Episode 9: Tawara Goode

SUMMARY KEYWORDS

work, developmental disabilities, podcast, diversity, disability, inclusion, linguistic competence, people, terms, article, cultural competence, leadership, important, programs, equity, cultural, disabilities, space, focus, opportunity

SPEAKERS

Tawara Goode, Matthew Wappett

Matthew Wappett 00:15

Hey everybody, welcome to the Developmental Disabilities Network Journal Author Insights Podcast. I'm Dr. Matthew Wappett, the DDNJ editor in chief and I am also the executive director of the Utah State University Institute for Disability Research Policy and Practice Utah's UCEDD program, and it's my privilege to host this podcast. This podcast is actually one of my favorite things that I get to do because it gives me a chance to talk to so many different researchers and professionals who are out in the field today making a difference. In fact, many of the people we have on the podcast are literally changing the world in their own quiet way. And today's podcast is especially special for me because I get to visit with my friend and colleague Tawara Goode. Before we jump into Tawara's intro and her interview, though, I do want to give you a little bit of background. This podcast, the author insights podcast, was part of our ongoing commitment to increase the accessibility of the Developmental Disabilities Network journal for a wider readership. Not everyone has time to sit down and read an entire article these days, let alone an entire issue. And more and more people are choosing to get their information through podcasts and audiobooks. I've said this in past podcasts, but the last year I've listened to more audiobooks, than I've read physical books. And that's a first for me. But I think it's indicative of the shift that's going on in our country and more and more people are wanting their content in different multimedia formats. So the launch of this podcast is an attempt to capitalize on that it also means that you can access DDNJs content while you are on the go. And it means that you can share it more readily across social media and other platforms. You don't have to send somebody an article or a book, you can share a link and they can go listen to the conversation themselves. We recognize at DDNJ, that it's important that we present our information through a wide range of media to help increase the accessibility of this information. And we hope that this podcast will help provide another alternative for you and for your stakeholders to access the great research that is being put out through DDNJ. So with that said, please be sure to subscribe to our podcast feed so you get updates on the latest. The latest episodes, we are on Apple podcasts, Spotify, Stitcher, overcast pod bean, anywhere that you can access podcasts, you can access the DDNJ author insights podcast, please leave us a rating and a review. And again, please share this podcast with your friends and colleagues sharing this and getting the links out there and helping people know that this is a resource helps us build our following and helps get a wider audience for the work that we are publishing through DDNJ. So with

that said, as I mentioned, I'm really excited about our conversation today. I have known Tawara Goode for many, many years. And Dr. Goode has become a great friend and it's just a privilege to sit down and talk to her. So you'll notice that our conversations maybe a little more relaxed than others. And part of that is the fact that Tawara and I have known each other for a long time. And so it's a I felt like there was more of a flow in today's conversation. And so it's just again, it was just such a fun time to sit down and to pick Tawara's brain and to really understand better the history of the work that she is doing, and just how long it's actually taken for Tawara and the National Center on cultural competence to get traction within the field. I had no idea that they started back in the 90s doing this work. And, you know, it's really only been within the past 10 years that I think we've seen substantive progress towards addressing some of these issues in the disability services. So Tawara gives us some really important insights on this. And I think again, it's a really informative conversation that I've had with her. But before that I should introduce her for those of you who don't know, Tawara, Tawara Goode. Dr. Tawara Goode is an associate professor in the Department of Pediatrics at the Georgetown University Medical Center in Washington, DC. She has been on the faculty of the Georgetown University Center for Child and Human Development for over 30 years and has served in many capacities. She is currently the director of the Georgetown University Center for Excellence in Developmental Disabilities and focuses on a national level to advance and sustain cultural and linguistic competence as evidence-based policies and practices that promote diversity, equity and inclusion. She has worked at Georgetown for over 35 years and has extensive experience as a principal investigator for federal, state and private sector grants and contracts. She is also the director of the Georgetown University National Center for Cultural Competence at the UCEDD there and again, as I mentioned earlier, the National Center for Cultural Competence was originally funded in 1995 and Professor Goode has served as the director of the National Center for the past 26 years. The mission of the National Center for Cultural Competence is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address the growing diversity, persistent disparities and to promote health and mental health equity. Professor Goode is recognized as a thought leader in the area of cultural and linguistic competence and building the National Center for Cultural Competence into a nationally and internationally recognized and awardwinning program. She as many of you probably know, she's been an invited scholar, lecturer visiting faculty, she's worked here in the US she has worked internationally. And anyway, her just impact I think within the Developmental Disabilities Network. But within the disability field in general is really unmatched by many other people who are working today. Tawara continues to conduct research on cultural and linguistic competence, and is using that research to help address disparities across health and human services. She is the author of the concluding article in our special issue on diversity, equity and inclusion. The title of that article is "Advancing Diversity, Equity and Inclusion in Developmental Disabilities, the Essential Role of Leadership for Cultural and Linguistic Competence" and we're excited to get Tawara's insights on why leadership is so important. The choice to end the most recent issue of DDNJ with Tawara's article was intentional, because she really does highlight that making a difference, making our organizations, making our service providers, making any group right that is trying to serve a diverse population, more culturally competent, and linguistically competent requires leadership. And her article really does highlight the importance of leadership and what that leadership looks like when we're trying to make advances in this area today. So anyway, the episode today is a wide-ranging conversation with Tawara on the origins of the National Center on Cultural Competence, her work promoting diversity and inclusion. She really is one of the most intelligent and wise individuals that I've

