

DDNJ Author Insights Podcast

EP 14 Micah Peace Urquilla

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SPEAKERS

Matt Wappett, Micah Peace Urquilla

Matt Wappett 00:15

Welcome to the Developmental Disabilities Network Journal, Author Insights, Podcast. I'm Dr Matthew Wappett, the DDNJ Editor-in-Chief and Executive Director of the Utah State University Institute for Disability Research, Policy and Practice, and it's my privilege to host this podcast. This podcast, as I say, every single episode is one of my favorite things to do because it gives me a chance to visit with the different researchers, authors, professionals who are out in the field today working on disability issues and trying to make a difference. So, it's really, yeah, it's really fun for me to have this time every month or so to sit down and to really dig into what some of these folks are doing. It's probably the best part about running a journal is you get to see all the research and all the things, and you get to meet new people. Anyway, it's really been a great experience for us, but the real reason we started this podcast is that it's part of our commitment to accessibility and to bring DDNJ to a wider readership. We know that not everyone knows how, wants to, or is even motivated to read an academic journal. And although we try to make it as accessible as possible, more and more we're getting our information through video and audio and other sources. In fact, I said this in the last few episodes, I listen to about an audiobook a week now, and I'm listening to my books more than I'm actually reading them, because I'm always going. So anyway, that's part of why we did the podcast. It's chance to get the author's work into your ears, not just on the page. So anyway, this means that you can access a lot of DDNJ's content. We don't get to all the authors, because that's a lot, but we get to some, and we get to kind of choose who we think is going to be most exciting. And we also like to really bring on self-advocates, and that's what we're doing today. So before I introduce our guest for today, though, I please just want to ask you to subscribe to the podcast feed on Apple, Spotify, Stitcher, Overcast, Podbean. Wherever you get your podcasts, you should find it. It's DDNJ Author Insights. Please leave us a rating and a review and share the podcast with your friends and colleagues. That's the other thing with a podcast, it's easier to share on social media, so those likes, shares, reviews, they all help us get the word out about this important work that's being done in the field of disability research today. So with that said, I want to introduce our guest today. I'm really excited to have our guest on. One of the things we really

tried to do when we started DDNJ was ensure that we had advocate voices, self-advocate voices. People who lived the experience of disability, lived in the systems that we do research and work within. And almost every single edition issue of the journal, from the very beginning has had a self-advocate voice, and today we get to hear from a remarkable self-advocate, Micah Peace Urquilla, who is an autistic, multiply disabled educator, community organizer and researcher from Louisville, Kentucky. I met Micah a few years ago through some of the mental health work that I do, and it's just a really great opportunity to have them on the podcast today. So, Micah works as a Research and Training Associate at the National Center for Start Services, where they serve as a co-investigator on the PCORI funded study called the Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual Disabilities. That's a very long title, not terribly accessible title, but it's a very important study, and we will talk about that today. Today, Micah is going to be talking about the PEIS, which is the Participant Experience Inventory Survey, which is a product that's been developed through this PCORI project. So, Micah's approach to this work is an interdisciplinary approach and their own personal experience of having a disability. And I think that comes through very clearly in the interview today. Micah really strives to foster collaboration between disability service providers and the disability community, to promote true access inclusion and empowerment through creativity, radical acceptance and collaboration. Micah's professional interests include participatory research, peer mentoring, and other forms of popular education, and the intersections between intellectual and developmental disabilities, systemic experiences of oppression or marginalization, and trauma. Heavy stuff, but I think, as you'll learn in the interview today, Micah has had some experiences that have really informed their approach to this work and those lived experiences are key to the outcomes of the PCORI study and the development of the tool that Micah is going to share with us today. So anyway, in their free time, Micah enjoys spending time outdoors, game nights, and napping with their cat, Sophie in Kentucky. So anyway, with that said, we are really, really excited to welcome Micah to the podcast today. Well, thank you for joining us today, Micah, and why don't you begin by telling us a little bit about your background and how you got involved in advocacy around mental health for individuals with intellectual and developmental disabilities.

