

Justice Shorter:

Greetings, good people. Welcome back to Disability Inclusion: Required. I am your humble host, Justice Shorter, and today, we are prioritizing the parents. I am so pumped to discuss Parenting While Disabled with Melissa Lomax and Dr. Morénike Giwa Onaiwu. Melissa serves as the Director of Employment and Transition Services at Family Services Resource Network, a New Jersey-based nonprofit providing statewide employment, family support, advocacy and case management services for youth and adults with disabilities. She is a board member for the National Federation of the Blind in New Jersey and the Government Affairs co-chair for the New Jersey Association of People Supporting Employment First. Melissa has collaborated with youth leaders in Syria on the development of a Silver Scorpion comic book, which features a superhero focused on global peace and disability representation rather than cure narratives. Now, that's a comic book I am all types of into. She holds a bachelor's degree in English, a master's degree in public administration and a project management professional, PMP certification.

Morénike is a research fellow in the social dynamics of intervention lab in the AJ Drexel Autism Institute at Drexel University. She is the founder of Advocacy Without Borders at grassroots nonprofit supporting community activism. Morénike is an award-winning transdisciplinary scholar activist for global human rights. She is a prolific writer, a self-advocate and a parent in a multicultural neurodivergent family whose work focuses on intersectionality, meaningful community involvement, disability justice and neurodiversity. Morénike is a highly sought out keynote lecturer and public speaker. Let's get into it. Morénike and Melissa, thank you both so much for joining us. How you doing?

Melissa Lomax:

I'm great. I'm happy to be here. I'm happy to share with this wonderful space about parenting.

Justice Shorter:

Mm-hmm.

Morénike Giwa Onaiwu:

Likewise, happy to be here with you all.

Justice Shorter:

We are happy to have you. I'm so looking forward to today's conversation and I actually want to invite the two of you to introduce yourselves by telling us what is the phrase that you repeat the most as a parent and then follow that up by telling us what is the phrase that you hear the most from your children? Morénike, can you kick us off?

Morénike Giwa Onaiwu:

Absolutely. So the phrase that I repeat the most, and this is going to sound really cliched, is I love you.

Justice Shorter:

That's beautiful.

Morénike Giwa Onaiwu:

No, don't say all, because sometimes I say it because they're getting on my nerves and I have to remind myself that I love them.

Justice Shorter:

That's good.

Morénike Giwa Onaiwu:

So, that's what I say most as a parent. The phrase that I hear most from them is, "Oh well," or, "Oh, I forgot."

Justice Shorter:

Very convenient, right? It's convenient for them to forget all the time. [inaudible 00:03:34].

Morénike Giwa Onaiwu:

I'm like, "Oh, you forgot? That trash is sitting right there and I thought I told you to put it out. You forgot though, right?"

Justice Shorter:

It's right there. And in fact, at this point, it's all over the floor. How could you forget? You're literally walking through it. I understand.

Morénike Giwa Onaiwu:

Okay.

Justice Shorter:

For real. It's a lot going on. Melissa, how about you? The phrase that you repeat the most as a parent and then the phrase that you hear your kid telling you more often than that.

Melissa Lomax:

So we also in our house, talk a lot about love and kindness. So I'm going to glaze over that one and get to the one that I use secondarily the most. And that is does safety come first or second?

Justice Shorter:

Mm-hmm.

Melissa Lomax:

These are the questions that we ask in our house because kids are exploring and doing things that I wouldn't do. So there's that. And then secondly, what I hear most from them is, "Are you ready to play?" And that's only because I am their best friend, their number one entertainer. And even when the babysitter is here, when I have to work late on some evenings and I'm in the house, they're trying to bring me into the game and I'm like, "There's someone else here who wants to play with you." But I do love it as well because I've always wanted that relationship and I'm glad that I have it now where my daughter and her brother, they're able to want to be around me and want to play with me.

Justice Shorter:

Come on, being the relationship that you most often wanted, right? Being the realization of that, I think that is extraordinary. I'm so happy you started there. Melissa, I'm going to invite you to continue us on in conversation. I want you to start off with your story a little bit here. Tell us about your journey to motherhood, if you will.

Melissa Lomax:

Absolutely. And I'm glad because I do often confuse people when I say my daughter and her brother, but my journey to parenthood started through tragedy. I'd recently resigned from my job and I was going on to a new career path and just as that happened, my younger sister passed away and she was in the process of adopting a little girl because she dealt with infertility and her and her fiance really wanted to have a child. So when she passed, I left my plans. I left Virginia, came to New Jersey and moved in in my mother's house because that's where my sister was and that's where the foster care case was opened. So I started the whole process from there being a resource parent and having her under my care and waiting two years for the adoption to go through.