had the privilege of working with over my career. And I'm just really excited to share this conversation with you. So without further ado, here is my conversation with Dr. Tawara Goode. So I am just going to go ahead and jump into Tawara. And, again, I do want to start by saying thank you for making time to do this. I know you're incredibly busy. And it really is just a privilege for you to carve out a little bit of time to have this conversation. So thank you.

Tawara Goode 08:37

It's my pleasure, and we're buds and when you ask anything I can do to be supportive of you. I'm there.

Matthew Wappett 08:45

Well, thank you, you are far too kind. So as you mentioned, we've known each other for a while. But not everybody listening to this podcast may know about your background. So I was wondering if you could just tell us a little bit about your background with the use of network and DD related programs.

Tawara Goode 09:02

All right, thank you for the opportunity to share. So I'll of just start off by saying, I've been with Georgetown University's Center for Excellence and Developmental Disabilities for many, many, many years. And so I get my start as it relates to really doing developmental screening and assessment for kids who may be at risk for developmental delay and disability. And that's what brought me to the, to the UCEDD at Georgetown. And it has just expanded outward for many years in a whole range of areas, largely focusing on addressing disparities, looking at cultural and linguistic competence within the context of disability supports and services. And I would say that across the lifespan, so that could include it community service activities, interdisciplinary training and community education. It would include research and evaluation, and also information dissemination. So this is my work at Georgetown. I have also been very actively involved in the AUCD network. I've served on the board, for one stretch probably six to seven years, as a former president of the board, back in 2020, and have shared wonderful relationships with my UCEDD colleagues, like you Matt across the United States. And, and within looking at our territories. That work is focused again, largely on really helping us to understand the cultural differences, responding to linguistic differences across populations, as it relates to persons who experienced intellectual development disabilities, their families, the communities in which they live, and the extent to which they are impacted by disparities and inequities overall.

Matthew Wappett 11:21

So I think, and I think that last piece there is probably what most people know you from is your work on diversity, equity and inclusion in disability related programs. And I think you'll have to correct me if I'm wrong, one of the things that you did there at Georgetown right was start the National Center for Cultural Competence. In collaboration with ACL, can you give us a little bit about the history of the start of the National Center for Cultural Competence and, and how you got that up and going and how you've been working with ACL to more effectively address diversity and inclusion?

