

**Intro (00:00:00):**

Welcome to Partners for Advancing Health Equity, a podcast bringing together people working on the forefront of addressing issues of health justice. Here, we create a space for in-depth conversations about what it will take to create the conditions that allow all people to live their healthiest life possible.

**Caryn Bell (00:00:33):**

Hello, and welcome to the Partners for Advancing Health Equity Podcast. I'm your host, Karen Bell, Associate Director for partners for Advancing Health Equity and Assistant Professor at the Tulane University School of Public Health and Tropical Medicine. I'm excited to have our guests with us today.

**(00:00:51):**

First, we have Olivia Cleveland. Olivia is a co-researcher with IDD working on the Disrupting the Cycle Project. She is a community advocate for social justice issues, specifically around disabilities and healthcare. Hi, Olivia.

**Olivia Cleveland (00:01:07):**

Hi.

**Caryn Bell (00:01:08):**

Hi. Next, we have Khalilah Johnson. Khalilah is an assistant professor of occupational science and occupational therapy in the Department of Health Sciences at the University of North Carolina at Chapel Hill. She is the owner and operator of #SlayingAcademia LLC and co-host of the Dr. Thoughts Podcast. Hi, Khalilah.

**Khalilah Johnson (00:01:35):**

Hi, Karen. Nice to be here.

**Caryn Bell (00:01:38):**

Great. And last but not least, we have Tajze Johnson, who is a current Doctor of Occupational Therapy student at Methodist University. He is also a certified occupational therapy assistant practicing at CaroMont Regional Medical Center in North Carolina. And he's joining us from the airport. Hi Tajze.

**Tajze Johnson (00:02:00):**

Hello. Yes, I'm currently in the airport. Unfortunately, I had a delay, but I'm happy to be here and happy to join you this evening.

**Caryn Bell (00:02:12):**

Great, great. Listen, we will interview you all, wherever you are. No problem at all. Thanks.

**(00:02:19):**

Thanks for hanging out with me today. We're going to get started by asking Khalilah if you can share what your project is now and how you got there?

**Khalilah Johnson (00:02:31):**

Yeah. Thank you again for having us on. Always excited to talk about Disrupting the Cycle. Our project broadly has been an action research project aimed to better understand how Black people with intellectual and developmental disabilities navigate the health services system in North Carolina, and to see if through community, and that's bringing together people with IDD, people without IDD, providers, could develop what a model of supports looks like that is both culturally affirming, but also anti-ableist. Something that is going to support people both from a cultural standpoint, but also affirms their ability to be able to participate in their own healthcare.

**(00:03:26):**

And so currently, we are in process of developing products out of that work, and part of being here today includes that dissemination process, but also participating in community health events, writing academic papers, doing public speaking of all kinds. So that, one, we are sharing the stories of what happens to Black people with IDD and their healthcare experiences, but also to help funders see the value of this work because it certainly has not been an easy project to find funding around. So we are still doing the work, but also looking for some more money, Karen.

**Caryn Bell (00:04:16):**

I totally understand the issue of looking for more money and what it's like to not have your work be at the top of the mind of funders or people who think that they are supporting the type of work that you all are doing. They're actually not doing it, and not sufficiently. So thank you for giving that summary. If you could give an explanation for our listeners who might not know what IDD is?

**Khalilah Johnson (00:04:47):**

So IDD stands for Intellectual and Developmental Disabilities, but intellectual disability itself is a type of developmental disability that is typically diagnosed before age of 18 and is not sort of exclusive to just limitations in intellectual or cognitive functioning, but also includes some limitation in what we call adaptive functioning, so those additional skills that people need to be able to participate in daily life in all sorts of ways. Yeah. That is a sort of basic and broad understanding of IDD.

**Caryn Bell (00:05:26):**

Great. Thanks for explaining that for us. Could you talk about your motivation for this study?

**Khalilah Johnson (00:05:32):**

Yeah. Oh, man. We could talk all day about that. I won't say in part, probably in totality, motivation for the project came out of my experiences as an occupational therapy practitioner working with people in community, but also in intermediate care facilities, so developmental centers and things for people with intellectual disability in North Carolina. And just finding it very, very difficult to do the type of work that I'm, one, mandated to do as an OT, but the type of OT that I feel like I'm called to do in terms of people being liberated, excuse me, in their ability to exist as both Black and disabled in community.

