

test test test test If want so now if you want to give your background information and we will see if any questions come in and we will go from there. And if it works for you, we can do the same -- the same way that we did before with Ida and then Felicia and then Cheryl.

>> Ida: So I'm Ida winters and I am the parent of three young men, all special healthcare needs. Ages 16, 17 and one soon to be 21. And my youngest son is 16, and he was diagnosed with autism a week before his 14th birthday. So, um I do a lot of work with, um, early identification and early intervention. We missed the market for all of it, but we did, um, attempt to get diagnosed with screening and evaluation, but we just didn't get it. And I work currently with Waisman Center and on various projects because this is something that is near and dear to my heart. And I have done a lot of work with family navigation and I still do -- even using personal time, because this is something that is Important in my community. And I do a lot of stuff with policy work and I'm actually right now in D.C. at a conference for policy. But this was important. So I just took a break to come and to talk to you all. So I will pass it off to Felicia.

>> Felicia: Thanks, Ida. Again my name is Felicia Turner-Walton and I am the Mother of six, two which are rangeels. My oldest son was diagnosed with epilepsy at the age of five. Through that entire process, in being a black Mother to my black son, I didn't know about the services that existed such as the Waisman Center. He did have a lot of needs, including things related to his IEP, and my personal and professional work, I am also the founding CEO of Healing our Hearts Foundation and I'm a peer support specialist and a certified educator and a parent peer specialist. This work as Ida mentioned is so vital and important and necessary and needed for me, that it doesn't matter what I am doing, I will drop my hat to show up for children and, most importantly, for children that look like my black son who did not receive any sorts of support. So it was about three years ago that I became aware of the Waisman Center and the services that the Waisman Center offered. And that was through my granddaughter actually being diagnosed at birth with Turner's Syndrome, so she's a client there at the Waisman Center and I'm happy to be here to offer my

insight and what can be done to support children

like my son as well as his daughter.

>> Cheryl: My name is Cheryl Funmaker and I am a Native American with my Father being from North Dakota and my Mother being from Wisconsin. And I grew up in the Twin Cities in an urban environment. And as an adult, I moved back to Wisconsin, where my Mother's people are from. And I have raised a family here amongst the Ho-Chunk people with my husband. Together we have four children. The youngest is now 23. Or soon to be 23. And he -- he is the reason that I came into the field of special education and disability. My son was in birth to three services, all the way through and we are still sorting out his adult services right now. And I'm an educator. I strongly believe in our our cultural teachings. And our beliefs. And applying those to our -- to our families, to help navigate the systems here. We have very distinct cultural differences. We don't have a word for "Disability" traditionally in my language. It doesn't mean that disability didn't exist -- it did. And then I also tried to address equity in our -- my work with our people. And I see value in both systems. And I am a staunch believer that we can be culturally and equity-minded in the work that we do. And there's a lot of work to do. Thank you.

>> Thank you all. We have a few questions starting to come in, so I'll read the first one. And then y'all can just answer as feels right. So the first one is "Wisconsin is starting to make some progress with advocacy for people living with a disability, but we have a long way to go. Which areas do you think that should be tackled first when it comes to advocating for youth and adults living with a disability? More specifically, what type of resources and services have you noticed are still lacking for the population?"

>> Felicia: On the more specific question on what type of resources that are lacking. One of them I would say -- parental support. When you are a parent of a child who has a disability, oftentimes what your mental health is left out of the equation, right. You're in spaces where -- what you are doing is so important for your child that most of the times you're forgotten about. So I think that thinking about that, we should be able to also to have advocacy around the support for the family that also has to go through this experience alongside of their child.

>> Cheryl: Yes, I would like to echo what Felicia is saying which kind of goes into the support network that we're currently piloting in the Midwest, where we're offering support to the families of children and youth with special healthcare needs. And it's like when you're a parent of a child with a disability, or complex medical needs, that, you know, you need that support, the sib licks as a whole because it's a diagnosis, not just for that one person, that diagnosis is for the whole family. It's the first day of the rest of your lives, this is something that you will have to deal with as a whole. So that support is usually not there, that they want to focus on the one individual and a lot of times when the focus is on put on that one individual, it puts a lot of strain and resentment on that family as a whole. So that's a big thing and then another thing is, we don't look at it as, yes, this child has a disability or a complex medical need. But there's also parents out here that have disabilities and complex medical needs and they're the parent of a child too. They need additional support. I know that I use lots of time caring for my kids and I neglect a lot of caring for myself, which I personally have disability and complex healthcare needs too, but I don't have time to have that, because I'm dealing with the needs of my children. Or I neglect one child trying to juggle and all three have medical needs. So, you know, it's a balancing act and we kind of have to figure out how to balance the scales.