And within that two years, the biological mother ended up having another child, a boy, and my mother adopted him. So that's why he's in the family. I say kids, though I legally have one child, I take care of both. And because that family couldn't stop, they had another child, another boy, and my cousins adopted him. And their final child, my aunt is fostering as we speak. So we have the last four of their 13 children in our family and it all started because of my sister having that desire to parent.

Justice Shorter:

Wow. Wow. Melissa, I had heard you mention a bit of your story to me before, but I did not know that it was so deep and so extensive and widespread with respect to multiple people in your family stepping up to provide safe and loving homes for these children. It's extraordinary.

Morénike, I want to invite you to come on into the conversation a bit here and just share a bit about how your disability has impacted your parenting. We're talking about parenting while disabled here. So tell me what that's like.

Morénike Giwa Onaiwu:

Yes. It's impacted me in different ways as a parent. In some ways, I think it has made me a stronger parent, a more attentive parent, a more intentional parent because I use creative problem solving for certain situations. I try to be prepared and not take things for granted. I try to consider things from multiple points of view. And so, in those ways, I think that it has strengthened my ability to be there for my children, to be flexible and patient, and also, to cultivate a relationship that's meaningful because of the fact that certain things that maybe other parents might take for granted might not be as accessible for me. And so, building our connection in other ways.

However, there have been some challenges as well. We live in a very ableist society where they don't... Disabled people are infantilized, disabled parents are seen as an oxymoron. And so, in those ways, I've had to battle things that shouldn't be battles with schools, sometimes with providers, with people's... Just things that might, to some people be as simple as attending a school activity or being involved and having to navigate that, being able to make that happen for me and my family and having to always put that advocate hat on.

Justice Shorter:

We're going to talk about that in way more detail, all of the barriers, all of the obstacles that are levied onto disabled parents. I'm really interested in hearing more about what that looks like and how disabled parents who are listening can also navigate that for themselves as well. I also really loved what you mentioned there about the creativeness, the resourcefulness, the problem solving, the absorbing and understanding and approaching things differently. Melissa, I know that that is also a practice of yours. You and I are both blind. Tell us a little bit more about how your disability has impacted your parenting.

Melissa Lomax:

Absolutely. I love what you said, Morénike, about the advocate hat. I feel like it got glued to my head when I became a parent because at that point, you cannot turn it off. So there were times maybe in my journey where I may have not advocated for myself. Maybe I said, "Well, that's a battle I have to just not deal with right now." Maybe I didn't have the time, maybe I didn't have the energy. But when I became a parent, there is no turning it off. I'm waiting for a phone call right now from a store that discriminated against me and getting the accommodations that I needed in order to shop for my child. I had to tell her, "Hey, I came home empty-handed because somebody wasn't open to letting me shop. They were judging my process for doing so."

And it's sad, but it allows me to, like Morénike said, allows me to open that space for my child to understand this is what I endure as a person with disabilities. So it may look different, but I love you so much and I'm dedicated to going through the journey no matter what it looks like.

And self-advocacy also looks like speaking up to strangers who assume that my child is taking care of me. Even when my child was three years old and throwing a big, huge tantrum on the floor somewhere, someone would go, "Oh, that's so kind that she loves you enough to take care of you. Take care of mommy." And it's not that way. And I have to educate people so often. I said, "Who makes the decisions here? Who's leading whom?" Because I am. I lead my child. She's distracted. She wants to look at beautiful flowers. I need to tell her where we need to go. I need to get us there.

And the second little piece is when it comes to my disability, it's understanding that there are strengths that come along with how I am programmed to think. And I've been able to teach individuals who are not blind how to use some of these techniques that I feel are second nature, but it's because of my disability. So a small example is I was afraid of my child choking on food when she was young. You know they put everything in their mouth, so not even just food. So I started being very extreme when I fed her and I would go, "Mm, yummy, mm." Every time. And people would look at me like I'm crazy. But when my kid picked up a bead off the floor and she was two rooms away, guess what she was doing? "Mm. Yummy." And I was able to run in and say, "What are you eating?" That was my workaround. And I think that people with disabilities should know that you have amazing workarounds that some people really want to know about too.

