

Ep 8 Elizabeth morgan ida winters final cut AS

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SPEAKERS

Ida Winters, Elizabeth Morgan, Matthew Wappett

Matthew 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. In fact, hosting this podcast is one of my favorite things to do. It gives me a chance to talk to many different researchers and professionals who are out in the field today making a difference, doing research really trying to change the world for the better. In fact, many of the people that we have on the podcasts are truly doing groundbreaking work that isn't getting the coverage, I think that it really needs. And so we're excited that DDNJ provides a forum to share some of this new and innovative work. The podcast itself is actually part of our ongoing commitment at DDNJ to increase the accessibility of our content for a wider readership. Not everyone has time to sit down and read an entire article these days let alone entire issue of a journal. More and more people are choosing to get their information through podcasts and audiobooks. In fact, I think I've said this on earlier podcasts, but I have read more audiobooks this past year than I have read in physical using my eyes, but that's true. I mean, I've listened to more books than I've read. And I think that may be a first for me, but I know that as my life gets busier as I'm walking around driving whatever I can listen, and actually take in that content without having to stop and dedicate time to actually reading a book or a printed out article. So the launch of this podcast means that you and anyone can access DDNJ's content while you're on the go. And you can share it more readily across your social media platforms or other online venues where you might want to Yeah, get the word out about the work that you and your colleagues are doing. We recognize that it's important that we present our information through a wide range of media and we hope that this podcast is going to provide another alternative for you to access the information within DDNJ, so with that said, probably don't need to say this, but please be sure to subscribe to our podcast feed on Apple podcast, Spotify, Stitcher, overcast, podbean, wherever it is that you kind of aggregate and access your podcasts. And please leave us a rating and a review. And please share this podcast with your friends and colleagues. Your ratings reviews and shares really help us share the important work that's been done in the field today. And it helps get wider visibility for the authors and for the journal. So with that said, I think that's really all of the housekeeping that I need to do today. I do want to, before we jump into today's interview, acknowledge that the authors who write these articles and I think this happens with a lot of scholarly literature are just a name on a page. We don't publish articles with pictures of the

authors. And it's rare to see video of authors talking about their work. And one of the fun things about this podcast is that it really acknowledges that authors are whole people. And it really acknowledges that they are more than a name on a page. And it's a chance to get to know these authors get to know who they are behind the publication, and to get a better understanding of the many diverse voices who are working in the developmental disabilities field today. So we really hope this podcast provides some insights into what motivates these authors where they get their ideas from why they do what they do, and why their work matters. So today, we are especially privileged to have the opportunity to visit with Dr. Elizabeth Morgan and Ida Winters who are two of the authors on an article entitled Paths to Equity: Parents in Partnership with UCEDDs Fostering Black Family Advocacy for Children on the Autism Spectrum. And this article is unique in that Yes, Dr. Morgan is the lead author on it. But there are several parents who participated in the entire process and who contributed and are acknowledged as authors on this work. Ida Winters is one of them and we're excited to have her with us today and to share her experience helping to pull together an academic publication. So by way of intro Elizabeth Holliday Morgan, Dr. Morgan, is an assistant professor in educational leadership at the University of California Sacramento, and a program coordinator for the UCEDD at the MIND Institute. Her area of research focus includes early childhood and early intervention services with a specific interest in underrepresented populations. When she isn't thinking about autism service equity, Dr. Morgan enjoys the theater and spending time with her family and their dog, Billie Jean. So, we have Dr. Morgan who's joining us from California today. And then we have Ida winters. Ida Winters is most importantly, as I mentioned, a mother and an advocate is the mother of a son with autism. She's a former LEND trainee, and is served as a family navigator with Mental Health America and as a group facilitator for the Autism Society of Southeastern Wisconsin, where she helps support other parents of children with autism. She is not a traditional academic, and this article in DDNJ, I believe, is her first publication as an author, so we're really excited to have the opportunity to hear her perspective, and to share her thoughts with you today. So this episode, as with all of them, I think, and of course, I'm biased, but this episode is an important conversation that touches on many important topics related to diversity, equity, and inclusion in the disability services. Perhaps most importantly, this conversation really highlights the value and importance of honoring parents' experience and voice. And it provides some insights on how to effectively partner with parents for both advocacy and research. So, as with other episodes, this episode also includes some fun, sort of behind the scenes insights and some innovative ideas that maybe you can use to improve the work that you're doing in your respective teams and organization. So without further ado, let's jump into my conversation with Dr. Elizabeth Morgan and Ida Winters. Thank you, Dr. Morgan, and Ida for joining us today for this conversation. Can you tell us a little bit about your background, and how you came to this work and how you came to be involved with this project? And why don't we start with you, Dr. Morgan, and then we'll go to you Ida - we'll kind of alternate as we run through this conversation.