Micah Peace Urquilla 06:18

Sure. Thanks for having me on today, and I'm excited to chat with you about this. Um, so I got involved in advocacy around mental health for folks with intellectual and developmental disabilities as a result of my own personal experiences. Um, I grew up in the psychiatric system, and it was a series of misdiagnoses and missed diagnoses that largely, you know, stemmed out of some of it being that I was very young. I was a kid, and kids have a very limited range of experience with language with which we can advocate for ourselves. But the other piece of it was that, I can't remember ever being asked or being directly engaged in my own mental health services until things really reached a fever pitch when I was in college, when I experienced crisis after transitioning to college. My first time being independent, my first time being a few hours away from home and you know, crisis is never a good thing that or a thing that anybody wants to go through. But in some ways, for as traumatic as it was, it was also a bit of a liberatory experience for me because it was literally the first time that a psychiatrist had ever had to engage with me one-on-one and meet me where I was at because there was not a parent or a caregiver or someone else there to speak for and frankly, to speak over me. Um. And one thing that came out of that initial crisis experience was that I finally got the correct diagnosis. I finally understood that just like my brothers, I have a developmental disability. I'm autistic and while they were able to get

supports much younger than me, a lot of that had to do with certain stereotypes that existed the ways that the providers were able to see what was going on with them easier than they were able to see what was going on with me. And that's not at all to say that they even necessarily engaged with my brothers. I don't think that they did, you know, until they became much older. But, but seeing that kind of stark difference in our experiences, and this stark difference in my own experience, from being young to being an older person who got to directly engage in my own care. It was very motivating to me. So, it was something that I couldn't help but speak up about.

Matt Wappett 09:21

Yeah. Well crisis is never something that we wish upon people, and yet it does have a way of motivating change.

Micah Peace Urquilla 09:33

Yeah, that's for sure.

Matt Wappett 09:36

But it's interesting that that's when you experience that, because you know, right, as we look at the research, the vast majority of adolescents experience their first mental health crisis around right, the ages of 16 to 20. And it's a very transitional time. There's a lot of uncertainty you know. It's a period of time where people assume that right, you're okay. And yet, you find, you know, especially if you leave home to go to college or whatever, that you don't have the tools, you don't have the contacts, you don't have the diagnoses, whatever it is to actually function effectively. It's a huge challenge.

Micah Peace Urquilla 10:26

Exactly, and just like you said, like it, how do I say this? It was such a big shift in context for me to go from thinking of myself as someone who's primarily dealing with mental illness. When I learned that I have a developmental disability, I was able to not only be more compassionate with myself, but to recognize that there was a way to structure my day. There was a way to go about communication. There were all of these ways that I could begin to support myself when before it had been a lot like, you know, trying to fit a square peg in a round hole, you know, and being able to talk face to face, directly with the psychiatrist about what I was experiencing. Because being able to talk directly with the provider about what I was experiencing helped also to pinpoint the source of the crisis itself. It was the lack of those supports in that transition. And it was also a medication that I was on that I should never, ever have been on, you know, and the campus therapist who sent me to that hospitalization. It was also even the result of her not knowing how to communicate with me as an autistic person, and separate what I was trying to communicate about I'm having side effects of this medication that are scaring me from genuine suicidal ideation. Does that make sense?

Matt Wappett 12:20

Yep, yep, for sure.

Micah Peace Urquilla 12:22

And getting off of that medication, the suicidal ideation went away. I felt better, and I had the means to, you know, I still have mental health struggles and lots of needs and things, but it became more of how

do I orient my life in a way that's supportive to me, rather than, how do I react and medicate these kinds of problems like retroactively?

Matt Wappett 12:49

Yeah, yeah, for sure. Oh, I can't even tell you how many times I've heard this story; unfortunately, right where you have kids living at home, they go to the doctor. The doctors give the kids medication to deal with behaviors or whatever, and the kids don't get right a proper diagnosis. They're not seen as a whole human being. It's not till years later that we find right that some of these medications are actually causing the behaviors, the thoughts, the reactions that are a big part of the problem in the first place. And I don't know, that notion you brought up earlier about you being seen, right, by that psychiatrist as an individual is so important. And yet, people with disabilities and I would argue, even children, are oftentimes not seen by providers as whole human beings.

Micah Peace Urquilla 13:52

I would absolutely agree with that. I would absolutely agree with that. And that's one of the biggest barriers, I think, that we face. There's a lot of factors that contribute to that, but there's also a lot of steps we can take to begin to address those.