Tawara Goode 11:59

What probably a little-known history fact about the National Center for Cultural Competence. We wrote the first grant in 1995, and it was actually was funded by health services, Health Resources and Services Administration, the Maternal and Child Health Bureau, so under MCH. There's a very astute

project officer named Diana Dibaba, who's now retired, who looked at programs supporting kids with disabilities and special health care needs, again, under the Maternal Child Health Bureau, and found that they were not reaching all of the children who have a variety of experiences within state title five programs. And she came up with the idea of starting a National Center for Cultural Competence. And in fact, our original name was the Maternal and Child Health, the National Center for Cultural Competence. So that's how we got our start, I wrote that first grant and fortunately, it was funded. And we have continued to do a range of things. And I just feel really fortunate and privileged to have been able to continue this work with many funding opportunities across the board. I would say that ACL came a little later to this space, just in terms of the kinds of funding opportunities that they offered, however, because they also worked within the UUCEDD that all the work that I did within the UCEDD always had a cultural lens, always took the language in consideration, always looked at diversity, equity inclusion. So to me, these things were indeed merged. So as I think about the most recent work with the ACL, we've done just a range of things. We had a community of practice that focuses on cultural and linguistic competence within the intellectual developmental disability space. We've done a project that looked at embedding cultural and linguistic competence within curricula for our UCEDDs related programs. There just a whole range of opportunities that have come through ACL, particularly most recently in a focus on looking at equity. So that gives you just a little bit of history about the National Center for Cultural Competence. We did not always stay within the intellectual developmental disability space. I could have been broader again, looking at public health, education, and the like. However, because of our commitment, we always brought disability to the table, no matter what, no matter what the project would be.

Matthew Wappett 14:46

Well, I had no idea that it started back in '95. I guess that's, that's on me for not doing my homework. But that's been that's incredible. And I didn't realize it HRSA it was the first agency to fund you. Yes. Interesting. Well, so at the very end there, you were talking about how you know, regardless of the group that you're working with or the domain that you're working with, then you've always brought disability back. And, you know, one of the things that we always struggle with at least those of us who work within disability programs that sometimes disability is left out of broader conversations about diversity, equity and inclusion. And sometimes you have to fight to get a seat at the table. Sometimes you don't think about it the other way that sometimes in disability related programs, we don't think about diversity, equity and inclusion or historically haven't done it. So it is a bit of a two way street. So I mean, I know this is going to be a basic question to you. But why is it so important that disability related programs be more mindful of diversity, equity and inclusion?

Tawara Goode 15:51

I think that in one way, disability organizations have looked at diversity, and have looked at inclusion, but that was through a particular lens. So I think that diversity may have looked more so the diversity of disabilities that will be within any given population. And then I would say, from the inclusion perspective, it's looking at inclusion through the lens of whether or not persons who experienced disabilities have the same rights, privileges and opportunities as others. And so I think that we have not looked at equity at all, in the space. We have used a term a lot, but we certainly have not looked at equity. That being said, the disability community also has not really looked at inclusion from the lens of diverse racial, ethnic, cultural, and linguistic and other identity groups. So that the inclusion was very disability

focused, not maybe looking at the population of people, the broad population of people who experienced disabilities. And so I think that we're late to the stage, late to the game as it relates to this. There are other fields, particularly I would say, health that are far ahead of us in terms of defining what is health equity. We in the disability space, not defined what is equity, and we have limited ways in which we have viewed inclusion and diversity. I hope that makes sense.

Matthew Wappett 17:38

Yeah, no, that absolutely makes sense. And I appreciate you making those distinctions. I think, especially within the past few years. And this is my opinion, of course, but this term of DEI or EDI or however people are doing those acronyms has people have come to see that as kind of a monolithic, you know, it's one thing, and I appreciate you breaking that out and really articulating, you know, diversity, is this an inclusion is this and inequity is this. Because I think sometimes those distinctions get overlooked.

Tawara Goode 18:11

I agree. I think, right now, I feel that the term equity is, I would say, overused, in that will delineate it. And so that it's used, I'm just, I won't say indiscriminately. It's, used in a very generous way to describe many things. And so one of the things that we get a request for training or something else, and they say, we want to do something in DEI, and then at listen and tell me more, and then they're still saying DEI. So I really do make an effort to not use the acronym DEI because when we do it, it clumps everything together. So when people ask, well, you know, tell me what you do in DEI, I will say which one? Are you talking diversity are talking equity? Are you talking inclusion, because they are related, but they're distinctively different. And we just need to be much more conscious about that.