**(00:06:21):**

And so I just really got tired of rehab managers or center directors telling me that as an OT, all I should be doing is distributing equipment, or it didn't matter if somebody could participate in community or not, because they were going to stay in these institutions until they die. Or seeing people in community and knowing that they needed assistance from OT, but had never seen an OT before. Or hearing doctors say, "Well, what do they know?" Or, "They can't do this, they can't do that, they can't participate, they don't understand."

**(00:06:59):**

And I just got tired of hearing it and decided that at the time, I was pursuing a PhD, and I'm like, "This is not just part of a professional commitment I have as an occupational therapist. I really feel like these issues are put in front of me because I am in a position to do something about it." And in doing so, Disrupting the Cycle also sort of developed out of that. And thankfully, Robert Wood Johnson Foundation saw the value in the work and decided to fund it.

**(00:07:35):**

But, yeah. Those clinical experiences really drove me into health services work that is specific to sort of dealing with issues around race, equity, and healthcare for people with intellectual and developmental disabilities.

**Caryn Bell (00:07:52):**

Thanks for explaining that. One of the things that stood out to me when you were talking is that you used the phrase being Black and being disabled.

**(00:08:02):**

And my next question on my list of questions is to ask about racial and ethnic inequities in IDD. And I'm not sure if that's the right question, but I'll ask it, and see if it's the right question? If I'm asking it right?

**Khalilah Johnson (00:08:21):**

Yeah, yeah. No. I think part of what I hear you asking is sort of the intersections of being racially minoritized and also disabled and how that shows up. And I don't think it's a surprise to anybody that we have healthcare, not even just healthcare, just disparities across all life domains if you are a minoritized person in the United States.

**(00:08:45):**

But when you couple that with also being disabled, as you can imagine, the health outcomes are even more poor. So everything from whether or not somebody has insurance, do they have housing, do they have employment? How have they been able to access education, in addition to whether or not they actually have a usual source of care, the numbers are bleak.

**(00:09:10):**

And so while I think as scholars, researchers, practitioners, even we, and I'm going to use the word admire, because I feel like people talk about disparities all the time. Disparities is a word that's not uncommon to us. The what are we going to do about it part seems to be left off of people's agendas.

**(00:09:32):**

And that is the part that this project is aiming to do, because we have known for a very, very long time that disparities exist for Black people, they exist for disabled. And if you are a disabled person, and if you are at the intersections of those two, you are fighting for your life essentially. Yeah. We have to get beyond admiring the problems.

**Caryn Bell (00:10:00):**

You use different words than what I use. When I'm teaching my classes, I talk about how we in our society talk about disparities or inequities as spectacle and how we literally gasp and, "Oh my gosh. It's tragic." It's all of these words that people are supposed to use when they see something that's a quote-unquote spectacle, but they don't do anything about it.

**(00:10:30):**

It's sort of like people can sit back and just observe, and they feel good that they're acknowledging these things, but they don't go beyond that. So, yeah. Thank you for using those words as well to describe the state that we're in. Yeah. I appreciate that.

**(00:10:53):**

My next question was going to be about racism. Structural racism, systemic racism, whichever phrase or term people like to use, how do you see that in your work or in these issues that you all are working on?

**Khalilah Johnson (00:11:10):**

Gosh. Social racism, it's the waters we swim in, right? I don't know that we are ever in a situation where it's not present in something we're doing, but as it relates to healthcare specifically, and even asking the question brought back a lot.

**(00:11:35):**

And we sort of refer to this as politics of the Black disabled body in the project. How you'll have practitioners who literally act afraid to touch somebody who is Black and disabled, who just don't even acknowledge that they're in the room, who use cognitive shortcuts and stereotypes to try to create intervention plans, make assumptions that care partners, or guardians, caregivers, whatever, term people are using that they do not have enough education or knowledge to be in a place to even advocate for their sons and daughters.

**(00:12:16):**

Hearing story upon story of how many children get left out of IEP services, or IDA-mandated services, right? So having an IEP and all of that, to getting late diagnosis for autism. It shows up in how people get screenings for basic things, because the assumption is made that somehow if you are 40 with IDD, you wouldn't want a mammogram or something. It doesn't make sense, right?

**(00:12:56):**

So some of the same sort of racialized experiences and barriers that those of us who don't have IDD are exacerbated in that community. Because not only do they see you as Black, but then

the assumption is you just do not have the cognitive wherewithal to either care or participate in the management of your health in any kind of way.

**Caryn Bell (00:13:22):**

I think I'll ask you, Khalilah, but I'm also going to ask Olivia and Tajze later, but Khalilah, I'll ask you right now, what do you want or what should healthcare look like for people with IDD? What do you want healthcare providers to do instead of what they're doing?