>> I'm sorry, could the question be repeated?

>> Yeah. So the question was -- which areas do you think that should be tackled first when it comes to advocating for youth and adults living with disabilities? And what type of resources or services have you noticed that are still lacking?

>> So I would like to say that the community which I have worked, the biggest issue has been to hooking our families up to comprehensive services. That would be waiver programs and many of our families are not enrolled in waiver programs and maybe they're not attending IEPs as well. And so what we do is that we try to have a trusted individual to work with our families, and to draw on our community, and have, um, mentors of sorts. And a group where we can reach out to one another and ask questions. So getting the foot in the door to services is the first thing that we try to do and it takes quite a long time, actually, longer than we

would think. So for our particular history, we have a distrust of certain agencies. And, you know -- you know, um, especially when it comes to social services. And removals and things like that. But I would say that getting the foot in the door in whatever system and that could be even with identification of disability, a diagnosis. You know, that's navigating the health system as well. So --

>> Moderator: Cheryl, this is sort of building off what you are saying and I would love to hear Ida and Felicia's take on it as well. Can you share an example when the disability services have worked well to support the families that you have worked with or your family? and could you also provide an example when it has failed to do so or it's conflicted with the cultural end values?

>> As far as the culture piece there I'm going to say that it wouldn't just be Native communities, I have a feeling that there's other communities where disability is sort of looked at differently. And what we do see is the stigma attached to disability in the mainstream society. And that's what we have pushed back against. As do our kids when able to articulate that. So I just want to throw that out there. But the other part of the question there -- what we have done is -- we are mentored throughout our lives and as old as I am, I'm in my 50s, and I'm still mentored by my elder women, the elder women in our clan, and we reach out to our families often. So when our son first experienced people were saying that there was an issue -- um, we reached out to our relatives actually first. And they counseled us that everything was fine and don't do anything different. And so -- so we were a little slow to pick up, you know, like getting a diagnosis, or signing up for a waiver, um, because -- you know, like I said, um, we -- we saw as a family some of the stigma and we didn't want that for him. And our belief, our children are born the way they are. We're born the way that we are. And that's that. If that makes sense. So, you know, we -- we're able to access resources through our own social services. We are -- tribes are tight knit communities. And we had a trusted individual in the -- in the department, and so I would ask them questions. And I'd say, well, what is this waiver thing, I don't understand it. What is this diagnosis? And how -- what is the therapy compared

to school services? And so -- I remember that. And so in the capacity of my work, we are trying to bank on that, reaching out to the people that we trust. And building a community, so we have like a family group that really helps and a family navigator. And we're -- and people -- people really are kind of floating around out there, not knowing what's going on. And I remember that feeling vividly. And it's not pleasant. So we're trying to capitalize on -- we want to reach out to our mentors. We want to have safe people to talk to. So, it's kind of a broad answer there, but --

>> Moderator: Yeah, so just really leaning into the community-based supports and having more of the family mentors and people working one-on-one is what has worked well then it sounds like?

>> Yes.

>> Moderator: Ida, and Felicia, do either of you have an example of when social services are -- services that you have interacted with have worked well or when they have worked poorly for you? And how that could have been different?

>> Ida: I can probably list a million negatively, but I want to speak in the positive experience and thinking of the whole. I was working with wrap around Milwaukee, but working with them for one of my other children. And, you know, you hear the word "Wrap around" and they're supposed to wrap around the whole family and provide services for the whole family.