Justice Shorter:

Yes. So many accommodations, so many great innovations have started off with individuals with disabilities as you both very well know. I love what you mentioned around critical conversations. And Morénike, I'm going to bring you back in here because as you know, April is National Autism Awareness Month.

Morénike Giwa Onaiwu:

Yeah, yay.

Justice Shorter:

Yeah, I'm saying in recent years you actually consulted on Disney's Proud Family reboot Louder and Proud. Now you know I am an avid fan of Proud Family, okay? When I was 16, 17, it was my show, but you-

MUSIC:

Proud Family.

Justice Shorter:

Oh my God, it was so good. You consulted on an episode that addressed various stages of awareness and adjustments within families who have autistic children. So tell us more about that process because that particular episode has been really applauded by many autistic advocates everywhere. So how did you all manage to get the messaging so right?

Morénike Giwa Onaiwu:

Thank you, Justice, for this question. And I'd really like to give a huge shout-out to Diane J. Wright of Autastic and to the Krab Family team and to the other people who were consulted and involved in this project. And also a shout-out to the Autistic Women and Non-Binary Network for their support with this.

It was a really meaningful episode. There were non-disclosure agreements we had to sign. So for months, we had to just sit silently on this matter when we wanted to talk about it so much, we were so excited. But first, I'm just thankful because a lot of times, it can be very difficult to get this type of messaging right, in terms of a message that is affirming of disability but isn't inspiration porn and that is also culturally appropriate and that fits in with the message of this animated children's show, a reboot that a lot of us love keeping true to that message.

And so, what we had a lot of conversations and I'll say that some of them in the beginning were a little tense because there were some really great intentions and ideas that they wanted to incorporate that we politely but firmly, shut down because that's just not the reality of our lives. It wouldn't have done justice to the direction of the show and to BeBe's character. And so, we had a number of meetings with the writers, with the producers and even the voice actors about our thoughts, about our experiences.

Diane, again from Autastic, brought in a team of all Black autistic parents to consult. And most of us had autistic children [inaudible 00:14:57] Black autistic children. And so, it was important for us for BeBe, first of all, to show that there had already been, I guess, the term is Easter eggs, pointing at elements of his disability. And for it to be something that a lot of non-disabled parents, they go through their process of trying to understand what things mean and how to adjust. And so, we wanted there to be the difference, to show the professionals that they went to go see and the information that they received, the parents trying to understand what this meant.

Sometimes, different family members will react different ways. So the father had one reaction versus the mother, but just all of the components of the intersectional element of having a Black son with a disability in a world that isn't accepting of either of those identities. And we just really tried to look at what might seem like very insidious, subtle things that are not, that are important. Him not wanting to wear a certain sock or certain clothes, his hair being not only the element of celebrating the different textures of our hair, but also, the sensory component.

And so we really just, I think, just had a lot of very pointed discussions that were very direct about what we wanted to see, what we thought should be removed. And even the person who voiced the doctor, Holly Robinson Pete, is a Black autism mom of an autistic son. And so, I just really feel like what happened is, I think, is that the lived experience of disabled people was valued by the team and it was not silenced, it was not disregarded. And I feel like that is how we got the messaging right.

Justice Shorter:

That is exceptional. And I truly mean that in the pure sense of the word, because it's not often, sometimes the experience of folks who are brought in to consult or give their experiences or their expertise on something sometimes. And you know this is, we as individuals with disabilities will be asked something and they're supposed to go in an entirely different direction or we'll be asked to participate in a listening session and we'll realize that nobody was really listening five years on.

Morénike Giwa Onaiwu:

Exactly.

Justice Shorter:

And what resulted from it was not at all what we had been told in the beginning. You mentioning that folks brought in Black autistic parents who had Black autistic children. That in and of itself, I think, is extraordinary. The fact that you all were able to tell them things that were not working, tell them things that needed to be removed, things that needed to be revised and folks listened to that. And you all came with your own ideas and recommendations about your personal experiences and how they could get it right and how they could steep it in reality, rooted in reality in a cultural context, a Black cultural context I think, is simply extraordinary. I'm so happy to hear it. Especially when you think about the various configurations of how people come to be in a family and how people have different understandings and expectations about what their family should look like and what their children should be.

And with that in mind, Melissa, I'm going to bring it back over to you because I actually want to talk about some of your firsthand experiences with navigating the foster care system, which is how you personally came to start developing your own family. But I want to talk about how you navigated that system as a disabled, single parent. Can you tell us more about that experience and what disabled parents need to know when interacting with foster care systems?