Matt Wappett 14:06

Yep. Yep. Well, so given kind of shifting the conversation here, and based upon your experience. You've become a tremendous advocate for mental health care for individuals with intellectual and developmental disabilities. Given your experience in some of the work that you've done, what are some of the major systemic barriers to mental health care for people with disabilities?

Micah Peace Urquilla 14:34

There are quite a few. And we could start, I think, with some usual culprits that we've seen that we've kind of been talking around, but I personally would fold under the umbrella of ableism. As you're talking about this inability to see people as individuals because we're viewing groups of people in aggregate. Whether it's based on their disability diagnosis or their age or level of independence, we're looking at people as stereotypes and monoliths. And this can show up in a couple different ways. In my life, it's showed up in diagnostic overshadowing, where like everything is a behavior problem or everything is stemming from this one thing that we've already diagnosed. So, it can't be anything else going on. Psychosocial masking, where sometimes even clinical professionals don't really have an accurate understanding of what's developmentally appropriate for someone with IDD. A lot of things that I did as a young person that were very normal. Things that I do now even could or could easily be misread as psychotic, when actually it's just this is how an autistic person functions, and some of it's quite adaptive for me, even if it looks a little weird to you. There's cognitive disintegration that can make it really hard to ask for help when people are in those times of crisis. Like how I struggled to say, like, I'm on this medication, and I never wanted to, like, hurt myself before, and now I get scared to go near balconies, you know, and that can really, it can be hard to identify what's going on until it becomes an unignorable crisis like it did for me. An intellectual distortion, where, again, like instruments aren't for formed a norm to be accessible to people like myself. So, I received a diagnosis of several different psychotic spectrum diagnoses because I was taking questions literally. Like, do you hear voices? Like, of course, I hear you talking to me, but as an eight-year-old, I didn't have the wherewithal, and the provider also

didn't have the wherewithal to explain to me, you know, not me voices, and I'd argue that, again, all of these can be connected back to a lack of direct engagement and communication between clinicians and the people with disabilities that they're serving. So many providers are doing the best that they can and operating off of what they know, but what they know is often not informed by our actual lived experiences. And so it necessarily falls short. People, even and sometimes especially providers, make a lot of assumptions about people with IDD, and those assumptions often lead them to not engage with us as much as they would a patient without IDD. But I think that there is a certain stigma around mental health that is pervasive even for folks who don't have disabilities who don't have IDD because these are stigmatized and challenging things to talk about. And it's not entirely the fault of clinicians that they've never been trained or have never had the tools to really have these difficult, sometimes like frankly existential conversations with people, let alone to do that in an accessible way. And I would argue also that this kind of umbrella of barriers contributes to a couple of the other really big barriers that we as people with IDD face. And those are, again, it's a lack of professional training and how to engage directly with people with IDD and all the factors that play a role in mental health and IDD. We have a higher prevalence of trauma. We have less autonomy and choice in our day-to-day. All of these kinds of different things, and we can't develop a sense of rapport with our clinician, let alone a sense of agency in our wellness or our services if we're not being directly and meaningfully engaged in our care. And this barrier stems from the overuse of proxy informants in a lot of ways. You know, it's another one of those. We did the best that we could for a really long time, but now we're learning that wasn't sufficient. The lived experience of caring for someone with a disability or having a family member with a disability is fundamentally qualitatively different from the direct lived experience of having and living with a disability. As such, proxy informants are important, but we have to remember that they're proxies. One a proxy is meant to represent the interests and perspectives of that person. So if we're going to properly contextualized proxy informants, we have to have that first person input first to orient it around, and it's not possible for any informant to give the level of insight that some clinicians rely on them for, and that's not because, like, caregivers aren't good enough advocates, or that they are, like, doing something wrong. It's simply because you can't know exactly what someone else thinks or feels without being in their shoes or asking them directly.

Matt Wappett 20:58

Right. Right. Well, and that proxy informant piece, I think, is so incredibly important, especially when we talk about mental health care. You know, let's take a physical condition. Let's say I have anemia, right? I go to the doctor, they take my blood, they can look at the blood, and they can see, oh, he has right, Anemia, low iron. But mental health care is not that way, right? Mental health care relies upon self-report in order to diagnose. And if an individual is not asked or engaged in a meaningful way, and somebody else is talking for them, right. It's going to completely affect the information that the clinician gets and shape the diagnosis right in a direction that's maybe not completely accurate to the lived experience of the of the patient.