And I never actually tested that theory to see if it really worked, until I had to test the theory to see if it worked. My younger son was facing expulsion from school and, you know, we were having a therapy session with wrap around and that was what was on my mind at the time I spoke about it. And they're like, hey, we're here to help. And, you know, I didn't know what he -- what services or what rights he had as far as school and being expelled and being suspended and everything. And, you know, they were there on the front line and ready and they're like, nope, he shouldn't be suspended, there's nothing in writing. No, she's been asking for an evaluation at school, for an IEP and this hadn't been granted. You know, every step of the way -- and I didn't know this. And they're like, nope, take him back to school and he'll be in class today. This needs to be in writing. We need this. He needs that. And, you know, they were there. And this was a service for a sibling. And it was to the point -- it was

like, oh, he has meltdowns in school. He can have a crisis stabilizer because this does affect the whole family. Because if he's having meltdowns in school and you're taking off work or school to go to school to tend to him and you're taking time out of this and I'm like, oh, so it really does wrap around the whole family. I wasn't utilizing those services because I had one child sign up for this, so I expected it to be like other programs, just focus on the one. But after that, after I found that out and seen how willing and actually helpful they were, I started utilizing the services and then I started recommending the services to other people because I actually knew what services they did provide and not just advertised that they provided.

>> Felicia: And I will mention like Ida, the kind of thing happened to me. So my son was actually diagnosed with epilepsy as I said at the age of five, and we were in Mississippi. And it was a lot of advocating that I had to do for him on his behalf. Where I just wasn't listened to. And we think about that as a cliché thing but it isn't a cliché, it's a -- "When you are in a space or a place where people feel like you don't know what you're talking about and epilepsy is not looked at as this huge disability, right, it's just the moment in time of a person going through this."

But I think that a lot of people are not understanding that. It affects a lot. It affects the person in the whole things such as urinating on yourself, really being sleepy and tired, not remembering what went on. Or what happened. So for me, instruction for my son was different. It wasn't until we moved here to Wisconsin that -- when he got connected to his doctor's office and it was like, there's nothing that we can really do for him. We would prefer to send you up to U.W. Madison to see this neurologist.

And in that conversation and I'm telling him what is going on with my son and he is like, I think that we need to really have another EKG done on him. And they do all of these things and he's like I will call you back in like two weeks to let you know the results of those, versus two weeks that we received that call in two days of them saying, no, bring him back in right away. Come to find out that everything that I had been advocating for in Mississippi, um, was -- was right. I should have been questioning those things because he was on the incorrect medication. They were giving him

medication for seizure activity all over his brain, when he had seizure activity that actually affected his frontal lobe. And that is when I saw, right, a doctor and I will say his name because he really helped my family and my son, Dr. Shaw, back before he moved to Florida. He was the most important person in my son's life at that time, he understood, right. And now we're up against -- we're putting him on new medication. This medication is going to contradict what he's been taking for the last four years. That is going to cause anger issues. That's going to cause him to be a bit irate and frustrated. So just like Ida said, those are were a lot of things that the school started to see from him, having to switch medications. And when it got to the point of oh, we're going to suspend him from school, that was where I was able to have a conversations like, no -- his doctor has submitted information, and then you all need to get in contact with his doctor. So that's where the process of him getting an IEP came -- came into place, where it began to be really valuable for us, right. Because it was a point where I literally almost lost my job because everything that happened -- at the school, with him -- they were calling me to come and get him. So Dr. Shaw coming into our lives and being such an instrumental person for him -- that is what helped us to get the IEP for him to -- for me to be a fierce advocate at this point for what he needed. And the space -- that you don't need to call me when he's simply has had a seizure and needs a moment, right, if he needs to go home, he can call my husband to come and to get himself from school. It doesn't have to be me. So through that entire process, um, it was long. I felt like at the end that we had finally broken a barrier that absolutely needed to be broken. And that I did everything right as a parent. It was just the system that was not listening to me.

>> Cheryl: And I want to jump in quickly and agree as well. I attend -- IEPs with our families and, um, we -- I have a doctorate in special education. And with my years of education, and being in the field, I have to use that to the benefit of our students. It's a lot of privilege that many families don't have, and that's what the field says -- that special education works best for families of privileged. So we're very fortunate. I'm very fortunate that, um, I was able to go through and to get these credentials and wave them

around in meetings at schools all these years. And that's -- you know, I'm sure that is reflected in the other fields as well.