Melissa Lomax:

Of course. A little bit of background about my family is that we have a decent amount of people who have adopted or foster. So when you look at our cousins and when we're all in the same room, half are biological or half are adopted. I'm no stranger to the foster care system. I'm also no stranger to wanting to adopt a child. It's just in my DNA. But I will tell you, because I've seen the system, I didn't actually want to go through it. I wanted to adopt through a private agency, a little bit more cushy, more luxury experience. So when tragedy struck and I did have to go through the system, I was not really happy about it. I will say, it wasn't the worst experience, I've seen worse, they're getting better, but it's not by any means a warm, welcoming environment for people with disabilities.

So I will say that they did adapt my trainings. I just asked them to describe the materials for me so that I can go through the trainings with everyone else. And their solution was, "You'll just go on the training by yourself on Zoom instead of in person." And I was like, "Well, that's not what I intended." And that was their accommodation.

Another piece that I noticed is that they did ask more intrusive questions. They felt that they had a right to ask questions, that it doesn't matter what home study, safe study you have, those questions are not up there. You don't need to know how my disability happened, how it progressed. That's not on your paper. You can't show me that. But they felt that because they were at these interviews, asking these questions, they had a right to dig deeper into things that they had no business digging into.

There were also assumptions placed when we had to do the study to make sure our home was safe, assuming that we would have people helping to get that process done. I was like, "I'm spearheading it. It's going to get done." My mom is also blind, so, together, we're doing it.

And then the last piece I will say is, there were times where you can tell that they were talking down or assuming that I would be incapable of getting things done. And it was unfortunate because when I first became a foster parent, as I shared, I left my plans. I was in Virginia when everything happened. I left everything to come to New Jersey. I did not have a job at that time and I was also not taking social security benefits. I was living off of my savings from my previous job until I was able to find a new one and I had to endure their talking down on me and where I was in life and things like that.

And it wasn't until I got a job where the resource worker started celebrating me like, "Oh wow, I'm so proud of you," as if I was some kid or some baby who couldn't get the job. And it was unfortunate that I then had to throw in bits of my work and my education when I felt that they were belittling me. And it's

unfortunate because not everyone with disabilities has that experience and they shouldn't have to. I want to be very clear. You don't have to be well-educated. You don't have to be employed. You can get a job, you can get an opportunity to do this work without those two elements. And yet, if you don't have them, there will be people who may talk down to you, who may belittle you, who may say the wrong things, ask the wrong questions, not be helpful.

I felt like a pariah when I had to go into the office to have them notarize my ID, something along those lines. I can't remember why I was in there, but I felt like a pariah. They're like, "Are you going to help her? Are you going to help her?" It's uncomfortable to say the least. But I would say because I was aligned with my vision and the reason why I wanted to do it was for love for a child, I endured that harsh treatment and I encourage other people to do likewise.

Justice Shorter:

Love is what was leading you. And I just want to linger on that point just a little bit because often, people are curious as to why? Why endure such treatment? That piece that you mentioned around being infantilized, around people talking down to you, people being condescending or people feeling as if they are entitled to know the entirety of your disability origin story or how your disability has progressed so on and so forth. I have literally had to train this out of people because I'm just like, "You do not have the right to know this. I am in a bathroom trying to wash my hands, use the bathroom. I'm not about to tell you the origins of my disability or give you my medical information as a stranger before you ask my name. You are trying to learn about my medical information or even just information about my personal history," because some people have come to their disabilities quite honestly, through violent ways too.

There's people among us in our community who have had traumatic brain injuries or through domestic violence or whatever the case may be. So having strangers just come up to you and feeling as if they can implore you to share such details on a whim without even figuring out who you are as a human being is demoralizing to say the least.

Melissa, let me just ask you one quick follow-up question before I bring Morénike back in on this. Tell me, what are the changes that you believe are needed? You told us about some of the discriminatory... Quite honestly, discriminatory treatment, whether it was the explicit or implicit treatment that you received. Tell me about some of the changes that are needed to make sure that disabled families navigating the foster care system no longer have to be burdened with some of these barriers and challenges that you faced.

Melissa Lomax:

Oh, for sure. So, we can say that, of course, we would hope that there would be increased training. Like you said, the fact that we have to do it on the daily is sometimes exhausting, but there should be training. There's high turnover in that field. We know that. So maybe training for initial hires as well as reoccurring opportunities for them to understand more about the disability community. That'd be great. That'd be a dream.