Matthew Wappett 19:14

Yeah, no, I I totally agree. They are unique and different in how they look at the issues and how they approach the issue. Certainly. So you've been doing this since 1995. You mentioned around the National Center for Cultural Competence. But what are some of the big changes or have you seen changes over the last 10 years around how the disability field is addressing diversity, equity and inclusion?

Tawara Goode 19:40

I would say that, yeah, I've been doing this since 1995. And I had to look at perspective. So in 1995, and were originally funded and again, looking at kids with disabilities and special health care needs. It was hard to quote, "give it away". We had these federal resources. We had all these things that we could do. And it was very hard to get into title five programs, and other programs that support children and youth with intellectual development disabilities and special needs. So if I look at that, and gauge that to where we are now, there's been significant changes. just even terms, something as simple as a website, and what are the images that are reflected on the website, or in brochures, or an other visual media. They used to be pretty much all the same. Now we see those same images, different images, I would say, that reflect more of the people across the board by race, ethnicity, and other identity groups who actually live in this country. So just something as simple as that has expanded over the last 10 years,. We've seen more centers coming out of ACL that have been funded with requirement that they're looking at the diversity of populations that reside in the US, tribal nations, and territories. That is

a big emphasis in terms of change. What also, if we look at training programs, for many of the different disciplines, whether speech and language, psychology, etc, there's been a greater emphasis on looking at not just diversity, equity inclusion, also cultural competence and linguistic competence within this context. So those are some of the things that we've seen. I feel that many people are much more invested. Many people are much more open, although that there are some pockets of I'm gonna say resistance, or just not seeing the value. So being able to see more papers that have been written, more studies, articles, that are really examining, what does culture mean, in a disbelief space? What are quote, "evidence based practices", which is another one of my pet peeves? I don't know, if it's an evidence based practice. I always ask evidence base for whom. So if your population of focus isn't inclusive, or is only has a certain racial, ethnic or other group, then that may be evidence based practice for that group. But I can't generalize that because your population wasn't broader. So I think that there's still significant things that we need to be able to look at including defining what is equity? What does it mean, in in the IDDC space. We need to really look at ensuring that curricula and faculty have the capacity to actually teach this. That there's opportunities for community engagement, in which faculty and students go into spaces within communities that, you know, may have been historically minoritized. How do you engage? I mean there's so much that we need to do in a space, and it needs to be systemic. It doesn't mean that one person really likes this area, and they're going to focus on it. It needs to be part and parcel of all we do in this space.

Matthew Wappett 23:38

Yeah, well, and I couldn't agree more. But you didn't mention a little bit earlier on in your response there that there has, or maybe there is some resistance emerging to this. And I know here in Utah, particularly in this last legislative session, there was an attempt to pass a law through the legislature to have to stop universities from doing DEI related work. And I know that's not unique to Utah. I know, there's several other states that have attempted to do that. Have you felt that same sort of pushed back in the work that you do? Is that something that you are feeling and seeing impact, the progress that you've made?

Tawara Goode 24:20

I would not say the progress that we've made, because that's there. It's solid. It's an evidence base, and people know the integrity of our work. I will say that there are maybe technical assistance requests that come in from a variety of states, indicating that the social, cultural and political environment has changed. And that they're struggling with some things in terms of how to approach these efforts within state programs where you are limited in terms of what you're able to say? So I think that kind of resistance will always be there in certain segments of, I don't know, a policy, etc. On the other hand, there are many more states that are motivated to really dig into equity. And what does that mean within this context? And what does inclusion mean and diversity be within the context? And so I feel that working to support those organizations would get my first let's see, how can I say this. Will receive the attention? And those who are being resistant? Perhaps things will change in the future? But where do you focus your time and energy and resources? And I'm going to call it and I won't quote the source, but we're going to work with the coalition of the willing.

Matthew Wappett 26:07

That makes sense, that certainly makes progress a little bit more satisfying, as opposed to working with the unwilling. I appreciate that perspective.