Elizabeth Morgan 07:31

Okay, that sounds great. Well, um, my name is Elizabeth Morgan, and I'm an assistant professor at California State University, Sacramento, and I'm also a program coordinator at the UC Davis MIND Institute in our center for excellence and developmental disabilities, which is one of 67 UCEDDs around the country. And the way that I came to this work is that first of all, I'm an educator by training, I always say I'm an educator at heart. So I started off as a classroom teacher, then I became an administrator. And be while I was doing that I was involved in had many children that I was including in my schools, or

in my classroom with various disabilities and developmental disabilities. And so I came to the disability field as a general education educator. And knowing that, you know, my part of my job was to include into effectively include children with various disabilities. But over time, I think that my passion, I would say, got even more intense because I became a parent. And when I became a parent, two of my, my two children both have developmental differences, and my youngest is on the autism spectrum. And so I learned what it was like to be on IEP table on the other side of the IEP table during that experience. And I one of the things I observed, both being a educator, but also a parent, is that when it came to black parents in particular and families of color, families who are from historically marginalized populations, there were always other things that were going on that were keeping them from being able to have access to information and as well as know how to be able to support their children and being effectively including having their rights. So that led me to where I am today. I went back to school after 13 years of being in the field to get my doctorate and become a developmental scientists and so I conduct empirical investigations specifically focusing on what are some of the barriers that are a part of our institutions such as school institutions, medical institutions, that keeps us from being able to provide family centered care and patient centered care for black disabled people in communities. And so that's really what led me to the work. And also the paper we're going to talk about.

Matthew Wappett 10:17

How did you get involved with this project Ida?

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I am a parent of three wonderful young men, all who have special health care needs. My youngest son is on the autism spectrum. And a week before his 14th birthday is when he finally got a diagnosis of autism, which, all in all, all along, I knew something was different with him. But I couldn't pinpoint what it was. And he got all different types of diagnoses, and but not the right diagnosis. And he got all different types of medication. But still, he had things going on. And I just, you know, searched everywhere, turned over many rocks and nothing happened. And then I started working, I got the opportunity to work within the system. And once I got work, started working within the system and learning about the system, and how to research things. I saw how many barriers were there for black families and put up there and saw how easily, services were obtained for other cultures versus for black families. And I was like, unacceptable, still didn't have a diagnosis for my son, I still hadn't gotten much assistance for my son. But I still wanted to start working with other black families so we can get this system working in our favor, together. So that became my mission. So I also wanted support in my community for black families who were going through the same situations that I was going through, and I was a trainee with Wisconsin land at the time. And my mentor asked me, What did I want to do what was missing in my community. And I told her support for black families going through this with their children with special youth and children with special health care needs. And I wanted something and she introduced me to Elizabeth. So that's how I got involved with it.

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That's awesome. Well, it sounds like you both have personal experience that has that has informed this project. And I think that's definitely reflected in the article as well. So the article actually just came out. It's entitled Paths to Equity: Parents in Partnership with UCEDDs Fostering Black Family Advocacy for Children on the Autism Spectrum. So, you know, we kind of talked about how you came to this topic,

but why is the specific issue so important for disability related programs? And specifically, I guess for you know, UCEDDs, but also schools, service providers, why is this topic so timely and important?

Elizabeth Morgan 13:15

You know, I think, first of all, this topic is something that Ida and I are both personally connected to, for, you know, and have, you know, intersectional identities that make this topic, so important. And I think that, that's the reason why we need to have these discussions. So, you know, in our systems of care, one of the charges that we actually give in the article is for providers, researchers, policymakers, those who have any influence to recognize that our systems that are set up, have never been set up with black families and black children in mind, right. So whether it's school system, or, you know, our even our medical systems, if we look at the origins of those institutions in our country, they have excluded black children and black families. And so when we think about why the black families are having a hard time having access, why black children are having a hard time to access, it's because you know, the systems are functioning, how they were set up to be. And so we just really need to recognize that you have that and then you also think about the history of exclusion for persons with disabilities in our country, right. So any system that's set up for people with disability is to exclude right and to keep them separate. And so when you have intersectional identities, such as being black and having a disability have this double oppressive experience, right? It's almost, it's not like they are two different things happening at once. It's because they're happening in, in tandem right together there. They have they have their own experience as a result of, you know, being both a person of color being a black person, but then also having a disability. And therefore, we have to recognize how our systems have to really have an honest look at ourselves and those who was of us who are in these institutions, we need to have honest look and think about what are the current practices, policies? And personnel? Right? How are we doing things? And procedures, right? How are we doing things that will counter the narrative, right will counter the way that our systems are set up to to operate, we have to do things differently if we really want to support black families and black children. So I think this article in particular, was really powerful, because we center the voices of the black mothers who basically partnered with our UCEDDs and our LENDs to come up with programming that was not was really about the community giving influence about what they needed, and what was necessary in order to provide family centered care, and supports. And so this is really just highlighting that. And I think it could be an example for, you know, any institution that really wants to do the work of addressing systemic inequalities, and, you know, supporting and uplifting the rights and the voices of marginalized populations.