**Khalilah Johnson (00:13:45):**

Hmm. Wow. That is a big question. One, to first see them as human beings that are there to participate in the healthcare process and to make sure that they provide the necessary time for people to process and participate in ways that they need, which also means that providers need to educate themselves on what it means to have an adapted healthcare experience.

**(00:14:24):**

So if people need alternative means of communication, that that's made available. If additional education around what happens in the healthcare encounter is needed, then that happens, or to do some continuing education just about disabilities in general. Why is disability a specialty? Or why is it just a module in someone's course? Or why do we sort of just leave it to those who end up being developmental pediatricians? People who are children with IDD grow up to be adults with IDD.

**(00:15:07):**

Care should also look integrated, you know? And I believe that for everybody, but especially for people who have specialized services, providers should be in communication with each other about the care as well. People with IDD should not have to be re-traumatized and have to tell these health stories over and over and over to people who may or may not even get it, you know? So having a healthcare situation where people are first seen as people and that their bodies are seen for and cared after with the utmost respect ultimately. Yeah.

**Caryn Bell (00:15:54):**

Thanks. I'm going to ask some questions of Tajze and Olivia. First I want to ask Olivia, why did you decide to join this study?

**Olivia Cleveland (00:16:05):**

It was an opportunity to use my voice to speak up on something that I felt powerless usually speaking up for, which is my health, especially with doctors or nurses, so yeah. The opportunity to share my experience and have it matter, have it documented, so that people like me don't have to go through this.

**Caryn Bell (00:16:38):**

Thank you. Tajze what about you? Why did you join this study?

**Tajze Johnson (00:16:44):**

What got me to want to join this research is, well, one, I wanted to know who Dr. Johnson was, first of all, so I wanted to know what was her reasoning behind it? Because I was actually

introduced to this at a convention. I didn't even really know what it was at first, and then it sparked an interest in me because this is what I was already doing. I just didn't know anyone else who was doing it.

**(00:17:10):**

So this was the opportunity to really increase awareness, improve training, policy changes. Just kind of get involved in the community in another way where OT really wasn't involved or where OT really didn't have a place in a sense because no one was really doing that work. So it was a great opportunity just to improve on disparities.

**Caryn Bell (00:17:35):**

Thanks. I think I will want to ask a question about the process of putting this study together, and how did you, Khalilah, recruit providers? I know there are different types of people in the study, but how did you recruit each type of person? Really providers, other researchers? Olivia has the title of co-researcher. How did all of that come together?

**Khalilah Johnson (00:18:05):**

Yeah. So all of our Disrupting the Cycle partners are included sort of at the level of co-researcher. I just believe in action research that if you are really aiming to address the needs of the community, that they are key personnel too.

**(00:18:25):**

And so part of my recruiting efforts were tapping into people I was already in community with. Some of these relationships have existed since I came to North Carolina in 2012. And so when those people were able to connect me with others and vouch for me, vet who I was, because I have been in this space, and I'm also a Black-identifying female, does it mean I automatically get access to people? So it was really important that I had people in the community who could serve as brokers, really, to help cultivate additional relationships.

**(00:19:09):**

And so while I felt that was fairly easy to do in the IDD community, it really fell flat with providers, which I guess I shouldn't be surprised by, but I'm a part of an academic healthcare institution, so I was legit surprised.

**(00:19:30):**

So as Tajze sort of referenced, because I had some providers who consented to be a part of the study but wouldn't show up for meetings and what have you, a mentor recommended that I try professional meetings and conferences, and so adapted my IRB to be able to do that, to recruit, and also collect data in the same place. Pitched the idea to the North Carolina OT Association as a way to do a forum as part of my presentation, with the understanding that I am here to do this particular theme, that this is how it addresses sort of the theme of the conference. They were willing to approve it, and I had 27 attendees in the session, which numbers, it doesn't sound like a lot, but given that this is a conference that only a couple-hundred people go to, I thought it was pretty good.

**(00:20:38):**

And so talked to everybody about Disrupting the Cycle, the importance of race equity in healthcare, the purpose of the project, and really how it was going to elevate the profession in terms of our visibility in the IDD community, but our commitment to justice and really what our code of ethics called us to do as practitioners. And I really think that that resonated with people who see their practice in that way.

**(00:21:10):**

And so thankfully, Tajze, along with several others, consented to being a part of the project, and it has just been amazing is an understatement, but to have people who are practitioners but also have deep experiences in the IDD community, not just professional experience, but lived experience as well, has been invaluable to the project. And so I'm glad I listened to that mentor to do that, because I really think it changed the project in ways that I just didn't anticipate.

