be implemented ultimately.

Nick: That's a good way to think about that; that the pandemic's moving faster than policy. I mean, that's true for, that seems like, everything here. Not just specific to what we're talking about, but everything in the US right now at least. I'm just curious 'cause *[laughter]* we have other questions and we should wrap up, but in your perspective, for a lay person like myself, Supreme Court, what are the estimates on how quickly they'll act on the Biden administration's appeal?

MaryBeth: That's a really interesting question, and I think you have to think about there's different layers of decisions going on in these cases. There's the what we call the "merits decision," the substance of the appeal. Right? The lower court said, "We're blocking the rule."

Then the federal government took that to the appeals courts. Those kind of final merits decisions haven't been made yet. What was also going on is that motions were filed to say, "While you make those final merits decisions, please—to use legal terms—stay the preliminary injunctions. Lift the preliminary injunctions allowable to go into effect." That's really what is at the Supreme Court right now. Unclear what will happen, but I think it is very likely that that question is going to end up on what's known as the "shadow docket," which isn't getting a lot of attention lately.

Potentially it may be one judge making that call. It could be the whole court, you know, depending on how they decide to handle it. I think more likely than not, this is going to be a decision not subject to full briefing and argument, the way we usually think of the Supreme Court handling questions. This kind of [*unintelligible 23:45*] question about whether the rule is temporarily blocked while the rest of the litigation plays out will probably be handled that way, and probably more quickly than it would if—you know? Ultimately, once we get those final decisions on the merits of the appeal, that, I think, we can also anticipate will go to the Supreme Court, and that would more likely be on the regular. You know? Subject to full briefing and argument. You know? There's a possibility that they could ask for that to be expedited as well. Just so that raises a whole host of questions about process as well.

Nick:

Wow. [*Laughter*] I guess while we're on the topic of slow-moving policies, [*laughter*] I think you've touched on this a little bit, but let's transition back a little bit. You talked about the American Rescue Plan Act a little bit and its effect on policy. Then currently, right now the Senate is editing, reframing, and debating the Build Back Better Act, which was passed by the House and sent to the Senate. In your takeaway—and I know Build Back Better is an extremely comprehensive in so many different areas that it's affecting, including many that have strong implications for Medicare—but what are the biggest implications of these acts on Medicaid, Medicare, for people with disabilities or chronic conditions?

MaryBeth:

Yeah. I think the single biggest provision in both the rescue plan act and in what's pending in Build Back Better, related to HSBS for people with disabilities, is the new federal funding. The rescue plan act was really notable because it was the first new federal funding for Home & Community Based Services since the Affordable Care Act in 2010. I think that's really important to underscore. Many of your listeners probably already know that Medicaid is funded jointly between the federal government and the

states, so states draw down federal matching dollars for what they spend. What the rescue plan act did for HCBS is increase that federal match, so states can get an enhanced federal match for their spending on Home & Community Based Services. The idea was to allow them to at least maintain what they have and potentially expand access to Home & Community Based Services in light of the pandemic for all of the reasons that we've discussed about why that system has been so stressed during the pandemic.

I would say the new funding is really notable. One of the things that could be limiting about the rescue plan funds is they are time-limited, so they expire after 12 months. CMS has certainly invited states to think about not only shorter-term initiatives, like using the new money to expand access to COVID vaccines for people with disabilities, or provide some sort of time-limited services targeted to the pandemic—like additional home-delivered meals during this time—but they've also invited states to think about longer-term investments to expand services and serve more people and expand eligibility. One of the challenges for states because they have to balance their budgets may be that, you know, I think they are more likely than not to be hesitant about adopting longer-term investments without knowing that that federal money will be there to support them because those funds expire.

If passed, what Build Back Better would do is build on that, and this would be really significant for states because the bulk of the 150 billion—that's billion with a "b"—new money for Medicaid, HCBS is not time-limited as it is under the rescue plan act. This is an enhanced federal match that states could rely on. The program is set up so states would develop plans and analyze what the barriers are to accessing Home & Community Based Services in their state, and then come up with a list of policies that they would adopt to expand access and support the direct care workforce, but knowing that enhanced federal funding will be there as long as they are meeting these program requirements and participating in the new program.

This could be especially important because our survey of Medicaid HCBS programs, which we released over the summer, found that the provider infrastructure really declined during the pandemic. Two-thirds of states that responded to our survey reported that they had at least one permanent HCBS provider closure. We've heard a lot also about the impact of the pandemic exacerbating direct care worker shortages. I think the new Build Back Better policy is designed to address both of those things.

Two other things that are in the Medicaid, HCBS Build Back Better provisions are finally, permanently funding the Money Follows the Person program. This has been a grant program that's really had a lot of state interest, and states have put a lot of work and moved a significant amount of people from institutions like nursing homes and other congregate sites to the community. The challenge for states has been that it's been, you know, it's always been grant funds that are expiring, and Congress periodically has pre-authorized it, but there's always that question about is the program going to end, or not. Making Money Follows the Person permanent, I think, would go a long way in stabilizing state efforts and really helping them feel like that they can commit to continuing to expand in moving people from institutions to the community for Medicaid.