Micah Peace Urquilla 21:49

Absolutely! And consider what the dynamic can do also to sit in a room and watch someone else be asked about your experience, and to watch them and listen to them give inaccurate information as inevitably they will, you know, I mean, some folks can get really close to the mark. But there's always, always something that goes missed or under- emphasized or parent, staff and caregiver needs can

accidentally, kind of take the front seat, because that's who we all are as individuals. We are first and foremost in our own experiences and to be almost a fly on the wall as that's happening. I mean, for a long time, I had the sense that not only was I not seen, but in somehow, I wasn't. I didn't; oh, how do I say this? I didn't exist as much as the other people in the room, and it led to a lot of stress and anxiety before appointments. It created some challenges in my own relationship with my mom, who was my primary supporter. Because it's uncomfortable to hear people talk about you. To feel as if folks are more interested in how what you're going through is affecting them, and how well you are following their directions, then you know if you're in a psychiatrist's office, you're going through something right? And to sit there and to need help, to need support, but hear that you need to do better, or this thing is really hard for your loved one. That's creating, actively building a barrier to rapport in and of itself.

Matt Wappett 23:59

Yeah. Yeah, for sure, for sure. So, I want to go back and before we move on with the questions, and bring up a concept that that I'm not sure everybody will understand, and that's diagnostic overshadowing. I brought that up at the very beginning. What do you mean by diagnostic overshadowing, and how does that show up in a mental health care context?

Micah Peace Urquilla 24:24

So diagnostic overshadowing is this tendency when a person whose journey is a little bit opposite mind. They've received their IDD diagnosis first. For someone with that IDD diagnosis to be going through a mental health challenge or struggle, and yet, everyone around them, their clinicians, are constantly attributing their struggles to their IDD. To their autism. They're saying, oh, this is just a behavior. In this way, certain misunderstandings about IDD and mental health tend to overshadow what is really going on for a person, and make it so that we're talking a lot about this concept of seeing and when someone gets a very stigmatized diagnosis like IDD, it becomes all that people see. They don't see you as a three-dimensional person who has feelings and aspirations, and needs for things like connection and community anymore. They mainly see behaviors to be managed, and this can lead to a really unfortunate cycle for a lot of people. Of not getting the supports they need, of being retraumatized, of losing even more agency under the guise of shaping or improving behavior. When it's not behavior, it's a human expressing an incredibly human need.

Matt Wappett 26:12

Yeah. Yep, and it really does. You know, it's sad that it's taken us this long to get there, but the recognition, right, that a person with an intellectual or developmental disability experiences the same range of emotions and needs as everybody else, right? I can have Down Syndrome and feel anxious, right? I can have an intellectual impairment and feel depressed, right? And those are separate from maybe that underlying developmental disability, and they're valid in their own right,

Micah Peace Urquilla 26:51

Right, right. And we can't like they're often related. We know that people with IDD have a higher prevalence of mental health challenges and needs. But part of what is so great about, you know, finally, coming to this realization, is that we can begin to separate those two, and we can begin to ensure that both and not only both, but all aspects of a person in their context can be supported.

Matt Wappett 27:24

Yeah, absolutely. Well, on that note, we've talked about voice, your personal experience. Your article in the most recent issue of the Developmental Disabilities Network Journal is about a new tool to help individuals with disabilities have more of a voice in their health care and their mental health care. It's called the PEIS, but I'm going to ask you to tell us a little bit about what is the PEIS and why is it so important.

Micah Peace Urquilla 27:52

Sure. I am like, really excited to talk about this, especially light of you know some of my story and the lack of voice and engagement. So, the PEIS is really cool and kind of a groundbreaking new tool. PEIS stands for patient experiences interview survey, and it's a patient reported experience measure. Prems, which is the acronym of patient reported experience measure, help providers and researchers to learn directly from patients about their experiences and their satisfaction with their services. The PEIS is an exciting development because it's the first of its kind. Prior to our team developing it, or rather prior to its development, there weren't any instruments designed to be accessible for people with IDD in mental health care. And as I've talked about, the opportunity to give your feedback and share your own experience and your ideas about your needs and the care that you're receiving are directly connected to how engaged you're able to be with any given treatment, which I would argue is directly related to the outcomes, the quality of those services and the outcomes that you experience.