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How did you get involved with this project Ida,

Ida Winters 10:20

I am a parent of three wonderful young men, all who have special health care needs. My youngest son is on the autism spectrum. And week before his 14th birthday is when he finally got a diagnosis of autism, which, all in all, all along, I knew something was different with him. But I couldn't pinpoint what it was. And he got all different types of diagnosis, and but not the right diagnosis. And he got all different types of medication. But still, he had things going on. And I just, you know, searched everywhere, turned over many rocks and nothing happened. And then I started working, I got the opportunity to work within the system. And once I got work, started working within the system and learning about the system, and how to research things. I saw how many barriers were there for black families and put up there and saw how easily, services were obtained for other cultures versus for black families. And I was like, unacceptable, still didn't have a diagnosis for my son, I still hadn't gotten much assistance for my son. But I still wanted to start working with other black families so we can get this system working in our favor, together. So that became my mission. So I also wanted support in my community for black families who were going through the same situations that I was going through. And I was a trainee with Wisconsin land at the time. And my mentor asked me, What did I want to do what was missing in my community. And I told her support for black families going through this with their children with special youth and children with special health care needs. And I wanted something and she introduced me to Elizabeth. So that's how I got involved with it.

Matthew Wappett 12:36

That's awesome. Well, it sounds like you both have personal experience that has that has informed this project. And I think that's definitely reflected in the article as well. So the article actually just came out. It's entitled paths to equity parents in partnership with you Said's fostering black family advocacy for children on the autism spectrum. So, you know, we kind of talked about how you came to this topic, but why is this specific issue so important for disability related programs? And specifically, I guess for you know, you said, but also schools, service providers, why is this topic so timely and important?

Elizabeth Morgan 13:15

You know, I think, first of all, this topic is something that Ida and I are both personally connected to, for, you know, and have, you know, intersectional identities that make this topic, so important. And I think that, that's the reason why we need to have these discussions. So, you know, in our systems of care, one of the charges that we actually give in the article is for providers, researchers, policymakers, those who have any influence to recognize that our systems that are set up, have never been set up with black families and black children in mind, right. So whether it's school system, or, you know, our even our medical systems, if we look at the origins of those institutions in our country, they have excluded black children and black families. And so when we think about why the black families are having a hard time having access, why black children are having a hard time to access, it's because you know, the systems are functioning, how they were set up to be. And so we just really need to recognize that you have that and then you also think about the history of exclusion for persons with disabilities in our country, right. So any system that's set up for people with disability is to exclude right and to keep them separate. And so when you have intersectional identities, such as being black and having a disability have this double oppressive experience, right? It's almost, it's not like they are two different things happening at once. It's because they're happening in, in tandem right together there. They have they have their own experience as a result of, you know, being both a person of color being a black person, but then also having a disability. And therefore, we have to recognize how our systems have to really have an honest look at ourselves and those who was of us who are in these institutions, we need to have honest look and think about what are the current practices, policies? And personnel? Right? How are we doing things? And procedures, right? How are we doing things that will counter the narrative, right will counter the way that our systems are set up to to operate, we have to do things differently if we really want to support black families and black children. So I think this article in particular, was really powerful, because we center the voices of the black mothers who basically partnered with our UCEDDs and our LENDs to come up with programming that was not was really about the community giving influence about what they needed, and what was necessary in order to provide family centered care, and supports. And so this is really just highlighting that. And I think it could be an example for, you know, any institution that really wants to do the work of addressing systemic inequalities, and, you know, supporting and uplifting the rights and the voices of marginalized populations.

Matthew Wappett 16:44

Yeah. Well, Ida, you were one of the mothers who participated in this, you were one of the voices that was highlighted in this article. What specific barriers and challenges did you run into, as you were seeking, right, services, a diagnosis and services for your son?

Ida Winters 17:04

All right. Um, so for me, there was lots of barriers at every turn. Starting off, there's a cultural barrier. Where I'm from, autism in a black child is almost unheard of. So that piece is there first, and, you know, traditionally in our mind is discipline - that comes first, oh, they just need discipline, or they're spoiled. Or a lot of times when you take them to the doctor or something like that, it's a boy, he'll grow out of it. Or he needs he just needs to be around his cousins a little more, you know, you know, he's not socialized or integrated into society a little more. They didn't want him to stay in school. With my son, he's the youngest of three. And from K-3 until fifth grade, I was at school with him either the whole day, or half of the day, and I was a permanent chaperone on field trips. So you know what this looks like, as far as me working, and tending to the other children, or anything else I had during the day. Doctor's

appointments, we went in for evaluations and things we didn't get evaluation, we just got to automatic diagnosis, ADHD, OCD, ODD, things like that. And here's some medication. So those were barriers and the teachers...he was even put out of school and told this kid this school, yes, we cater to kids with disabilities, but not EBD. And I was like, What is EBD? I don't even know what EBD is. And she's like, "emotionally disturbed. We don't cater to them." And I was like, um, what does that mean? And this was another black woman. So it was like, really disturbing, but this is what happens.