>> Moderator: So one thing that all of you have touched on is really just listening and having that established trust, but as we talked about earlier, sometimes, especially in the social work field, there's been such a history, a bad history, of interaction between communities and the profession. So one of the questions that we have is -- as a Social Worker or as the profession of Social Worker -- social work -- how do we build back that trust that has been lost? And how can providers work to establish a relationship that allows them to both provide the additional support, get you connected to not only resources, but the right resources. How does one establish strong trust?

>> Felicia: You know, there's been many instances, definitely in the black community, where mistrust have shown up. We could go all the way back to the experiment, right, and beyond. It's hard, you know. One of the things that I share through our lend program which I am part of as a family advocate to, you know, students who are graduate students, or students in going to school that if you don't use your voice for the people in which you are serving, you're doing an injustice and you are much more a part of the problem than you are the solution. Right? When we see things that are occurring in communities, right, whatever you want to call them -- underprivileged communities, low to marginalized communities -- whatever you want to say, we have to also know that human beings are human beings. It's not about a color, or any of those things. And so to sum that up, I think that we like to throw around the thought of listening to black people or listening to black women, but when in reality, it's about listening to people. We live with ourselves and our children each and every single day. We know what they're going through, what this experience looks like for us. And when you -- when you depreciate the value of simply being a Mother, right, and then, of course, of the skin complexion, when those are the things that you use to depreciate that value, you're causing more harm. And so I think that it's so very important and necessary that you should show up, right. You really are truly an ally in that you really are truly a co-conspirator and showing up and not just utilizing people for research and not using them

when you are trying to use the bill that you are trying to fit.

>> Ida: Yeah, I totally agree with Felicia and I say, ask questions and show up and don't just extract information. It's a knowledge exchange, it's give and take. You have to look at it as community. People love community. There was a study done before where they had people -- wear these jerseys. And the majority of the people wore jerseys. And we'll use, for instance, we'll use Minnesota Vikings jerseys and the Packer jerseys and some people had no jerseys on.

And there were the majority of people in Vikings jerseys. So the people who saw -- most people in Vikings jerseys, they were like rooting for the people in Vikings jerseys because they had them on and there was more.

And someone got hurt that had on a Packers jersey and more people walked past and didn't help them. They said that they were more likely to help a person who didn't have on a jersey with a name on it at all, than somebody who had on the lesser one. Because they were more in sense of community and looking for separation. But when they put everybody in, and they all just had on blank jerseys, everybody was more likely to help the ones that looked -- because they all looked the same. So we all need to look into community and where is the common ground, where we're just alike and recognize that we're all the human race. And, you know, it's a good connection when we realize that everybody has something in common. We all need something. We all need healthcare. All need good health. And we have that in common and that's the little bit that we can connect on. And if nothing else, we can discuss that.

>> Moderator: Cheryl, do you have anything to add on how to earn back or to gain back that trust for Social Workers?

>> Cheryl: I think that, um, it's very apparent when someone has done work on themselves to be anti-racist, and culturally responsive. Those are two different things. And I -- I think that our -- our people -- and I'm sure that every community is this way -- we love to have -- to bring people into our community. But we can tell if somebody is authentic about that, or not. And, you know, we want -- so we're very -- we can be the best allies, and that I really don't think that has ever been tapped into, not really. And so the best thing just

from our family perspective, you know, we have had people who have attended our cultural -- like a pow wow or come to some -- like a basketball tournament, you know, people that -- if we see out and about in our community say hello. And I know that -- you know, there's some concerns about confidentiality and whatnot, but not -- not everyone has that same border, I guess, or, you know, it's worth discussing in a separate conversation about that. But I would say that, like I said, you know, anybody who has done some work about being culturally responsive, and not judgmental is the big thing. So if somebody doesn't really like to do a service, you know, give them some breathing room, and ask them later, you know, if there's someone that I need to talk to, you know, to later revisit it. And in our community, I have been taught to not speak quickly. That's why I ask people to repeat things a number of times to make sure that I think about things. And then we always can have the capacity to -- and we are encouraged to revisit things in general. You know, so -- so we revisit it -- initially we didn't want anything to do with diagnoses and waiver programs and things like that. But we thought about things and we talked to people that we trusted. And one of them was a Social Worker. And we were able to -- that is very successful, you know, that you can have somebody who can -- you can reach out to later to talk about things as well.