But if they cannot implement all those training elements, I would ask them to do two things. And that's number one, ask the question. What access needs do you have, to every single person who wants to be a resource parent, regardless of what they look like or what they've disclosed to you. Because everybody has access needs and maybe in order for them to be a successful resource parent or to learn because people do have learning disabilities and I don't know if everyone knows, but you have to take certain courses to become a resource parent. You have to pass certain tests, depending on which course you take.

So if someone has a learning disability, they have access needs too. They just don't realize they'll need to disclose it to get to be a resource parent. So asking that question, what are the needs that you have in order to be a successful resource parent would be wonderful?

And the second bit is helping people with disabilities to see themselves and to know that they're actually welcome to this opportunity. I still get calls today from people across the country going, "You're blind. You've done this work as a foster parent. Can you help so-and-so? They want to try it too. They just don't know if they can." I love to be that, but I wish it weren't like that. If there were materials that included people with disabilities in the pictures that welcome stories of a person with disabilities who was a resource parent who had a wonderful opportunity, then we would see ourselves in those stories and we would know that that door is truly open and not have to live in fear that once again, it'd be an uphill intense battle against ableism.

Justice Shorter:

Embed our experiences and our very existence into all of the other everyday materials that are used within the foster care system. Morénike, let me pull you in. Do you have anything to add on this point around what changes are needed within the foster care system? I'm going to ask you about CPS and other government resources in just a moment, but let me just ask you specifically on this point, is there anything you have to add?

Morénike Giwa Onaiwu:

I definitely echo the point about needing more training and more visibility. I also would add that I think another change is that, Melissa, you made an interesting point about initially wanting to work with a private agency, but ending up, because of circumstances, working through the state foster care system rather. I would just say that there's definitely some inequity in some of these programs, but even some of the private entities have some problematic policies that I think need to be changed. And because they're not regulated in the same way as the state agencies, if anything, sometimes they feel that they have license to be discriminatory. We've been openly told, actually reject... I might still have the letter somewhere that per agency policy, parents with disabilities do not meet the criteria for a particular private agency.

And so, yet there are still federal laws that prevent discrimination. So the fact that someone actually feels that they could have that in their handbook and send that to someone with impunity says a lot about where we are as a system and that's definitely a change I'd like to see.

Melissa Lomax:

I did not know that. So thank you for enlightening me because I didn't have the chance to go through the private avenue and I guess that's why we do the podcast and the education. Had no idea.

Justice Shorter:

Listen, all of us getting educated by each other and by the things that we are living and surviving through. Morénike, I want to keep you going here because you're on a roll. Talk to us more about paternalism within philanthropy, more specifically, as it relates to how philanthropic organizations engage with disabled parents in particular, and parenting communities in general.

Morénike Giwa Onaiwu:

Well, this will be a short answer. Terribly.

Justice Shorter:

Elaborate. Tell us more.

Morénike Giwa Onaiwu:

Right. Terribly, if at all. I think there are definitely some examples of some philanthropic organizations that are trying to make a change in a number of ways. I think we've definitely seen some regression in recent years due to administration changes and other things that I think are trickling down in the philanthropy world as well, unfortunately.

But I think that it is problematic for me that there's still these silos. This is education, this is race, this is gender, this is sexuality, this is parenting, this is disability, as if these things do not coexist. And it almost seems like some organizations seem to... If they're focused on disability, they prefer to amplify the voices of non-disabled parents of disabled children or of disabled individuals who might not be parenting. And you can definitely gain insight from those groups, but you need to have a more thorough view. And I think that ultimately...

And then in terms of parenting grants or programs, they seem to overlook disability as an area of importance that needs funding, that needs focus. And so, I really feel that the paternalism is real and sadly, it's not even intentional. I guess there's just such lack of understanding or lack of awareness of our existence that they aren't even intendedly excluding us. It's just like we aren't even there.

Justice Shorter:

Paternalism, glaring omission, sometimes the reluctance to redirection and quite honestly, the invisibilization of families with disabilities, particularly that point you mentioned, Morénike, around non-disabled parents of disabled children and how that completely erases the experiences, erases the inclusion of disabled parents of disabled children or disabled parents of non-disabled children. It's a really great point.

Melissa, I want you to come back in because the other side of the foster care coin is Child Protective Services. And I promised that we were going to touch on this. So can you share some examples of how disabled parents are often more heavily scrutinized? You talked about this, right? You were a bit more scrutinized. People were asking you questions that they should not have been. Give us a couple of more examples about how disabled parents are unequally scrutinized or heavily surveilled by government services in general and what direct impact does such treatment have on disabled families?