Matthew Wappett 19:10

Yeah. Wow. That's, that's incredible. I cannot even imagine having to be there at school all day, every day. With with my kids. I mean, yeah. How could you work? How could you take care of the other kids? That's incredible. What a huge Oh, well, thank you for sharing that. I mean, that. I think those are things that many people unless they hear the voices of those who are affected, wouldn't know that kind of stuffs happening, you know, and that that's out there. So, one of the things that we like to do when we're when we're interviewing authors on this podcast is kind of not just talk about the content of the article, but also a little bit about the process. And there's always a journey that goes into writing an article like this, especially when it's participatory, and you know, includes the voices of many different people. So one of the questions I like to ask is, were there any memorable aspects or events or experiences as you wrote this article, it could be funny, exciting discoveries, new opportunities or collaborations. But as you pulled this project together, which has been, you know, almost probably over a year long process, at least working with the journal, it may have existed well before that, too. But were there any memorable aspects of writing your article? And why don't we start with you this time, Ida? Since you were one of the participants.

Ida Winters 20:33

Anybody can tell you, Elizabeth is amazing. So she took the lead on everything. And during the process of writing the article, or trying to put everything together at the same time, I was trying to launch Sankofa Midwest. So I'm trying to launch this at the same time, her and her team who's also part of coauthors for this article, they're training and supporting me in the framework for this. So at the same time, we're co authoring where they're mentoring me, I'm attending the Sankofa, I say family, support. And I mean, at the same time, she's like, coauthor, Coach, support. I mean, she's playing all roles for me, I think. For a minute, she was mom for me, because everything I needed, she was there, like supporting me in it. So we've like, gained a great relationship. We're on different sides of the country, but we've gained a great relationship. And we like bonded over the article, the launch of Sankofa and our children in the community. So that's most memorable for me.

Matthew Wappett 21:56

Yeah, so most of our listeners aren't going to know what Sankofa is, Can you can you share a little bit about what that is?

Ida Winters 22:03

I'll let Elizabeth share that.

Matthew Wappett 22:04

Okay. All right. Well, let Elizabeth

Elizabeth Morgan 22:06

I'll start off, but I could also add, so Sankofa so first of all, just to kind of give you a little bit of a background in history to the group, but also the meaning. So the group that I was referring to was actually started in 2015, at the UC Davis MIND Institute, and it started directly as a result from focus groups and interviews that I and other members of our faculty did, as a result of wanting to get to know various research projects and really wanting to get to know more of what our black community members needed from our institution. And so as a result of those intentional discussions, and partnerships, we formulated a group for families, black families who have children with developmental disabilities, and we were first under a different name a long acronym, and we realized that wasn't working. And so we went back as a as a team as a group and said, Okay, what would be a name that would be appropriate, and we decided on the word Sankofa and the word Sankofa actually comes from the Twi language that's located from from Ghana, West Africa, and it means go back and fetch it. And so Sankofa is a concept. And really an ideology that was that predates our group, predates, you know, I'm talking, you know, hundreds of years ago, right. And the whole idea is our group is about doing having the mission of giving back to our community, right. So the information that we have the resources that we have any type of ideas and supports that we've been given, we want to share with our community members, and that really aligns with the Sankofa ideas. And so when we decided on that name, which, like I said, is so much bigger than, you know, just our group, we realized that, you know, we were also joining in, in a bigger concept, right, a bigger movement. And so that's the reason why we're excited about the idea to be able to help spread the framework that we use. So we're currently in the in the, in the process of modularizing our Sankofa framework, so that we can be able to share with other uses and with other institutions and organizations that really want to do this work. And Ida and her team at the Wisconsin, UCEDD and LEND were one of the first to partner with us to help really help pilot this endeavor. So she can talk a little bit about the work that's being done in Wisconsin.

Ida Winters 25:13

Yeah.

Matthew Wappett 25:14

Yeah. So what about the stuff that's happening in Wisconsin? So is this group, I guess I can ask a follow up before I turn it over to you. Is this a group that exists nationally? Or is it just in several locations?

Elizabeth Morgan 25:26

Good question. So it's a group that can exist nationally and internationally. Right now we are centered in Northern California. So we're the the only support group for black families in Northern California who have children with with disabilities in Northern California. But because of the pandemic, we have now a virtual presence, right. So most of our meetings now are virtual, whereas they were in person before and we provided childcare. And we provided food for families through grants that we were able to receive. But because we're now virtual for we have two meetings per year in person right now. But we have people calling from all over so we have people that call in from, you know, Washington State from Florida, from Wisconsin, from New York, from Virginia, there'll be people that are calling from all over the place now. And so of course, Southern California. So it's a it's a wonderful opportunity just to be

connecting fiber and unit for families who, for so long, enriches the reason why we started the group have just felt so isolated and doubly isolated, right. So isolated, from, you know, not only not feeling like they were heard by providers and practitioners, but also feeling isolated from their own family members, because of not knowing how to talk about disability and how disability, there's still stigma associated with disability in our community. So there needed to be that space, and Sankofa has been able to fill that need. Yeah,

Matthew Wappett 26:58

That's incredible. That's incredible. Well, and so I should tell readers that if you want to know more about Sankofa, they do talk about it in the article, it's totally worth going to get a good overview there. And to kind of get a perspective on on sort of the role and the function in the in the structure of the group. So, you know, Sankofa, I think leads into my next question here, which is really your articles about how researchers, educators, service providers can build partnerships with black families? What are some methods as you explored this topic that researchers and educators and providers can do that? How can they be more effective in building partnerships?