>> Moderator: So truly, truly showing up is what I'm hearing with a lot of listening and then following through, not just talking about things, but putting action behind it. This is sort of shifting the topic a little bit, but I know that you all have a lot of experience working in different groups and working with individuals, with disabilities. So this question is -- how do you collaborate and conspire with adults with disabilities around disability justice issues? And knowing that there's a tension sometimes between parents and disabled adults or adults with disabilities over things like language or other types of supports, what are examples where you have worked collaboratively with others? So basically when have you worked collaboratively with adults with disabilities? And how do you manage parent/child conflict in a way that is productive?

>> Felicia: For me, like I said, my son is 26 years old and now he's really an adult. [Chuckle] so oftentimes we still clash, right? Him not wanting

to completely accept, right, that he has this disability because, again, it goes back to the world's view of what disability is. And oftentimes it seems like if it's a person who is not -- if it's not a physical disability, then it's often not recognized, right? So for him it's like, well, do I really have this thing? I know that I forget things sometimes but everybody does that, right? And it's like, no, you have been diagnosed with this thing. You need to utilize the support that you have, right, as it relates to being in this space and for us I think that it really showed up in school for him where there were, like, extracurricular activities such as football and things like that, that he wanted to do that he just could not partake in. So imagine this 14, 15-year-old boy who is now, you know, a Freshman in high school, and he's coming to a place where he can advocate for himself. And it's like, no, you can't play football, you can't withstand that hit that you receive. But it was Dr. Shaw who said let him do those things. And it's like I'm afraid as a Mother. And so now I've given him even -- right now actually, I'm still on him, did you take your medicine, did you do this -- he's like, Mom, I got this. And it's like, okay, you know. I can back back a little bit. So allowing them I think to make decisions as it relates to themselves and their healthcare is one of the most important things, bringing them into the conversation. Tammy Baldwin says it best, oftentimes when you are outside of the room, the conversation is about you, but when you're in the room, the conversation is with you. So allowing him into that conversation as early as 14 or 15 years old is why we are where we are today. And he's able to advocate for himself. I don't have to do that all the time and I can kind of stand in the background and to be his coach if he needs.

>> Ida: Yes, I agree with you Felicia on autonomy. That's the best. I have an adult child, and even though he's not making the best decisions right now for healthcare, but -- which he has a provider right now that I'm not agreeing with the plan that he has, but it's my son's decision to keep him. But I always think about, you know, it's his life and sometimes, you know, sometimes it's peak and sometimes there's valleys and sometimes we have to go through it to get to where we're going. But I have to think about myself and anybody else. You have disabilities, and sometimes your disability

doesn't show and it's not at the forefront. So instead of thinking about it as disabilities, a lot of times it's variabilities. And that's how our life goes. Today it varies. And today I might feel great and today I may not have a disability. It's not showing. And a lot of times you have to -- they're having a good day today, let them to enjoy the day and not just saying, you have a -- remember that you have a disability, so don't do that. And rightfully so with the sports thing -- all of my boys wrestle and my middle son, he has a bleeding disorder, it's absolutely no to football. But he wanted to wrestle. And he wrestled. There was no incident. And, you know, he's still beating down the walls and telling me you should have let me play football. But, I mean, that's the thing -- a lot of times with the young adults and the youth, that we disabled them more by constantly reminding them they have a disability instead of letting sometimes it being a variability. Or diverse ability. And we're supposed to let them live their best life or their life to the fullest and a lot of times we hinder them from that, and thinking that we're protecting them but a lot of times we're protecting ourselves. So, how do we work collaboratively? We need to find out what their goals are and how they feel about it. And a lot of times we don't ask that because we feel that we know best, and they're not ready to make these decisions, so, sometimes we have to get our little heart and our feelings crushed, but we learn. And we live, we learn. And our thing is to pass on to other parents what it is that we learn to help them along their journey.