Melissa Lomax:

Absolutely. When it comes to this, a prime example is my daughter and her biological mom. So her biological mom has a very, very significant cognitive disability, developmental delay. And that is not the reason why my daughter was taken away from her biological mom. It was actually the father and his very, very bad, very questionable record. The state of New Jersey got, in a sense, so fed up with the fact that this woman, my daughter's bio mom, was trying to have children so much and getting them all taken away, mainly because of the husband and his situation that they said to her, "We will pay for you to have someone live in an apartment full-time, help you care for a child if you divorced that man." And she did not divorce that man until it was too late. And when she finally did, the offer was not on the table, at all.

But it would be my hope that there would be more chances for people with disabilities to have parenting classes that actually give real examples of parenting and not just, this is how you change a diaper. You don't see it enough. You see them getting trained for employment or even how to groom themselves. You see classes on how to date while having a disability, but you don't often see how to parent. And like Morénike said, it's because they believe that the two shouldn't go together, and Justice you said it as well. It's like an oxymoron. And so, when you get some parents who have disabilities who get their children taken away from them, it's often because they didn't know how to advocate for themselves or maybe there was just a certain thing that they struggled with as a parent that they could have been taught to do.

And yet, society's like, "Hey, instead of teaching them, instead of helping them, let's just take that child away from them because that means that the child is in danger." And it's unfair because I don't know, maybe there's extra prideful people out there and I haven't met them, luckily, but I don't know of people

who approach parenthood going, "I know all the answers. This will be so easy." But yet, people with disabilities are dinged for their struggles a lot more readily. It's to the point where I would be lying if I said I wasn't afraid of maybe the one day where my kid goes to school with a bump on her face. Maybe they'll assume that I let her get hurt instead of her being a typical kid.

Or I will get embarrassed sometimes if my kid, she's in first grade, she likes her own fashion. And I will tell you that fashion is not the stuff I've studied before. So when she goes to school looking crazy because I say, "This is the one day per month where you can pick out your own outfit," usually because she loves every outfit, but I fear that people are going to say, "Oh, she can't take care of her." And sometimes it just pops up. It'll come out of nowhere. I don't live life in that fear at all times, but it does come up. It does pop up when things happen or when I'm at the park and I'm just having to keep my kids close to me where all the other parents can hang out and socialize because they can see their kids from a distance. I have to just get in there and get involved. And you just wonder what are people thinking when they see how you parent?

And I know that other parents with disabilities face that and it's a real thing. I've had people tell me that their children were taken away from them or I've helped families fight that situation and advocate for what's going on. But unfortunately, nothing will officially change until society stops seeing people with disabilities as inferior and stops assuming that any child who's parented by us is in more danger or is not as blessed or fortunate.

Justice Shorter:

Morénike, you do a lot around this very issue and supporting families through those fears, those very real fears that Melissa has spoken about, talking with institution systems about a lot of those perceptions of inferiority. So is there anything else that you have to add about the experiences of disabled folks working through CPS, Child Protective Systems or government services and the discriminatory treatment that they receive?

Morénike Giwa Onaiwu:

Yes. I would just like to add that unfortunately, I know a lot of the agencies that are designed... Like the independent living centers and the protection and advocacy agencies that we work with are usually ill-equipped to address some of this discrimination. Same thing with a lot of the legal clinics that exist, that people might... Legal aid or even a lot of the... People will say, "Okay, well, let me go to the disability rights center. They have legal aid services." And often, they'll tell you, "Oh, well, the attorneys that we work with aren't capable of addressing family law matters with regard to this." And so, people find themselves challenged. And so, it's really important to be careful because there is heightened risk for us. Approximately, there are more than 35 states and territories in the United States that use some form of disability as grounds for termination.

There are about several different combinations of disabilities that are utilized, whether it's physical or sensory, psychiatric, intellectual developmental disabilities that are utilized to basically put a person at risk of losing custody. And in some of these states, even in the absence of any allegations of neglect or abuse, it could simply be two parents, one wants custody and is non-disabled and the other does, and it is factored into those decisions.