Elizabeth Morgan 27:44

I'll hop in for that, too. I think, you know, what the article says, and, you know, it's so important, it's about relationship. And it's about really building partnerships that are not superficial, right, that have deep connections and a roots. And that we are really, you know, providing not only just a seat at the table, but also power and influence, right from people in the communities. So it's, it's actually real stake, right. And I think that, that, that means that for, you know, providers and institutions, there's going to have to really be points where you're gonna have to look at your institutions, look at your boards, look at your practices, and say, Okay, what have we done that? And what are we doing to be able to address this in a meaningful way. And so, you know, that is the, you know, the work that has to happen, and it's not going to be comfortable or fun, but it's necessary if you're really serious about doing work to address systemic oppression, such as racism, sexism, classism, ableism, you know, all of the all of the oppressions that really keep people from being able to have access. So I think that that's, you know, the first thing that we need to really address in order to do that, yeah.

Matthew Wappett 29:13

What about you Ida, what are some things that people have done to effectively sort of build partnerships with you and your family?

Ida Winters 29:22

Yeah, I have to agree with Elizabeth actually have stake in it, and really invest in it. And, you know, ask what is it that you want? Be a true partner. Don't research me. We all are researchers, we all want to know something. And what's the value of research, not to just the researcher, but the one who you are trying to research? What value does this have? And for me, dissemination is really important. If you've done research on me, or you've done research with me, I still want to know what the results are. And I want to I want the whole thing to be transparent - transparency is good, because I've signed up for something and at any point where it comes to, it's not what I signed up for? I'd like to know, so we can at least work this out. So honesty and transparency and a true partnership.

Matthew Wappett 30:30

Yep. Go ahead, Elizabeth.

Elizabeth Morgan 30:33

I was gonna also add to that. So we have to, if you're doing research in communities of color, and in particular, in black and brown communities, I think that as researchers, we have to acknowledge the fact that we need to do it differently, if we're going to counter the harm that has been done to these communities. So it really cannot be about taking away any more than has already been taken. We've taken enough, it's about giving to the community, right? So if you're getting information, you're also giving resources, you're giving information, you're giving opportunity, you're giving, you know, influence and power to decisions that are being made and in our institutions, right. So, you know, I think if we are like I said, you know, really partnering, then we have to recognize, you know, that by just taking from, you know, our communities and not giving back, we're doing more of the same, right, we're doing more harm, and continuing in the same thing, which is really the reason why many communities of color, distrust our institutions, for very good reasons. Because not only historically we've harmed but also we've done nothing to address it and to correct.

Matthew Wappett 32:09

Well, I mean, I do think it's important to acknowledge that, historically, right institutions of higher ed and other research organizations have been about taking knowledge and using it to elevate right privileged voices and not giving back to their communities where that knowledge potentially came from. And so yeah, it's a big shift in that dynamic of research. And that requires, you know, retraining, I think the researchers as well is to right, how do you do this in a way that is empowering and that elevates, and, and provides opportunity, and doesn't just take away and then leave the community again, at a loss? So yeah, but there is unfortunate, a long, unfortunate history along those lines. But yeah, I mean, that's why I think your article is so incredibly important, because it provides a practical example of what this looks like, or what this can look like. So kind of along those lines, you've talked about right, having the participants be stakeholders, be involved. Are some other practical examples of policies or practices that researchers or even service providers schools could use to elevate the voices of black families? And why don't we - can we start with you on that one, Ida?

Ida Winters 33:33

Well, a lot of times, I think like community advisory boards, or councils, or core councils, things of that nature, or parent, student advisory boards, things where they can get together. For my son's school, I was there all the time. Anyway. So I would meet with parents who had children who had concerns for their children's development and things like that, I would meet with the parents and we would talk and I would suggest services and resources that they can use to help. But at the same time, I will talk to the teachers and other staff members about resources and things like that. They need to make things like that available, because it's not just teaching the parents or the the teachers just teaching the students. Staff need to be taught. The parents need to be taught, as well as the children because disability is something that everybody in the world is going to have to deal with. So everybody needs to be educated on it. And it shouldn't be something that has to be normalized, it should be normal because this is another part of life. So schools need to, or us as a community need to be educated as well. Want to integrate that into the school system?