Tawara Goode 26:18

I mean, we don't have unlimited resources. So how do you funnel those resources, and I just think we are where we're at a period in this country where there's a lot of divisiveness, around race, around gender, around gender identity and expression. Even things like social emotional learning that used to be neutral, but now it's politically charged. So part of leadership is being able to navigate through these periods of time. To stay true to the science into that evidence base into your work, and also not get too distracted by the noise that may just cloud our thinking, and our approaches. And, you know, fortunately, in the District of Columbia, that's not an issue. We are doing some work with New York and also California. When I say it's not an issue, it's not a let's see, an obvious issue, there's going to always be pockets of resistance.

Matthew Wappett 27:37

Absolutely. It's, it seems to become becoming more and more prevalent, I guess, and more and more visible, you know, as before, it may not have been visible. People may not have been comfortable expressing their resistance. But I don't know, at least over the last few years, my opinion and my perspective has been that people are more willing to voice their dissent. Which, again, is a is an important, right, I think, but it does create some unique challenges as we try to continue this work.

Tawara Goode 28:11

It does. And I think part of leadership is that the work will go on because there's always going to be what we call an adaptive challenge. There's always going to be an adaptive challenge. And just want to speak a little bit to this. So if we're looking at what folks within our network may be doing in the diversity, equity and inclusion space, including cultural and linguistic competence. I often see that as looking at curricula, looking at training in a project. And I would say that often, those approaches just training, say for instance, in and of itself. This is not the solution to an adaptive problem. So that if we're looking at how do we differentiate technical from adaptive challenges, we look at just basically asking this one question, does making progress require changes in people's values, their behaviors, their attitudes, and their actions? And if you answer yes to that, now, again, think about this in a diversity, equity and inclusion space? If you answer yes to all of those that tells you that you're in adaptive work. Anyone can do a curriculum. The adaptive work is being able to train people to want to use that curricula, understand the content, convey it to their students, and feel very motivated to do that. And if I've only taught a particular way, but now you're asking me to add all of this content. That is an adaptive challenge and I think that we have to be smarter about how we approach our work, so that we're not getting a technical solution, develop a curriculum when it's really an adaptive challenge.

Matthew Wappett 30:05

Yeah, that's a that's a really important distinction. I think. And as you mentioned a couple of times in your response that requires leadership, which I think is a good segue. In the most recent issue of the Developmental Disabilities Network journal, we kind of closed that special issue out with your article on leadership. It's entitled "Advancing Diversity, Equity and Inclusion and Developmental Disabilities, the essential role of leadership for cultural and linguistic competence" because we felt that your article

really highlighted the important role for leaders and leadership within the space. Could you give us just a quick summary of that article?

Tawara Goode 30:47

Yes, and thank you for the opportunity to publish within the journal. We were very, very excited to have big celebration, when just our abstract was accepted, as it relates to this space. So this article really is a couple of things. It's taking a look back on a federally funded project, from administration and community living. On our work in leadership, and how do you advance leadership for cultural and linguistic competence, specifically within the intellectual and developmental disabilities face. And looking at that across the board. So this article really looked at what did we learn through our comprehensive evaluation of that. I think it stretched into six-year program. And going back to visit people who participated in our leadership academies to see what stuck. How they currently using this work to really advance cultural and linguistic competence within their respective settings. It gave us this opportunity to share our lessons learned. And the Leadership Institute had multiple components. The biggest is the leadership academies that we conducted in Santa Fe, New Mexico, for a particular reason. It's a wonderful place to be, it exudes calmness, and peace and harmony. And we wanted to put our values in our money where our values are, so that we contracted over this whole period of time with a only primary American Indian owned hotel in Santa Fe. And that was just an amazing, amazing experience, just in terms of just the how the hotel was laid out, its design and the people. With those leadership academy, there was intensive one week, really looking at leader looking at understanding yourself as leader, which is looking at it from the person versus what is leadership, which leadership is a function, and we believe that anyone can learn leadership skills and to be able to apply them. We had just a number of sessions there over the period of time. Those participants also had an opportunity to have post leadership academy coaching and we found that very important because folks fall off, and they get all excited in there in a course of study, and then it ends. And all the camaraderie and all of the guidance ends with it. So we committed in this model to one year of coaching for our faculty, for each of the leadership academy graduates to work on a particular leadership challenge in the Diversity Equity and Inclusion and or cultural and linguistic competence space. So that was another thing. We also offer mentoring, which we know is so important. And we know that some of the mentoring mentee/mentor relationships have continued past that period of time, we're able to document that. We also worked at an organizational level with Association University Centers on Disabilities, National Association of Councils of Developmental Disabilities on National Disability Rights Network, Family Voices and SABE (Self Advocates Becoming Empowered) to really look at how do you not just do this individual level, but how do you begin to support the capacity of organizations to engage in this work? So those were pretty much the summary parts and we also did just a series of webinars that still live on our website, focusing on cultural and linguistic competence and leadership. And so this part reticle gave us an opportunity to share what we've learned in detail, and maybe inspired us that maybe we need to search for funding and start it up all over again.