**Caryn Bell (00:21:49):**

Yeah. That makes a lot of sense, and thanks for explaining that experience. Olivia, I want to ask you a question. If you could share or just tell us, what about the experiences of people with IDD, and how do you think those experiences affect care?

**Olivia Cleveland (00:22:10):**

We sometimes go automatically feeling like we won't be listened to. At least for me, that's how I feel. Some of us may have a stutter, we may forget, we may take a long time to process things, so when we go into our doctor's appointments, or go into speak to our healthcare provider, we're either extremely, I want to say docile, but I think that might be the wrong word, but we are, "Yes, we'll take whatever you give us." A lot of the times, we don't argue, because we've argued before, and that didn't work out for us.

**(00:22:57):**

Some of us, we might get too loud when we get emotional, or excuse me. I'm choking a little bit because this is lived for me, and I've seen it happen, but some of us might accidentally become overly aggressive or overly expressionate, which turns our healthcare provider off or our doctor off to listening to us. They may just automatically close their ears to what we're saying.

**(00:23:33):**

Sometimes, we can speak too fast if we're really nervous, or we might have a special particular way of communicating. Maybe we wrote down what we want, and something that's not usual for a healthcare provider. And that our way of advocating for ourselves, if it's different, it may make our provider uncomfortable, and so they respond to us by dismissing what we're saying, or, well, dismissing us.

**(00:24:16):**

And I'm not sure how to explain it. It's not necessarily dismissing us on purpose, but the experience makes them uncomfortable because they don't know how to communicate with us or accept our way of communicating.

**Caryn Bell (00:24:38):**

Yeah. I think you did a great job explaining that, and it's a lot for people who don't have IDD to think about, even to just hear, so thanks for explaining that. My next question is, could you tell us a bit about your own experience and what you see?

**Olivia Cleveland (00:25:01):**

Yes, and I think I may have touched on this in the last question as well. Until recently, I've been very quiet and just accepting whatever the doctor would tell me because they don't listen. They haven't listened to me. I would come in and they would ask me, "What can I help you with today?"

**(00:25:35):**

But that's such a big question for me. My mind immediately goes to, "Well, my ride was late this morning. You help me with that." It's just it's such a big question. "You can help me with the homework I was trying to do last night." That's where my mind goes because of my IDD. So I would say, "That's a big question. Can you ask me something else?" "Well, why are you here?" And then I'll start thinking, "Well, it is a doctor's office, so I'm here to get help, I guess. I don't really know."

**(00:26:21):**

But before I walked in there, before they asked the question, I knew I may have written it down, I may have it on my phone. I just completely forget that entirely that I do have it written down or I do have my issue on my phone.

**(00:26:35):**

And so then I'm stuttering and I'm trying to sort through all the things that I could possibly need help with, or all the things I could possibly come to the doctor's for, like, "Well, I've been struggling to eat, my eye's been hurting. I did have a headache yesterday." It's just, it's a lot. And actually, even right now, I forgot what your question is, if you don't mind repeating it for me?

**Caryn Bell (00:27:07):**

Absolutely, no problem. The question was tell us a bit about your own experience and what you see?

**Olivia Cleveland (00:27:15):**

Yes. Okay. So that was my experience. I have seen in the waiting room, nurses become a bit aggressive if the patient coming in speaks to them too loudly or doesn't use the right words to express what they need or to express their time crunch.

**(00:27:41):**

There was a lady with a slur. She came into the doctor's office, and she was saying, "How long is this going to take?" She was saying, "This is taking too long. I have to go somewhere. I have appointment." I'm not able to really repeat what she said because she was speaking in a broken way. She was using broken English.

**(00:28:09):**



But she came in and she was loud about it, basically. She was very aggressive, very animated, arms up and all over the place. And the nurse said, "Ma'am, I need you to sit down. I need you to back up away from the desk and relax." And she didn't mean to be aggressive, and I know that because I've been in that situation. She was just panicking because she had somewhere else to go, and she needed to understand how long it was going to take for her to see the doctor. So that's what I see.

**Caryn Bell (00:28:56):**

Thank you for those examples. My next question is, what have you done to counteract negative experiences?

**Olivia Cleveland (00:29:06):**

I've decided to email my doctor before I go to see them and let them know what I'll be bringing with me, so I'm going to write down what I need help with, and I'm going to let them know ahead of time I have memory issues. I will prepare for my visit, but I might not always remember what I did to prepare. So just to let you know ahead of time, I'm going to bring a note with all of my symptoms written down, I'm going to bring a note with all my questions written down, and changes I've made to help with those, just so we can communicate better, because I think my issues have mainly been a lack of communication.