Matt Wappett 29:10

So, how is the PEIS different from what occurs now? And you've talked a little bit about your personal experience, but in general, right when a patient goes in, how does the PEIS, I guess, change the nature of that interaction between the patient and the provider? How would a provider use it? Does that make sense?

Micah Peace Urquilla 29:36

Yeah, that makes sense. And so, I talked a little bit about how you know I have no illusions that this is an easy conversation, right, even for clinical professionals who've been doing this for years, and what the PEIS offers is a facilitated opportunity to have these conversations. There is a guide and training on how to administer it so that providers can begin to get comfortable with that. And it guides the conversation really and helps the provider to ask targeted questions that can yield implementable changes, right. That can help them assess whether they are hitting the mark for a person or missing it. It's more concrete. It gives people the opportunity to say yes, this is what I needed, or no, I needed this, and it didn't happen for me at all. And I think that I personally am really excited about the way that it does it, and I talk about this in the article because it begins a conversation where both parties, both the clinician and the patient, and you know, a family member or caregiver, if they're so involved, are recognized as having valuable information about what is needed and what is going well in a person's care, and that both parties have to collaborate to make the right decisions for supporting a person.

Matt Wappett 31:17

So, it's a conversation guide, which it's kind of funny that we have to develop conversation guides, and yet, right? It's not happening.

Micah Peace Urquilla 31:29

It's both a guide to conversation and a means of assessing the overall quality of the experiences that person is having. And when we know what that level of quality is and what factors are contributing to or detracting from it, we can begin to make treatment plans and engage with people in ways that are more about meeting them where they're at than just managing a specific condition or disability.

Matt Wappett 32:01

So how have people with disabilities, and I know I didn't send you this question earlier, so if you don't want to, if you're like, I don't know. I'm springing this on you, but how were individuals with disabilities involved in developing the PEIS?

32:17

I'm glad you asked. So, we had a team on our study. We have a small engagement team of myself and three other people with IDD and mental health needs. We all have different disabilities, different styles of communication, different experiences with the mental health system. And the first thing that we did was we began with a very similar instrument called the FEIS that was created for families to ask families about their loved one's care and their experiences with it. And we felt, you know, wait, let me see. We created the PEIS for as an outcome measure for a broader no, we didn't. It's not an outcome measure. It's just a product. Let me redo that, but we created the PEIS as a part of a larger study. And when our team went to look for accessible measures to ask people with IDD about their mental health care, there were none. Joni, my mentor and colleague on the study was familiar with the FEIS and the use of family informants is highly prevalent in IDD. So, we felt that that was a good place to start, and we began by reviewing those questions, item by item, for their relevance and for their accessibility. Some of them we just adapted for language, and some of them, like the family involvement question, we actually adapted conceptually too, because a member of our team pointed out that, because I felt strongly, given my own experiences, that people may not always want their caregiver to be directly or like centrally involved.

Matt Wappett 34:36

Right.

Micah Peace Urquilla 34:37

And another member of our team who grew up in some other systems also pointed out that people may want someone involved, but may not have a family member who is there to show up for them, and that having a family member involved at all isn't the only thing that matters, it's how were they involved? Was the quality of the way that they were involved acceptable to you, or did it result in something like you being spoken over or crowded out of your own treatment? Right?

Matt Wappett 35:15

Yeah.

Micah Peace Urquilla 35:16

So, you have to look at both dimensions of it for people. After we reviewed those items, they all went for cognitive interviews with a larger focus group of other folks with IDD and mental health needs, and

they were also reviewed by focus groups of family members and clinicians. And all three of those focus groups looked at the ease of understanding and answering these. Were they the most important and most appropriate questions to ask and was anything missing? And we found that an overwhelming majority of folks found, particularly the people with IDD who actually did the cognitive interviews testing the PEIS, found that it was easy to answer and nothing was missing. And that was a pretty powerful thing for us. Especially when combined with the vast majority of family members and clinicians thinking a few things were missing, but overall feeling that this was hitting the mark. In addition to those steps, we also our team of self-advocates, led by Dr. Jessica Kramer, who's an OT and CO investigator on our project. But we also created several adaptive tools to muse alongside the PEIS. We created a visual explainer to help folks with IDD kind of wrap our minds around what is a prescriber? What kind of different professionals might I be seeing that I should think about when I'm answering these questions? A visual response scale for folks whom those levels of answers were a little bit too abstract. And we also created an instructional video in plain language explaining to patients with IDD exactly how the PEIS works and how to engage with it with your provider. And we're pretty proud of it.