And so, really, I would encourage parents. Brandeis University has the Lurie Institute for Disability Policy and there is a National Center for Parents with Disabilities. They have a dashboard of a lot of information about parental rights and parental disability. They also offer some technical assistance to... And so, I would just encourage people to reach out for help because this is a real true issue. Like Melissa mentioned, I've experienced it myself. One year I was literally at an award ceremony as adoptive parent of the year and the next year, I was fighting for custody because I was "incapable" or perceived as such of caring for the same children that had been with me for years. It's a real fear.

Justice Shorter:

Mm-hmm. Morénike, I want you to unspool this thread a little bit more because you have worked and written extensively about parenting resources, especially for people with disabilities. So what does it mean to you in practice to parent while disabled during times such as these that are really tough economically and socially and on a whole bunch of other levels? Just tell me on a day-to-day, what is it like, you in practice to parent while disabled? You shared some of these experiences before being awarded for being the adoptive parent of the year and then the very next year being under such scrutiny and having to battle to retain custody of your children. I just want you to take up some space and share anything else that you are willing to about what you have lived through.

Morénike Giwa Onaiwu:

Yes. Thank you for asking that because I think that for us, it can be draining. As Melissa mentioned, having the advocate hat plopped on your head, not even necessarily voluntarily wearing it. That aspect can be draining, although it is a necessity for us because we have to fight for ourselves or no one else will. And so, for me, it's important just as you mentioned, in practice, the practical element of people knowing, okay, people have good days and bad days. There's moments of joy and there's moments of frustration in parenting, but to parent out loud as a disabled parent. So for people to understand that, okay, there needs to be maybe a chair for an attendant or "Send me information in advance that I can review," or turn on the captioning or whatever it is. Different things.

I try not just for myself and my children, but for others who may be observing to model the explaining access needs, utilizing them apologetically and also, showing that there's still the same love and bond and fun and laughter and correction and whatever else it is in parenting while disabled for people to see that, that we are not unicorns, are just simply different and that difference is real and legitimate and that people for whatever experiences that we have... There was a long time that I didn't talk about what I went through because I felt like, well, this is just going to add the stigma of disabled parents already.

Then I was thinking, no, keeping silent about it is going to add to the stigma because we should not be in these situations and circumstances where we are more heavily scrutinized or judged or punished for existing with disabled bodies and minds if our non-disabled colleagues are not, if those parents are not. So, people have a right to privacy. As you mentioned, everyone shouldn't get to know our personal medical history or experiences. Some random stranger who's curious, shouldn't have to know. But in opportunities that we have where we choose to be open or disclose, doing so can help the next parent know that their existence matters and isn't something that they should have to try to hide or shy away from.

Justice Shorter:

Mm-hmm. I'm happy you mentioned that because that's precisely what Melissa was getting at in some of her previous comments mentioning that parents from all over the country are calling her because she has shared what her experiences has been like working within the foster care system as a blind parent and what that means and kind of all of the tips and techniques and things that she has done to figure it out and navigate through because there was no blueprint. Melissa, let me have you come back in here. How has parenthood shaped your professional perspectives? Because you also work with families and resources and services. What insights or lessons do you carry with you from your home space into your workplace?

Melissa Lomax:

Parenting has made me more patient. I know I've talked to other people who are parents and they're like, "Wow, these kids, they test my patience. They make me more frustrated faster." I'm like, "That's the opposite for me." I feel like I was more impatient back before I became a parent and I infused that patience in the process. I help youth and adults find jobs. I support staff who focus on promoting

competitive integrated employment for individuals with disabilities. That work is hard, for many reasons. I don't want to go into those. I will just stop at saying it is tough. And what I do is I equip my staff with the patience that they can infuse into the families.

And it's not just patience like wait for a job, but it's also stop trying to skip stairs on this employment stairway. It's okay if you are sitting on step number four for two years. If that means that what you're going to gain from this is going to take you all the way to the top. It's okay to start at the bottom and not assume that your child with disabilities is just going to start on stair eight because you did. It's okay.

Another piece that I infuse into my professional experience is education. So like you, Justice, sometimes, I don't want to educate people if I'm in the bathroom, if I'm going through my life. But in this space where I'm working with professionals who are doing the same job as me in different ways and different agencies, what I find is a lot of them are not truly aligned with the vision. And I consider that to be a very painful reality for the work that we're doing because yes, parents can have me and my department who truly believe in them and who operate in this understanding of empowerment, but then they can have others who don't, who are just trying to meet numbers and get outcomes, get case closures.