Matthew Wappett 35:04

Perfect. Yeah, I think, absolutely. And I couldn't agree with you more on disability as normal. That's actually what my classes called. We seem to treat it as an exception, right? And that this is something that's, that's rare and doesn't happen often. And yet, at some point in our life, we're all going to acquire, right, a temporary or a permanent disability, it's just the nature of being human. So yeah, thank you. So Dr. Morgan, what are your thoughts? What are some practical examples of policies or practices that you found elevate the voices of black families?

Elizabeth Morgan 35:39

Yeah, I think Ida said it perfectly. And, you know, I would just add that, you know, recognizing that black families are the answer. Right? So it's not about, you know, trying to find a solution. Black families have the answer, right, there's a great amount of resilience within the community. That and navigational skills and advocacy skills that have been able to, you know, really be bred and fostered throughout, you know, so many years. And so, black families have a wealth of information, a wealth of resources, that really are not or that are discounted, right and not appreciated in our systems. And so, you know, just really having that paradigm shift is really important, right into recognizing to recognize our implicit and explicit biases that are associated with that, I think another piece is to really think about and address, you know, how intersectionality impacts black families, right, so how, when they have a child with a disability, you know, the understanding and awareness of that disability, like you all said, understanding how to be able to really recognize that a part of their role is to really advocate and help manage and support their child in gaining their own advocacy for themselves, right. And so I think that intersectionality piece is really important, and really supporting our families. And that, that means that, you know, training for not only families, but for providers is key, right? So across the board, we need the type of training, the type of support that will allow that to happen. And I think the last thing, I think, with recommendation that we gave in the article really talks about providing spaces, safe spaces for families to be able to have conversations and network and gain culturally sensitive and relevant information to so that they can be able to use that as tools for advocacy. And so I think spaces like Sankofa are the are examples of that. And so we need to make sure that we have those spaces available for families ran by families and for families, in our institutions.

Matthew Wappett 38:16

That's yeah, well, that that kind of answers my next question, which is what is the main message you would like readers to take from the article? I think you've kind of you've kind of summarized that really well, there. But are there any other ideas that we haven't touched on that you feel like you'd like to highlight?

Elizabeth Morgan 38:36

That's okay. I think one of the things that we haven't touched on, and we've kind of, but I think what's important, I think, to make it really plain, is that the the authorship, even on our article was really intentional. So we have all of the black mothers that were pivotal in starting, both of the programs, are at the front of the authorship - right. And so we have various our UCEDD directors and LEND directors who are amazing researchers took the last places on the author list, because it was really intentional, while making sure that those who had the most stake in the involvement of you know, really doing the

work were positionally centered. Right. And so I think that, you know, that's a big piece when we're thinking about doing work with communities that we're really making sure that they actually have a center stage right and that they have their voices amplified. And so we you know, even within the article, we really fought to do something really unconventional which was include pictures of the participants - the leaders of Mothers, the advocates, that were a part of this. And Ida was one of them. And it really was because we wanted to make sure that we were centering their experiences and their voices. And that's uplifting them, which is really different than what research traditionally does.

Matthew Wappett 40:16

Yeah, yeah. So I have to ask it, is this your first formal research publication?

Ida Winters 40:22

It is my very first. And I was shocked that I was included every step of the way. Because usually, if I'm part of, you know, writing the grant, or whatever, in past, it was like, Oh, we only need you for this part. And you know, that was it. But instead, I was included. And I'm like, I don't know what this means. So I'm asking the researchers or whoever, like, I don't know what this means. But I felt comfortable enough to say to them, I don't know what this means. And they come back and take time out and say, well, this means this, this and that. And this isn't here because of this, this and that. So I felt that we were working together as a team. So it won't be my last article.

Matthew Wappett 41:16

Well, I'm glad to hear that. I mean, it is I'm glad that you brought that up, because it is definitely different within traditional academic research, right? Most participants are anonymous, participant A - given pseudonyms, you'd have no idea who they are. And the fact that you've been able to write be involved in that process, have your name on the article, is a pretty significant paradigm shift, I think, you know, from the outside, oh, it's just, it's a couple names and some pictures. But in the overall scheme of things, it's a really big change in the way that we view research and who can do research and who can publish research? Even so, ya know, we're actually quite privileged that you chose to work with us and publish in the Developmental Disabilities Network Journal, we're really honored to, to be involved in that and to help support that work. So thank you.

Ida Winters 42:12

You're welcome. Thank you, guys.

Matthew Wappett 42:14

Yeah. So two more questions here. But the first question, I asked this to everybody, what motivates you to do this work? Why do you do what you do?

Ida Winters 42:23

Things continuing to be like they are, that's what motivates me. One day, I see it changing. And I know, I probably won't see it in my time. But eventually, it'll change.

Matthew Wappett 42:38

But you've seen your efforts make a change in your, in your family's life?

Ida Winters 42:43

Definitely seen a change. And I'm a family peer mentor, with Wisconsin LEND, and we get trainees through there, future professionals. So I believe it starts at the root. And you know, the tree grows. And eventually we train them they're future professionals, and it'll get better.