Matthew Wappett 35:11

Well, I will tell you, I don't have many regrets in my life. But one of my greatest regrets is the fact that I was never able to participate in those leadership institutes in Santa Fe. I'd always see them come through, but I was not in a position where I could participate. But I have heard just incredible feedback. I know some of the people who have participated in it, and just what an impact it's had on their

leadership and their role within the programs that they work in. So, you've kind of taken a big overview of the article, in terms of just trying to boil it down and kind of make it accessible. What's the big message? What's the most important message that you would like readers to take from your article?

Tawara Goode 35:57

That in order to do the work of advancing cultural and linguistic competence, diversity, equity inclusion, that it takes leadership, and it takes leaders. So that that message is how is it that you are leading, you don't have to be in a, let's say, an appointed leadership position, some high position within a university. You can lead by what you do each and every day. So that is one thing. The other is that we need leaders across the board, and especially persons with lived experience of intellectual developmental disabilities, and their families definitely need to be in leadership roles. And so I think that that is the takeaway message that this doesn't happen just because of osmosis. That this work is ongoing. It takes leadership and individual leaders to help guide our path forward.

Matthew Wappett 37:00

This work is hard and it does require people who are willing to forge ahead and maybe encounter some challenges along the way as you try to make changes within our systems.

Tawara Goode 37:13

And, I must say this one part of the work we did with the leadership academy, and I have to make true confession, I never lead this aspect because I don't always practice it. But we really looked at self-care. And being a leader in this space, means that you have to take care of yourself, because it is so difficult. I think that we just keep plugging along, not really thinking of the kind of stress that we can encounter. And so being a good leader is being able to recognize that. It's being able to figure out what are things that I need to do to be whole and healthy, physically, spiritually, emotionally, cognitively, in this space. So I think that that is the second. And I shouldn't say a second, that is the other important message is taking care of self. And when you take care of yourself, part of that is also taking care of others. So it's all blended together, but it's very important.

Matthew Wappett 38:26

I couldn't agree more. It's hard to look at people outside of yourself. It's hard to work with systems. It's hard to work with groups if you haven't taken care of yourself first. Because working with others is exhausting. I mean, it takes something out of you. And so yeah, I have learned that through difficult personal experience.

Tawara Goode 38:48

And you said earlier again about the difficult times that we are in this country. That only heightens anxiety or reluctance, or I just don't want to deal with this. There's so much going on right now. So, looking at taking care of self, and also looking at how do we support others who may be experiencing the very same kinds of challenges?

Matthew Wappett 39:17

Well, so on that note, I want to I want to take a little shift here at the end, at the end of the podcast, we ask everybody two questions and to kind of get in more of an insight into right who you are as an

author, as a leader within this space. But I'm curious what motivates you to do this work? Why do you do what you do?