And so, I spend a lot more time educating professionals than what I ever thought I would. And that's because I know that they will encounter more parents and more families than I will because they're doing other agency work. Some are much larger than my organization, but if they're encountering them, I just hope that something I said, some gem that I taught, something that I took the time to explain would help them infuse that same level of patience, understanding and empowerment to those families. I just don't want another kid to have to endure feeling like they're pressed down before they even rise up.

Justice Shorter:

You mentioning that we just can't skip stairs, that is going to stay with me for a little bit. It's sometimes perceived as easier, especially when times are so hard, but retaining that patience, retaining the fortitude to keep moving forward, even if it seems like we're getting there slowly a bit by bit. We know that in the disability community, slowness is essential to how many of us move and operate and get things done on a day-to-day basis and using that to keep us grounded and rooted in knowing that things are happening, even when it seems like it's not, but knowing that we may get there a little bit slowly, but we are still on the move.

With that being said, let me invite both of you to help us close out here today. I ask both of you to create a message for parents, a message that you would want to give directly to disabled parents. So for all of our disabled parents listening, what is the message that you all have for them as we prepare to close out this episode of disability inclusion required? Melissa, can you get us started?

Melissa Lomax:

I want to encourage all parents who have disabilities to know that your child is a gift no matter what society tries to tell you about it and tries to tell you that you're not worthy of having it. Your child, your children, they are gifts and you are doing well appreciating them and stewarding them and helping them grow. And I want to say that when it comes to that process, you have the ability to raise up the next generation of leaders. So, it's essential that you share your disability with your children, help them to truly understand it, understand the fight that you do daily for them and for yourself because if we're raising up the future leaders, we may as well combat ableism at the same time and we can do that just by impacting the next generation.

My last bit is about yourself. Take care of yourself. I struggled a lot, initially, with pride. I was afraid that I wouldn't be as good of a parent as other people. I was comparing myself and that's not a healthy place to be in and I encourage you not to be there either. So, my advice to you is number one, find other parents who have similar disabilities as you so that you can learn how they do it, get the tips and the tricks. Because if you're looking towards parenting books or if you're even looking towards your own parents

who don't have your same disability, you may be looking towards an unattainable and unrealistic expectation for parenting that won't help you or your child or children in the long run. So, find community.

And also, find peace and knowing that you have permission not to be perfect, that you will make mistakes just like every other parent makes these mistakes. And it's not your duty to be on the stand defending these mistakes vehemently, getting defensive and protecting yourselves. It's okay to just walk away and say, oh, that was a rough time. I'll do it again better next time. You have permission to grow in the process of parenting.

Justice Shorter:

Thank you so much, Melissa. Thank you. Powerful words. Morénike, I want to toss it over to you, your message to disabled parents who are listening.

Morénike Giwa Onaiwu:

My message to my fellow disabled parents is you are enough and that might seem cliched and maybe you feel like you don't need to hear this right now. I am a stranger after all, but I offer it anyway because I guarantee you, one day, this message is going to matter to you. Perhaps less so on the good days when things are flowing as they should, you know this, you feel this, that you are enough, but when life is lifing, it's not as easy to remember. So I want to remind you, you are indeed enough. You are enough on the days that you are experiencing discomfort, pain, and/or flareups that might delay you from certain things. You are enough when there is a field trip, school, play, or other event that is inaccessible to you and that's beyond your control. You are enough when your child is acting a plum fool and you feel discouraged, frustrated, and want to resort to that old school discipline, you are enough.

You are enough when you are peppered with intrusive questions, dehumanizing rhetoric and/or ableist barriers that impact your journey as a parent. You are enough when you are drained from just the fatigue of the everyday battle of fighting a system that you shouldn't have to fight, yet you always have to fight anyway. You are enough when you have to request the very things that by law, should already be yours. You are enough when you're tired of hearing Baby Shark and you're tired of playing a card game. You are enough when you've got to grab McDonald's or DoorDash. You are enough when your child expresses to you that your family doesn't necessarily resemble other families and they need your reassurance that this is okay. And you are enough when the world tells you that families that look like yours aren't equivalent to other families. You are enough, period.

Justice Shorter:

Growing in the process of parenting. And as you just said before, Melissa, and both of you have echoed multiple times throughout this show, but Melissa, as you put it in one of your comments before, we all are working to assure that our children do not feel pressed down before they have the chance to rise up.

If you want to keep your learning journey going, visit the disability and philanthropy forum at [disabilityphilanthropy.org](http://disabilityphilanthropy.org). I'm Justice Shorter and this has been another episode of Disability Inclusion: Required. Thanks so much for tuning in and join us again next time.