Matthew Wappett 43:07

Yeah, well, I totally agree. So what about you, Dr. Morgan, what motivates you to do this work? Why do you do what you do?

Elizabeth Morgan 43:15

Yeah, thank you for that question. I really feel that because of my experience of being both a teacher and administrator, and then also a parent, you know, I see all the problems, and I've seen them from multiple vantage points. And I'm interested in being a part of the solution. And I also am interested in doing things differently. And so that means really wanting to be a transformative leader. I think of even my work, as you know, I'm a mother scholar. And then before, you know, scholarship, I'm a mother and I'm a parent. And I understand that, you know, the work that we're talking about, it's not just, you know, words on a paper, we're talking about lives, we're talking about, you know, human beings and their opportunities in life and their how services and in early assessment and diagnosis are associated with those things and how, you know, when they don't have them, how that really does impact the quality of life of a person and the opportunities that they have. And so, you know, I really want to be that kind of transformative leader. I even think about as transformative mothering, you know, engaging in really seeking to change not my child but seeking to change the world that my child is in, right and other children in my community are in because we really do need to do that in order to be able to address it and make make this is a better place for all of us?

Matthew Wappett 45:01

Yeah. Well, and I mean, as you bring that up both of you, I mean, this is a big shift in the way that we view mothers and the way that we view researchers and everything else, the idea, you know, historically, I think, at least from a professional standpoint, we have expected people right, to divorce their personal life from their professional life. And as we come to understand identity and the impact it has on it, and the role that it plays within our professional life, you know, being able to marry those two, and make them work together. To the accomplishment, I think of more human ends is just so incredibly refreshing. Instead of ignoring, oh, I'm a mother of kids with disabilities, but I'm not going to worry about that. I'm going to focus on this over here. I mean, being able to have those together, I think is much, much healthier.

Elizabeth Morgan 45:54

Well, Matthew, I was gonna say just, you know, just to that, you know, compartmentalizing and siloing ourselves is inauthentic. It is, right, it's not authentic. And so I think that, you know, we have been trained, right, as scientists, as, you know, empirical investigators that, you know, you want to be objective and to do that means that you're completely removed from the project. But that never has been the case. Right? If anything, you know, the researcher is always a tool of the....is a research instrument, right? Involved in the design and analysis of any project that you do. And so, you know, just

being honest about that process, forthright, I think, really adds to the trustworthiness and the rigor of any projects that we decide to do. Because, you know, it really adds breadth and depth to any project that we interact with. So I really do appreciate that that comment.

Matthew Wappett 46:57

Yeah, no, it absolutely does. And I mean, the the experience, and especially, I think, within your article, the experience that, that you and that idea and the rest of the the author's bring to this, and the fact that it's lived experience makes it so much more powerful than some objective research or reporting on some abstract them out there. Okay, well, last question here. And this is what I love to ask what is one thing that you've been doing recently to make your work more inclusive and accessible.

Elizabeth Morgan 47:34

So I think, a part of my quest in order to be able to make sure that, you know, the work that I do is more accessible, is, you know, things like this, I think it's so great that this podcast is available, to be able to really help translate and make plain research projects, Ida and myself have done other presentations, we just recently did a presentation for the African American Conference on Disabilities, we're doing a another presentation for..Ida remind me where we're going?

Ida Winters 48:09

M-TIP.

Elizabeth Morgan 48:10

Thank you. So we doing that together. And as well as you know, just the fruit of other projects that can that can come out. And so I think that's a big part of, if you're doing community work, you want to make sure that the community has access to it. Right. And so it's not just this esoteric, you know, piece that you know, only people in the academy or people in, you know, various higher education institutions will have access to. And so that's another thing I really appreciated about the DDNJ, Journal of having plain language requirements when it comes to the abstract. And I think, you know, we want to move to that overall, right, just making sure that our articles are accessible, and as well as the information when it comes to being disseminated that is disseminated, you know, to our community. So one thing that I'm doing, actually, this weekend, is I will be presenting at a local school district, they're having a conference for black families. And I'll be presenting, you know, kind of pulling in some of this stuff, but also just overall talking to families about how advocacy and how more we're talking about IDEA and disability rights. The root of those are have come from civil rights legislation, which you know, are directly connected to our community and many people within our community. We're a part of that legislation happens. So we're, you know, at the root of these things, and so our children and also us should have access to this information, because we've been a part of that. So it's just really making things plain in as well as making that concerted effort to really make those partnerships can connect with community stakeholders, and be involved and have a real vested interest in the welfare of our community. So I think that's a big part of what I tried to do.

Matthew Wappett 50:09

Well, thank you for that comprehensive response. And I totally agree. I mean, that's the reason that we do this podcast is very few people are actually going to go read a journal article. And yet we feel like

this information is so important that, you know, we've got to put it out there in multiple formats to make sure that people who want it can actually get it. Because I'll tell you what, I'm even afraid of reading journal articles. Okay, Ida what about you, what's one thing you've been doing to make your work more inclusive and accessible?