Tawara Goode 39:40

Yeah, that is such a deep question. That is a really deep question and I appreciate it. I think that as I look across this country, territories, tribal nations. We know that we can do better, to be inclusive, to support, and to welcome and offer a sense of belonging to all people who have intellectual and developmental disabilities. We are no place near that. And so as long as that, I don't know, sphere remains as it is, that motivates me to do the work. And to see outcomes for people who have had very positive experiences, in terms of being themselves, in terms of whether it's teaching, delivering services, advocating for oneself, just to see that change is motivating.

Matthew Wappett 40:46

I would totally agree well, but as you're working towards that change, again, that takes effort. That takes patience. It takes something out of you. So I'm going to, I'm going to kind of turn this question back on you and add something that I didn't give you ahead of time. So if you don't want to answer this, you can say nope, Matt, I don't want to go there. But what what do you do to take care of yourself as you do this work?

Tawara Goode 41:16

All right. So I'm not always good at that. So I want to put that there. What I have been doing, and I don't do it consistently is a definitely exercise. That helps me a lot. I also have taken to having worked free days, meaning like if it's a Saturday, and it's been a particularly difficult week than I don't even turn the computer on again until Sunday, or Sunday evening, because I will get sucked in. The other thing in terms of taking care of itself is because the work is stressful, I have confidants of people that I can talk to that I know that will listen, not necessarily just solve anything, but just listen to what the struggles are. I have a very, very, very supportive husband, who makes me laugh, and says, because I'm two serious all the time. And I think that the other thing you do, and this would be outside the space, because you have to be really cold to be in this space, is to have two adorable granddaughters, my son and his wife live in Stockholm. And I get joy just out of looking at videos, FaceTime, looking at drawings. Just some other aspects of my life, that sometimes don't always get the prominence. So those are things they're not magical. They're not anything else like that, but those are things that have worked for me.

Matthew Wappett 42:59

Well, I think there's a there's a consistent theme there. And if we look at right, some of the emerging research around mental health and just wellness in general, having a strong social support system is just essential, really to be healthy and well balanced. As you talk about having confidants and having family and everything else. That it's clear that that's an important part of your success and your resilience. So last personal question here, and we ask this to everybody. But you know, one of the focuses of the journal is to try to make this information more accessible, and more inclusive. So I like to ask all the authors who we interview, what's one thing that you've been doing in your personal life to make your work more inclusive and accessible?

Tawara Goode 43:50

In my personal life?

Matthew Wappett 43:52

Yeah. or in your work life.

Tawara Goode 43:56

So I would say in a work life, looking at making this work more inclusive is to really think about the diversity of audiences that need to have access to information, and how do you deliver that information, and multiple ways to multiple groups so that they get what they need. So if that's by video, if that's by plain language, if that's by word of mouth. If that's by abstracts and articles for for publication, but really rejecting is one size fits all, to really be able to tailor so that we're talking about inclusive. I also think that when we look at disability in particular, and just thinking about a meeting that we had today, with a particular department, in the District of Columbia, is to help those departments that may not be focused on disability. Being more attuned to the fact that people with disabilities experience that there are departments services and support. And what is that experience like, for persons with disabilities and their families. And I think that those are things that we look at. Others would be to ensure that we are having written products in multiple languages. And, again, that would be geared toward a particular audiences to avoid the one size fits all. So if we want something for families that is created in a particular way, then we should do that. We have things for persons who experience intellectual disabilities in particular, we should do that. And I would want to make sure that as I say, plain language. sometimes I see that the focus has been to put things in such plain language, that the person with disability is at a distinct disadvantage, because some of the words that they really need to know aren't there anymore. So I am big on if you're going to use a big word, because you need to use big word, because that person is going to continue to encounter that big word. Than it needs to be explained in a way in which the person can understand. But they have that within them. They have that in their in their cognitive abilities to say when I encountered this word, this is what it means. And this would mean in our life. And I think that our, I don't know, our anxiousness to include plain language, that we've sometimes done persons with disability a disservice by not preparing them for things that they're going to see and hear in their environment. So those are some things I would say, around inclusion, and to always think that disability is a universal experience. And that because we live in America. And because there are so many different racial, ethnic, cultural and identity groups, that inclusion means that we think about all of those groups in our work. I couldn't agree more. And I appreciate how comprehensive and articulate you are in expressing the importance of that. When you talk about diversity, and I heard this in your last answer, it's not just diversity of the people we work with. It's the diversity in the way that we approach the work, right, we have to have a variety of tools and be able to use the right tools for the right audience so that the information is accessible and useful and all those other things. And, I would add to that we inclusion means that persons who have lived experience of intellectual developmental disabilities across all groups and their families, are indeed, very much involved in creating, co creating, and leading what it is that we do. And I think that sometimes that gets bias as well. So that how can I design a program for parents with intellectual and developmental disabilities, help them navigate systems without involving them in the kind of content that they need, the way they want to learn? And what their interests are. So that's inclusion from that perspective that we have to include people with lived experience and everything that we do.