Matt Wappett 37:37

Yeah, no. And I mean, it's a great example of the saying, "Nothing about us without us," right? A lot of these tools are developed by academics and providers, and professionals in the field, and they often miss the mark because they're not coming from the perspective of the population that's being served. And the fact that this was developed by and for individuals with lived experience of disability, I think, makes it a really, really cool new addition to sort of the healthcare toolbox, as it were. So, the PEIS you mentioned there's some training out there. There are some videos that folks can watch about how to use it. Where can people learn more about the PEIS?

Micah Peace Urquilla 38:29

You can learn more about the PEIS on our study website. It is located at the IODs website, and I can send you that link for the show notes on that study webpage. We have information about our broader study. We have more information about the PEIS, and you can even request the PEIS for your own use in your practice there.

Matt Wappett 38:53

That's awesome. So, kind of as we get to the end of our conversation here. You've done this. You're working on both sides. You're working with researchers right who are trying to develop new tools to make healthcare more responsive and accessible, and you're also working with practitioners on the other side, in your personal life and your professional life. In your perspective, what should researchers and practitioners focus on to advance the field of mental health as it relates to people with intellectual and developmental disabilities?

Micah Peace Urquilla 39:31

I think that the biggest thing that researchers and practitioners should focus on is engaging people directly and building out more adaptive and accessible mechanisms for doing so. And frankly, also being willing to stretch your comfort zone when it comes to doing that because it can be a challenge because it's because it is a new way of concern. Conceptualizing and approaching things that have been entrenched for a long time, but that's okay. We have you know when we know better, we have to

do better, and we know from experience, from our findings, and throughout our process of creating this tool that engaging people directly and that creating things that are for people with disabilities with the input of people with disabilities leads to better products and better outcomes. I also think that one thing that researchers and practitioners can do to deepen their ability to engage with people with disabilities directly is to focus more on plain language dissemination and popular education. I can explain that concept if you want me to.

Matt Wappett 40:57

Sure.

Micah Peace Urquilla 41:00

Do you want me to finish?

Matt Wappett 41:02

Finish, and then we can explain that. Yeah.

Micah Peace Urquilla 41:05

Okay. I think that focusing on plain language dissemination and popular education methods for all research and developments can go a long way toward making it easier and for people with disabilities to engage. We have a right to the information that concerns us, and particularly if it has an impact on our health, our wellbeing and our ability to have agency ensures choice toward those ends and to explain popular education is basically any means of educating people on a subject without taking typical classroom approaches. It is accepting the responsibility that we as professionals and folks with expertise have a responsibility to make sure that that knowledge and expertise is not just for us. That it is disseminated to the people who stand to have not only the greatest the greatest benefit from it, but the greatest vested interest in it. You know, this is my life. Like, while it is my professional work, I never get to stop being a person with multiple disabilities. I never get to take that hat off. And so you know, and I have the unique privilege of being in both of those kinds of worlds and I have made the very conscious choice to make it my business to try to bridge these gaps, but people who are just like me as a teenager sitting in the hospital have just as much of a right to this information as I or you as folks who are directly involved in research around it do. And plain language dissemination is one way that we ensure that happens. My background before I became a researcher was in special education. I taught elementary school, and I just firmly believe if you can't explain something to a five-year-old in a way that they would understand it, then you don't really understand it yourself, and you're not doing a very good job communicating about it. And you know, everybody knows you're an expert. Everybody knows them letters behind your name means something, but the real test of your talent and expertise as a clinician is, can you help somebody who doesn't have the years and years of training and expertise that you do? Can you help that person to understand and to be just as engaged and just as aware about the choices that they have and things? I have one more thing, and this is like just a drum that I have to beat. As particularly as a person who talks good for someone with my disabilities, but we have to do more to ensure that all people with IDD have some means of functional communication. Regardless of how normative or non-normative that may look. What matters is that a person has the ability to express their wants and needs and have those wants and needs heard and respected. There's a fabulous organization called Communication First. You can find their work on communicationfirst.org, but they