Ida Winters 50:39

Well, I talked to the people in my community. So I work for UW Madison Waisman Center, but I am a satellite employee. So I'm actually living in Milwaukee, Wisconsin. And a lot of work is done at Waisman center. But Milwaukee, they don't quite see everything that happens out there. So instead, what's going on there, I bring it out to the community, I'm in community engagement. So to make sure they get what's going on there. And they get the benefits of what's going on there and make sure I bring it back here to the community. And make sure that community partners and stakeholders here in Milwaukee, are involved in what's going on there. Like we have groups that's integrated learning, they can learn about the same thing that they're learning about in Dane County, and put the input of what's going on here in Milwaukee and learn better ways to make it work and give input to help what goes on and works in Dane County. So you know, we kind of put it together because things don't quite function as a state. Instead, it breaks down by county, how it works, but maybe we can make things more cohesive and accessible for everybody, no matter which county.

Matthew Wappett 52:02

Yeah, no, and Wisconsin's always been that way, hasn't it? I remember doing work with Wisconsin many years ago, and the counties are so incredibly powerful there. But every state is different. Every state approaches the work differently and requires yeah, a different mindset, different strategies, different tactics. Well, I want to thank both of you for your time today. This has been just such an enlightening conversation. So Ida is one of the participants in authors on this paper, but who were some of the other participants and authors who have contributed to this project?

Elizabeth Morgan 53:18

Yeah, thank you for that question. We actually have several amazing authors on our on our project on this particular project, including my two colleagues at the MIND Institute, which included Benita Shaw, she's a strong parent advocate, and community stakeholder in our Sacramento community. Dr. Jasmine Burns, who has been on the MIND Institute for several years, but now actually is practicing in Texas, we have Chiffon King who is a parent, navigator and strong advocate within her community in Wisconsin with Ida and then our two directors. So Aubyn Stahmer who is the LEND and UCEDD director for the UC Davis Center for Excellence in developmental disabilities at the MIND Institute, and Gail Choudron who is the director at for our the Wisconsin LEND. So all of us were able to really come together, bring our ideas, and just really helped make this paper what it is, which is something that we're all extremely proud of.

Matthew Wappett 54:33

Well, it's it's an incredible team. And honestly, it's an incredible paper. I get the privilege of reading all of them, and so does Alex and I learned just such an incredible amount through through your paper and just your approach. And I mean, and even this conversation, I mean, I think that the way that you're approaching this and is just so important to talk about and to acknowledge and to promote. And anyway

I'm just going to encourage everyone to go read the article, it will be linked in the show notes. That's all I can say go read the article, download the podcast. Listen to that, listen to it two or three times. There you go, you'll be a better researcher for it. Well, anything else that you would like to cover?

Elizabeth Morgan 55:18

Just thank you for the opportunity.

Matthew Wappett 55:20

Yeah, well, thank you both for taking time out of your day to talk to us. So that's it for our conversation today. I would like to thank my guests Dr. Elizabeth Morgan and Ida Winters for their time and for their insights. I hope that you found the conversation. As interesting and insightful as I did, I really enjoyed visiting and getting to know both of them both of our guests much better than I did before. I would also like to thank DDNJ, managing editor and Author Insights Podcast Producer, Alex Schiwal, for her hard work to get this podcast out. Alex has been the managing editor for a little bit here and she actually helped us get out the special issue on DEI and we're excited to have her more integrally involved with DDNJ. So if you want to email us, you can the email address for DDNJ is editor.ddnj@aggies.usu.edu. I know that's kind of long. I'll do it again. editor.ddnj@aggies.usu.edu. And Alex is the one who answers those. So if you have questions about the podcast about the journal about the author's whatever, Alex will answer your emails quickly, so please feel free to reach out. We would 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 and for the journal. The journal also received support from the Utah State University Libraries and Digital Commons and we are grateful for their ongoing efforts to help us keep this running. As I mentioned earlier, please be sure to subscribe to our podcast feed on Apple podcast, Spotify, Stitcher, overcast PodBean again, wherever you get your podcasts, please leave us a rating and a review. And please share this podcast with your friends and colleagues. Your shares especially make a big difference in getting the word out about this work that's being done. You can learn more about the Developmental Disabilities Network Journal at our website, which is digitalcommons.usu.edu/ddnj or you can just go to your favorite browser and type in DDNJ - I believe it comes up as the first result now, you can also download a podcast transcript in English and Spanish for this conversation and all of our past conversations. And you can learn more about our podcast guests at the Institute for Disability Research Policy and Practice's webpage and that is idrpp.usu.edu. And on that page, you'll find a separate page dedicated to the journal and the podcast. So we'd encourage you to go there, find pictures of our guests and learn a little bit more about the podcast and the journal. So with that said, thanks so much for tuning in today. Thanks so much keep up the great work, you are all making a difference, and we want you to know that what you do matters please tune in next month for our next conversation which is with Dr. Tawara Goode from Georgetown University. And with that said, have a great rest of your day.