Then the other thing that the Build Back Better provisions would do is a wonky but important quirk in eligibility for long-term care. Under federal rules there's what's called "spousal impoverishment protections." This means if you are a person who is applying to go into a nursing home funded by Medicaid, there's a certain amount of your income and resources that are set aside so that your spouse, who will continue to live in the community, has money available to meet their needs. Until the Affordable Care Act, it was optional for states to apply those same rules to people who were seeking long-term care in the community.

Some states were doing it, some states weren't. If they weren't doing it, you can see how that's creating unequal incentives. You know? Your spouse is going to have money to support themselves if you go into a nursing home, but may not have the same amount of money protected if you get long-term care in the community. The ACA had temporarily said states have to do this: they have to treat both institutional and Home & Community Based Services equally. Then that also had been time-limited and expiring, and extended by Congress a number of times. Build Back Better would end that uncertainty there and make that permanent and so say finally, "Yes. States need to apply those same eligibility rules so the people have equal access, whether they want services at home, or they decide to go into a nursing home."

Bonnie:

Yeah. Thank you.

Nick:

Wow. Sorry, Bonnie. I was just gonna say this fundamental theme that I think is so true for so many things beyond disability as well when it comes to healthcare is that when things aren't permanent, no matter how wonderful they sound, we don't plan for the next

four months or the six months, we plan for decades because that's how we have to think for these institutions. They're large and cumbersome. I mean, at a fundamental level you're just making this amazing point that we can't maximize the potential of any of this funding when it's short-term and when it's not baked into the system. We can't make systemic change. I just find that to be this very strong pillar of the way we make change in healthcare when it comes to policy, when it comes to insurance providers, when it comes to the healthcare providers themselves even.

Bonnie:

Yeah. I also wanna add. I think, to me, this is important moves from moving disability from a charity case model, which has been *[laughter]* the status quo to one of equity. That's important, and I wanna make sure that's elevated. Right? I think these moves to make these policies permanent would help in getting there. It wouldn't completely get there, but it would help in getting there. I think that's just so important. To your point, Nick, it's that opportunity for longer-term planning. It is that. Right? It's for a better chance of equity. Yeah. Thank you for sharing that and describing it that way. I think that's an important point for the audience to recognize and understand about this potential for the policy change, so hope *[laughter]* for the future if it passes. I wanna just end by asking if there's any other topics or issues that you or your team are working on that you wanna share with our audience in closing.

MaryBeth:

So many things are keeping us busy, but I'll try to highlight just a handful. We do have, hopefully and early in the new year, the results from our 50-state Medicaid Home & Community Based Services survey coming out. This would be the first data about the number of people receiving HCBS and spending on HCBS since the pandemic, so very much looking forward to that. Then also using that as a baseline to look ahead and see how some of these policies like the rescue plan funds and potentially Build Back Better, if that's passed. You know? What impact will they have in the future?

The end of the public health emergency is going to be a really important time for everyone with Medicaid, including people with disabilities. Right now Congress, during the public health emergency basically, has frozen Medicaid enrollment and said, "We want people to stay connected to coverage during this time of the pandemic, but we know that the public health emergency will be ending at some point, and there's a lot of work that states will have to do to renew eligibility, review changes and circumstances."

You know? A lot of this work has not been done, or it may have been done but not implemented. It's going to be really important to make sure that people's current circumstances are evaluated so that if they remain eligible, they stay connected to coverage. If circumstances like income has changed so that maybe now someone is now eligible for a Marketplace plan with subsidies instead of Medicaid; that those transfers happen smoothly. It's just really going to be, I think, a heavy lift for states, for CMS. You know? Great impacts for people who rely on these programs for coverage. That's an area that we're going to be definitely following.

Then just the general pandemic impact and state policy responses. We've seen a lot of ways in which states were adopting policies to expand access to HCBS through these public health emergency authorities. Will states continue to keep some of those changes? There is a lot of changes that they could make permanent parts of the program, and so that, I think, will be another question. Then, along with that the data gaps. Right? Continuing to learn what we can, but hopefully to improve the data that's available so that we get a more complete picture of what the pandemic's impact really has been across the care continuum, across, you know, people with similar needs, no matter where they're receiving services. I think that's gonna be really important.

Bonnie:

Thank you for ending on the data. *[Laughter]* You know that is near and dear to my heart as well, and I can't agree with you more on all the things you indicated and discussed. Thank you, MaryBeth for this important work. I so appreciate everything you're doing. I know Nick does too. Thank you for taking time to talk with us today.

MaryBeth:

Well, thank you again so much for inviting me. I have been a fan of your work as well so I'm just really grateful to have the opportunity to speak with both of you.

Nick:

Thank you for joining us for this episode of Included: The Disability Equity Podcast. Thank you to our Included podcast team and everyone who made this podcast special, especially, **Pratik Tashwani 36:49**, Curtis Nishimoto, and our guests. Music is by Molly Joyce.

Bonnie:

This podcast is brought to you by the Johns Hopkins Disability Health Research Center. You can learn more about our work at disabilityhealth.jhu.edu.

**Included Podcast Episode 34 Expanding Behavioral Healthcare During the COVID-19 Pandemic and Beyond- MaryBeth Musumeci
Nick/Bonnie/MaryBeth**

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