**(00:30:00):**

Also, sometimes doctors or nurses see that I have facial paralysis, and they act like it's something that could rub off on them or a disease, which makes me feel really small. So I'm going to try to just explain to them this is a symptom of my brain injury that I had when I was little. It's not something to be worried about.

**(00:30:32):**

I'm getting emotional because I'm afraid to experience that again, but yeah. That's what I'm doing to prepare for my next doctor's appointment.

**Caryn Bell (00:30:48):**

I'm thinking about what that experience could be like, and I'm wondering what would you want the experience to be like? Or let me re-ask that or restate that. What would you want an experience to feel like when you are going to the doctor or going for some sort of healthcare?

**Olivia Cleveland (00:31:11):**

I would like to feel heard and understood. I know that there's a time crunch between appointments, but if I was given the time to get my thoughts out, given the space I need to repeat myself and not feel like I have to mask or come off a certain way in order to get what I need.

**(00:31:43):**

And, gosh. I would love to go into the doctor's office, and sign in, and they give me a questionnaire saying, "Here you go, Ms. Cleveland." And I'll be able to fill it out, and read every question right down how I'm feeling before I get into the doctor's office, and the doctor have that with them.

**(00:32:06):**

Sometimes, they do, but sometimes, they don't. But to be able to say, or to just be able to when I schedule the appointment, to put that in there, that would be helpful, because I'm not always able to do that unless it's a special circumstance.

**Caryn Bell (00:32:30):**

Thanks. I think one of the things that stood out for me, and actually, Khalilah, you first mentioned this, but Olivia, when you were describing both your experiences as well as other people who have IDD, their experiences, how this idea of disability being a specialty, some doctors should know about this, excuse me, should know how to treat and provide care for people with IDD.

**(00:33:11):**

But it sounds like all doctors and all providers should be not only knowledgeable, but their practices should be accommodating to people with IDD. Am I hearing that wrong, or right, or correct me? This is an additional question, so-

**Olivia Cleveland (00:33:33):**

Not just for people with IDD, but for people with disabilities in general, all of us together feel like we're not listened to. Well, I feel like this is too much to ask, but I feel like a doctor's office should be a safe place. We should be able to come in with whatever we have and not feel judged. I'm sorry. I forgot your question. I apologize.

**Caryn Bell (00:34:10):**

That's okay. And you were saying that anybody with a disability should feel or be treated a certain way?

**Olivia Cleveland (00:34:23):**

Yeah.

**Caryn Bell (00:34:23):**

Yeah. Go ahead.

**Olivia Cleveland (00:34:24):**

We should feel heard and feel like we're treated normally. Yeah. Actually, well, I'm going to cry when I think about this, but the most normal I've ever felt treated by someone was someone with what I had.

**(00:34:50):**

And the only reason they were able to treat me normally was because they had extensive training, and they were able to communicate that to me, and they were able to break down the questions for me. It was a job interview, and I just cried. I was like, "Oh my God. Thank you so much. I never felt this way before."

**(00:35:20):**

Which after the interview, just made me feel worse because why haven't I ever felt that way? Why haven't I ever felt like I could communicate with someone on my own without my mom being there or without a family member or someone else? Just I don't understand. Especially in the doctor's office, that's when it really hurts. Yeah.

**Caryn Bell (00:36:00):**

First of all, you don't have to apologize. Second of all, it's not fair. I'm sorry that you've had those experiences. And really, that was my last question directed specifically to you, Olivia. But I think that the remaining questions, if you have comments or anything else that you want to add, just unmute yourself or say, "Hey, I have something to say."

**(00:36:28):**

But what you shared is more than I think most of our listeners have ever thought about, so yeah. Your voice is definitely being heard. Yeah. Thank you.

**Olivia Cleveland (00:36:42):**

And I'm saying sorry so much. Well, I can't remember enough to say why I'm saying sorry, but it has to do with feeling like I'm taking up too much space or too much room or being rushed so many times, not just in the doctor's office, but in general.

**(00:37:12):**

I feel like sometimes I have to say sorry for existing or being the way I am because of how I'm treated like an inconvenience, so that's why I do it so often. That's why I cried and I said sorry for it, because I was like, "Oh, darn. I'm breaking up the mood or bringing it down," so yeah.