are led by and for people with people who with a range of intellectual and developmental disabilities, who can't rely on speech to communicate. And they hold that anybody who can direct their gaze, who can move their body, who can leave a room that they don't want to be in, can manipulate objects or throw things if they're not happy with it. You know, this is somebody who can communicate their wants and needs, and it's down to everyone else to learn to listen and to respect what those people are saying. And this is what engagement looks like.

Matt Wappett 45:27

And that's really, you know, it goes to what you mentioned earlier about healthcare, just the ablest bias that's sort of ingrained in all of our systems. Education, healthcare, social services, whatever, right? We assume that people talk, hear, see, right, and not everybody does. And, yeah, and we have to, I totally agree. We have to do a better job at accommodating those communication preferences and teaching others how to do that effectively.

Micah Peace Urquilla 46:00

Because there's always going to be people whose disabilities are significant. Whose impact is significant and we're still trying to understand ways that we can continue to make the PEIS even more accessible in terms of language and communication. But we can't let needing to be perfect, or needing the people that we're trying to serve to meet a certain standard before we serve them.

Matt Wappett 46:04

Yeah. Yeah. Yep, for sure. Well, and I was going to say earlier, as you were talking about plain language. One thing we've one of the things that we really try in the journal is to make sure that every article has a plain language summary so that it is accessible to folks who maybe don't have a typical college education. We have no illusions that, you know, very few people read research journals for fun, right? And yet, we want to make them we want to try to make it as accessible as possible to folks who do want that information. And our biggest challenge is getting some of these incredibly educated individuals to write a reasonable, plain-language summary. It is hard. It's the hardest thing we ask them to do. And I mean, can't even tell you how much back and forth we have on these plain language summaries. Because we don't teach people that right as people get more and more educated, we teach them to talk in more and more complex, convoluted ways, and that I don't know, it isolates them as an individual, and it makes the information inaccessible to the folks that they're working with. And I'm just as guilty of that as anybody, and yet I appreciate you bringing that up because it is. I totally agree; if you can't explain it to a five-year old, you probably don't understand it.

Micah Peace Urquilla 47:59

Yeah, and it's a process. We don't know what we don't know, right?

Matt Wappett 48:04

Yep.

Micah Peace Urquilla 48:06

That's part of why I'm so excited to get to do this work and to have this conversation with you.

Matt Wappett 48:13

Well, so last two questions here, and these are questions we ask every guest on the podcast because I like to end with sort of these broad, big picture things. But I think we can get a picture from our conversation today about what motivates you. But the question is, what motivates you in your work? Why do you do what you do?

48:33

Well, I think I mean, as you said, some of it definitely comes from my own personal experiences and I have had the absolute privilege to see some of the worst experiences that I have had be turned into something that can help people. And that is absolutely that is incredibly rewarding and something that keeps me coming back. Oh, here's exactly what motivates me. There is a Toni Morrison quote that one of my college professors said to me as our class was wrapped or said to all of us as our class was wrapping up for the semester my freshman year. And on the tail end of one of one of my big crisis experiences. She said, it's a Toni Morrison quote, and Toni Morrison said, "Just remember, whenever you get these jobs that you have been so brilliantly trained for, remember that your real job is to free somebody else. If you are free, your job is to free someone else. If you have been empowered, your job is to empower somebody else". And I can think of no better summation of my story then I had the opportunity to be empowered. And so, I feel a very strong responsibility to turn around and give that back to my community.

Matt Wappett 50:06

Well, and I think you certainly have through your work on the PEIS and your continuing work with, yeah, the Institute on Disability there, and the National Center for Start Services, and all the other groups that you work with. So last question, oops, sorry. Did you want to say something there?

Micah Peace Urquilla 50:24

I just want to add one more thing.

Matt Wappett 50:26

Go for it.