- 11 -

Matthew Wappett 48:48

Yeah, that participatory work is so incredibly important. And on that note, I want to thank you, you're incredibly important. And the work that you've done has made a huge difference. And it's been a privilege to visit with you today. Do you have any last thoughts you'd like to share? Before we wrap up.

Tawara Goode 49:05

I just would like to thank you. And also thank the amazing faculty and staff that I've had just a greatest privilege to work with UCEDD and our National Center for Cultural Competence over these over these many years. Also, our collaborators and partners that we've worked with, have just really supported and embrace this work and contributed. And that is really very important to me. And as I look at the stage in my career, and closer to retirement, that being able to express gratitude is so important, and I'll share one quote. This is a quote from French educator who's deaf way back when helped start one of the very first schools for deaf children. And the quote is, "gratitude is the memory of the heart". And that's what I feel to all the people I've had the privilege to work with over these many years, including you Matt. And I look forward to continuing this as I move toward retirement.

Matthew Wappett 50:20

Yeah. Well, I think it's fair to say that anybody who works in this space wants to change the world. I think it's fair to say that you have, in many ways helped to motivate a lot of that change that we've seen over the last few years. And, again, I'm just grateful for you and for the opportunity that I've had to work with you. And for the opportunity just to have this conversation with you today. This has been incredibly enlightening, and, helpful, and thank you. Thank you for all that you do.

Tawara Goode 50:54

Thank you, Matt. Be well,

Matthew Wappett 50:55

You too. So that's it for our conversation with Tawara today. I would like to thank Dr. Goode for her time and for her kindness in this conversation. I hope that you found this conversation as insightful as I did. Truly I interview a lot of people for this podcast and for other things. And it just was a joy to visit with Tawara today. So I hope that you find the conversation useful. I would like to thank those who are making this podcast possible. I'd like to thank the DDNJ managing editor and author Insite Podcast Producer Alex Schiwal, for her hard work to get the podcast out. Alex does a lot of the behind the scenes work and she is the one who makes things look good and sound good. So thank you, Alex for all of your help with that. If you would like to reach out to us, you can email us at the DD NJ editor email which is editor.ddnj@usu.edu. That's editor.ddnj@usu.edu. We'd also like to thank the Utah State University Institute for Disability Research, Policy and Practice. The UCEDD for their financial and in kind support of this podcast in the journal. The journal also receives support from the Utah State University Libraries and Digital Commons and we're grateful for their ongoing efforts to get this work out there. As I mentioned earlier, please be sure to subscribe to the podcast on wherever you get your podcasts and again please be sure to leave us a rating and a review. And please please share this podcast with your friends and colleagues so that more people can become aware of the good work that is happening out there today. You can learn more about the Developmental Disabilities Network journal

at the DDNJ website, which is digitalcommons.usu.edu/DDNJ or you can go to Google and just type in DDNJ and the Developmental Disabilities Networks Journal will pop up as your first result. You can also download podcast transcripts in English and Spanish and learn more about our podcast guests at the Institute for Disability Research Policy and Practices webpage which is idrpp.usu.edu and once you get to the homepage there go to the drop down menu with about and you'll see a page for the journal and the podcasts there. So with that said, I think that's it for our episode today. Thanks so much for tuning in. Keep up the good work you're making a difference and we want you to know that what you do matters. Stay tuned for our next episode and we'll see you next time.