**Caryn Bell (00:37:45):**

You're not, and I had to teach myself to stop saying sorry, so it's not an uncommon experience for Black women in particular to always having to be saying I'm sorry or I'm in the way. And you can take up as much space as you want in this podcast, in this recording, so yeah. Whenever you want to jump back in, totally up to you. Just let me know. Okay?

**(00:38:13):**

All right. Sorry. Now, see, I just said sorry. Yikes. All right. Let me ask a question to I think both Tajze and Khalilah. And Olivia, again, if you want to jump in, just let me know or just let us know. It's no problem. The question is, what are some of the ways that care providers are getting it right, and how are they getting it right?

**Khalilah Johnson (00:38:43):**

I'm happy to jump in. I think I got the nod from Tajze. And I think it speaks to some of the incredible examples Olivia just provided. It's the provider who touches base with their patient and their family before the visit. They ask the questions. What supports do you need before your visit? So that if transportation is a problem, the practice can actually help out with that. There are not too many places that do that, but if you're receiving Medicaid services, transportation is a part of that, so making sure that your patient can even make it to an appointment. And

spacing out the necessary time that is needed, so adding another 30 minutes either on the front end or the back end, automatically using that buffer.

**(00:39:47):**

Making sure that the sensory experience is what it needs to be, so whether or not there are going to be a lot of people in the waiting room when someone arrives, if the lighting needs to be adjusted, if temperature needs to be adjusted. Just making sure that people are being thorough in their asks for what kinds of supports are needed.

**(00:40:10):**

And doing that additional planning around what the actual sort of care looks like in terms of if an exam needs to happen? If there's not an exam, what other sort of procedure or non-invasive procedure needs to happen, and doing the necessary education around that.

**(00:40:30):**

And in a way that the patient needs. It doesn't always need to be written language. Do you have video available? Is there auditory available? Do people need picture symbols as part of their treatment and evaluation when they come into the visit? Just thinking about what does support look like? What do adaptations in our daily practices look like, and doing that work on the front end?

**(00:41:03):**

I think too often, providers, they're scrambling on the back end, and then you end up having the kinds of experiences Olivia has. Whether it's intended or not, harm is done when you don't do the work upfront. But also being willing to say you messed up, and asking, being a partner, a thought partner, with your patients about how to make this better so it doesn't happen again for them or perpetuate the same sort of harm with anybody else with ID or any other disability that comes into the office.

**(00:41:38):**

And in my 18 years of practice, I've probably only seen that happen twice. That's how bad off we are, and we have the ability to do better. And where that starts and ends can be up for debate, but we clearly have so much more work to do. What do you think, Tajze?

**Tajze Johnson (00:41:58):**

Wow. So I think some of the things I need to focus on is culture competency training. Excuse me. Culture competency training. I know that was something that my cohort focused on heavily just because we had a push, we had a voice for it, in the classroom, right? You probably don't have that everywhere.

**(00:42:23):**

And then having this podcast available even right now, right? So learning, having that experience, listening to now, and understanding the unique need for a better experience for marginalized people with IDD. Also, some collaborative care, so involving different specialists, social workers, physicians, all healthcare professionals so that they can address the same aspects of the patient's health and wellbeing so that they're all on the same page, right?

**(00:43:04):**

And then advocating for transportation. I know that's one of the biggest things. How is the patient going to get there? So advocating at the local or the state level to have, excuse me, more access for individuals with IDD, right? More funding for IDD, more improved insurance coverage, or just better support for the caregivers in general.

**Caryn Bell (00:43:32):**

What I'm also hearing, or what you all are doing and what you all are asking for is probably, not probably, definitely, a huge difference from what providers are currently doing. So I wanted to ask about the provider's experience, when they do decide to buy into the study, when they decide to participate, how are they responding to some of the things you all are doing?

**Khalilah Johnson (00:44:00):**

I feel like it's been mixed, you know? When I've spoken about Disrupting the Cycle with larger audiences, I think of mixed groups, the reception has been, "Oh, yeah. We know this is a thing." And that's sort of where it stops. But then you have some that are like, "Okay. I recognize that I have missed the mark or admit that I clam up with somebody that has a disability because I'm afraid of X, Y, Z."

**(00:44:39):**

And so there's some real curiosity, if you will, about how to have a better practice, but also a praxis in making sure that they are providing the utmost care for all their clients, and doing so in a way that's meeting the needs in a way that people need. Meeting their needs in the way people need. It's you say a need a lot, but there needs to be intention in providing care in a way that is most effective and meaningful for people. I'll say it that way.