Micah Peace Urquilla 50:27

I try very hard not to speak about their experiences and to stay grounded in my own experiences, but I've talked about my brothers. I have another sibling as well. Um, we're all disabled, and they are always, always with me and always on my mind when I'm doing this work.

Matt Wappett 50:43

Yep. And that's the interesting thing that we find. Most people who work in these fields have personal or family experience.

Micah Peace Urquilla 50:55

Takes a lot of heart.

Matt Wappett 50:56

Yeah, absolutely. But sometimes, unfortunately, it takes seeing how bad things are for you to get involved to make change?

Micah Peace Urquilla 51:03

Yes, yes, it does.

Matt Wappett 51:07

But so last question here, and it's a question that we keep asking ourselves at the journal, but also in all the work that we do, and we're always surprised at what people come up with. But how have you been working to make your work more inclusive and accessible.

Micah Peace Urquilla 51:26

For me it always starts with making sure that I'm never the only person doing it. That I'm never the only self-advocate in the room. In the past couple of years put a lot of emphasis in my own professional development, in learning more, in advancing and honing my plain language skills in terms of both writing and facilitation. I facilitate a lot of meetings for our study that involve our other self-advocate team members, and we put a lot of effort into making sure that the concepts, the processes that we're going through are adapted, are in plain language. That we're asking people the most important questions. And I try whenever I facilitate to always leave room too for feedback. It's okay if I'm asking the wrong question. It's okay if my focus is in the wrong place. I want the other people in the room to correct me. And Professor Tawara Goode has taught me a ton about cultural and linguistic competence as it applies to IDD and beyond? Yeah, I think that those are the biggest factors that I continue to try to ensure I'm including in my work. Because if you've met one person with a disability, you've met one person with a disability. I also try to collaborate with a lot of different organizations and groups just to stay on top of what is going on in the field, and it helps get connected to lots of other self-advocates. We can be pretty isolated. That's the nature of living with disabilities in a lot of ways. And actively fighting against that isolation and just building community with other people with disabilities. That informs my work and it makes my life richer.

Matt Wappett 53:35

Yeah, for sure. Well, you do an outstanding job at it. I've had the privilege of kind of watching your work over the last few years, and I've learned a lot from you. I've learned a lot from this conversation and yeah, just thank you for what you do and for your willingness to share your experience with us today.

Micah Peace Urquilla 53:57

Absolutely, and thank you so much for the for the high compliments and the time. It's been really awesome to have this conversation with you today.

Matt Wappett 54:04

Yeah, awesome. Thank you, Micah. So that's it for our conversation with Micah today. I'd like to thank Micah for taking time to come on and share their experience and the PEIS tool. I would encourage you to go read their article and to check out the PEIS tool. There's a link in the show notes. And yeah, please, please, please take to heart and share the message that Micah shared today. That lived experience and especially understanding and addressing the mental health needs of individuals with

developmental disabilities is so incredibly important and so overlooked in our society today. So, anyway here at the end, I'd like to thank our DDNJ Managing Editor and insight podcast producer Alex Schiwal for her hard work to get the podcast out. Alex is the one who gets the journal rolling. She manages the reviews; she edits the podcast. She really carries a lot of the load here with DDNJ and she's kind of the force behind the scenes to make this all work. So, thanks to Alex for her help. We'd also like to thank the Utah State University Institute for Disability Research, Policy and Practice, for their financial and in-kind support for this podcast in the journal. And the journal also received support from the USU Libraries and Digital Commons, and we are grateful for their ongoing efforts to get this research out there. We are excited to note that the DDNJ Journal is now indexed with the Directory of Open Access Journals. And we're in the process of getting indexed on several other sites. We now have enough content that we can get indexed, and we're hoping that increases the visibility and the impact of the journal in the near future. So as I mentioned earlier, please be sure to subscribe to our podcast on Apple Spotify, Stitcher, wherever you get your podcast. Share the podcast. Help us share this important work and the voices of these important advocates and researchers who are doing this work today. So you can learn more about DDNJ at our website. You just go online and type in DDNJ. It's the first thing that comes up. And you can also go to the Institute for Disability Research, Policy and Practices web page, and we have a podcast page there where you can download transcripts in English and Spanish and links and more information on our guests. So anyway, thanks for tuning in today. Thanks so much. Keep up the great work. You're making a difference, and we want you to know that what you do matters.