**(00:45:17):**

I think in the sort of current climate that we're in, around understanding disability, equity, inclusion, accessibility, justice, belonging, all of the buzzwords that are DEI or DEI-adjacent, I think in that though, people have a real concern of making sure that they are providing the utmost care and not doing harm. But there seems to be a disconnect with either how to take the evidence that is there from the literature and apply it in ways that makes sense for their practice.

**(00:46:01):**

Olivia and Tajze have already talked about time and sort of what people with IDD need versus what is actually provided and how these needs, it's hard to sort of situate them in the ways that medical appointments specifically run, right?

**(00:46:27):**

And so I don't know. I sort of get the sense that while people care about it, it's also, "Well, what can I do about it?" I think in occupational therapies, those specific spaces, there's a sense that people have like, "Duh, we're OTs. We already know about this, and we can already sort of meet the disabled community where they are."

**(00:46:54):**

But what people don't hear in that is the very sort of paternalistic and "I know best" kind of tone in that. The OT is the expert and not the person with IDD as being the expert in their own bodies and their own experiences, and sort of failing to turn that critical eye inward to say this is why the disability community has also critiqued and problematized OT because we have always positioned ourselves as the people who fix, instead of approaching care from a collaborative standpoint and as the learner and the facilitator and not the authoritarian. And those disciplinary habits are hard to break.

**(00:47:46):**

And so while I still have a sense of hope in terms of what we're able to do from a practice standpoint and a research standpoint, I recognize that the system in which people have to work, so whether that is both practice or research, layered on with sort of the racialized ways that we are sort of socialized to live, I should say, in the United States, it really makes this quite the incredible hill to climb.

**Tajze Johnson (00:48:23):**

So from my personal experience, it's been like Dr. Johnson said. People give you that, "Oh. This is important." And you can train someone all day, but if they're all about productivity and time, because we all have productivity, not just the physician. If it's not in that two-unit window, three-unit window, four-unit window, it's not happening. They're going to move on to the next patient, right? So how do you get it to where you can explain that to a therapy manager?

**(00:49:01):**

So you have your own challenges too, and not everyone sees the importance of it. They just see the value and the dollar. So if it's not within that window, it's not within this time, it just won't happen. We'll have to push it onto another time, but there is no other time but now. So you just need more of a voice.

**Caryn Bell (00:49:24):**

Thank y'all for explaining that. What it makes me think of is you all are OTs, patients, providers. You're in this world.

**(00:49:36):**

And my question is for people who are not in this type of setting, what you all are doing specifically, our project here at Tulane, The Partners for Advancing Health Equity, is a national collaborative that brings together different sectors such as academia, philanthropy, the private sector, government, and community organizations to advance health equity.

**(00:50:05):**

That being said, how do you all feel your work should be understood and applied to other sectors like these that might not be thinking about this topic, this equity issue, like you all do?

**Khalilah Johnson (00:50:20):**

Yeah. Thank you for that question. Some of the things that immediately come to mind is that when you have organizations, whether it is related to training, funding research, practice, around these issues, if the communities you hope to reach are not actually a part of your decision-making processes or at least leading the work, it won't have impact.

**(00:50:49):**

And that is one of the things that I think probably gets under my skin the most about health services research, health equity, race equity work of all kinds. They say, "Well, disparities exist," but the boards of these groups are not diverse, the funding portfolios are not diverse. And even the research questions that they ask don't make sense for the communities.

**(00:51:18):**

And I think what I hope is that as people listen to this podcast, read some of the work, go to website, whatever, that they see that it is important that to do this work, and I think to do it effectively, the communities that are directly impacted have to lead, and at minimum, be partners in the work. Not just participants, but partners in the work.

**(00:51:47):**

And around education and training specifically, I would hope that in medicine and nursing, health sciences, anybody that interfaces with patient communities see this as an opportunity to really integrate. What's really coming to mind is sort of justice and anti-ableism, I mean, or anti-ableist, and culturally-affirming sort of tenets into how they teach, but not as this sort of isolated kind of a course.

**(00:52:33):**

This is something that should be a thread throughout the entire curriculum, so it is not an exception to how we teach, and consequently becomes this specialty, this thing that those other professionals do over there, right? That is my hope. That is my hope.

**Tajze Johnson (00:52:59):**

Yeah. So I feel it'd be great to have a participation in the training from the leaders. And the leaders in their own communities, their own workplaces, obviously for advocacy, community organizations, cultural competency, I can't say that enough.

**(00:53:21):**

Maybe individuals in healthcare just to share their best practices, like what's working in their profession? What strategies, what best practices are addressing the ethnic disparities of IDD?

**(00:53:37):**

Implement some competency training, access to care with the community organization, and then advocating with the participants. Advocating with individuals with IDD on the local, the social, I mean, excuse me, the local, the state, international level to increase the funding so that you have more time. Improve the coverage so that you have more time and then give better support for the caregivers, right?

**(00:54:09):**

And then lastly, just the engagement. Just actively engaging. Not just do it the one time. Actively do it. Continue to do it, continue to make it available, continue to build the trust that they need in IDD community, and then between healthcare providers as well and the minority communities as well. So it's kind of a list of things, but those four would be a great start.

**Olivia Cleveland (00:54:39):**

I just want to add in here, I think for us, for people experiencing this right now, just a quick booklet available, open source, accessible by everyone, online, listing how to communicate with people with IDD or people with disabilities, how to work with them, how to talk to them, how to give them the care they ask for would be nice, and I think that would be a good start. Classes are great, workshops are great, but not everyone is going to travel to it or pay for it.

**(00:55:31):**

And I see that coming from high school. My exceptional children's teacher, she would give a workshop every year to all the teachers on how to communicate with us, how to work with us, how to help us succeed in their class. And for a lot of people, they either forgot it because they have their own beliefs that were just so ingrained in them. Well, quickly, one thing being kids who need the test broken up are trying to cheat, or kids who need longer time are also trying to cheat.

**(00:56:21):**

So I think just having something that anyone can access, anyone can go to the patients as well as the provider on how to interact and communicate with each other, would be a good start. That would work for us.

**(00:56:42):**

I feel like I'm repeating myself, but I say that because we need something now, and if the doctor doesn't read it, the nurse will. If the nurse doesn't read it, the patient will. If the patient doesn't read it, someone in the patient's family will, and then they will communicate and it'll trickle down. Yeah. And I think everything else is awesome, but that's just from my experience for now.

**Caryn Bell (00:57:18):**

Thank you all for answering that question. I appreciate that. And you all brought up so many different things that it's going to be something that I think everyone who's listening, including our organization or our project, will be able to grow from and do better, really. And I really appreciate the urgency of now. This is something that we need right now.

**(00:57:46):**

For all of you all, if you all have a key takeaway, one or two things that you want the listeners to take away from this conversation, what would that be?

**Tajze Johnson (00:58:00):**

I would say some of, excuse me, the key takeaways regarding inequities for IDD would be just the importance of culture competency, training, the education, the essentials to provide effective care. That's one.

**(00:58:18):**

Two more, I have. Community engagement is a key. Engaging with the community, critically building the trust, and increasing awareness. And then lastly, advocating for policy change. Just



requiring the policy changes to include advocacy to increase the services for IDD, and this improved overall coverage and better support for them and caregivers.

**Khalilah Johnson (00:58:45):**

Okay. I think my final thought would be, and I can't underscore what Olivia said enough, is that we need something now. Action on this is long overdue.

**Caryn Bell (00:58:58):**

Olivia, do you have a final thought that you want to share with the listeners?

**Olivia Cleveland (00:59:06):**

No.

**Caryn Bell (00:59:07):**

I think you summed up a lot of what our listeners need to learn and to do also is what I'm hearing. That action is required and we need to stop just talking about stuff. Let's do something to get to equity and justice.

**(00:59:27):**

So I want to thank you all. Thank you, Khalilah, for starting and leading this work. Thank you, Olivia, for being here, sharing your experiences, and being an advocate. Tajze, thank you for your work, as well as recording this in the airport. We really appreciate you being here.

**(00:59:46):**

To everyone who's listening, thank you for listening. We hope you found this engaging, and we look forward to having you tune in for our next episode. And if you have any thoughts to add to the conversation, be sure to comment on our podcast episode page at [Speaker.com](https://www.speaker.com), or on our social media channels. Thanks for listening.

**Outro (01:00:09):**

Thank you for joining us this episode of Partners for Advancing Health Equity. Be sure to visit our website and become a member of our collaborative at [Partners4HealthEquity.org](https://Partners4HealthEquity.org). That's partners, the number four, HealthEquity.org. Follow us on Facebook, LinkedIn, and Twitter, and be sure to subscribe wherever you enjoy your podcasts.

**(01:00:30):**

Partners for Advancing Health Equity is led by Tulane University's School of Public Health and Tropical Medicine, is part of the Tulane Institute for Health Equity, and is supported by a grant from the Robert Wood Johnson Foundation. Until next time.