>> Felicia: I have to agree with Ida and I didn't say that my son wrestled too, Ida. And he would have went State. One point -- because the referee didn't call the call in time. So those are the types of things that we were talking about that are so very vital and important for them to have their own autonomy over their bodies. And that -- you know, anytime that his body hit the mat, there was me standing up like nervous, oh, my God, is he going to have a seizure. So I can attest and agree there.

>> Moderator: As a quick reminder, the question again was about collaborating with adults with disabilities around disability justice issues. And how to work with families and make sure that the family/child balance is there. Cheryl, did you have anything else that you wanted to add, otherwise we can move onto another question.

>> Cheryl: Oh, yeah. So I think that we've -- we tried to support our son to make his choices. We do a lot of prep work about different kinds of choices, you know, if you choose to stay up to four:00 and you have class at nine o'clock what will happen. And when I think about disability justice, we have to prep him, you know, my son is a hunking 375 pounds and six foot two and visibly Native American.

And we have to -- we have to work with him about, you know, about maybe not walk around in the middle of the night in the wealthy neighborhood where you are going to school, you know, things like that. Because I'm well aware of some of the more troubling and devastating things that happen to people with disabilities from other races. But one of the other things that we do want to do -- when it comes to our -- my son, is that we have really done a lot of work for his self-esteem. For him, he's not visibly disabled, but he is. And he's just different enough where, you know, he can't make friends. You know, and it's pretty tough. But -- and he could be -- so we do a lot of work about reasserting our values and to take away the stigma of disability, because sometimes it really hampers him. You know, he doubts -- he wants to be a Social Worker, and we have them in school and he's doing wonderful things. But he's second guesses himself quite a bit. And so that's been the case all the way through school. And so we've had to really talk about, you know, the way that schools are set up to individuals and attest that and reassert some of our tribal ideas about learning and the value of people. And so we've had to do a lot of -- what I call decolonization. So that he can feel -- because he's not going to overcome anything. You know, he's -- you know, his learning is the way that it is. And so, you know, we have to make sure that he -- he values himself. So -- and in my mind, you know, disability justice looks at how to instill that pride in our -- our people who learn differently. And can do different things. And, you know, so I think that that is the way that we have kind of looked at it from a personal perspective.

>> Moderator: Thank you. Well, we have talked a lot about a lot of different concepts, and one of the questions that we have here is -- how do you communicate to your children about their disability when we are living in a world like this where there's a lot of systemic inequity and bias around

disability. I'm sure that can be -- it would look different for every family. So how do you all communicate to your children about their disability?

>> Felicia: For me, of course, with my son I think that kind of being the oldest in the space, this is when he was nine years old where his actual teacher in the middle of class blurted out some things about him having a disability.

And he pees on himself. I think that was his first experience with his classmates knowing that something was different about him specifically. And that it was at that moment that I had to sit him down and say, hey, this is what you have, this is what you were diagnosed with. But this is also a part of you that makes you uniquely different than the next person. It's not -- right -- it was a conversation of telling him that it wasn't something to criminalize him because he was different than other children. It was something that made him who he was uniquely, uniquely the child that I raised, the child that I created. And just because his, you know, his disability wasn't something that people could see, but it was also up to him to educate people on what epilepsy is, and to let them know that this is what epilepsy looks like. It looks like me.

And so through that and through my -- through me being able to do that with him, right, there were other children who eventually came out and talked about the different things of them having -- even siblings with disability in their classrooms. And it was a conversation, you know, with his teacher, like that was not the place in the class of eight and nine year olds who did not understand what epilepsy was in the first place, for you to share something like that and it caused hurt and harm to him. And, you know, to also to educate, to teach him to educate his teachers about his disability and this is what could show up. For my son, he had absent seizures a lot at class and that could look like him staring off into space for 30 to 45 minutes.

And it was him walking to his classrooms, you know, moving to fourth and fifth and sixth grades and telling his teachers, yes, I have epilepsy and, yes, this is what it looks like. You probably need to pay attention to me a little bit more than you do the other kids. If you see me staring off, then I'm probably having a seizure, it's nothing that you can do about it, issue to when you see it -- make me go

to the nurses office because I'm probably going to urinate on myself. So he made it conversation where he began to be an advocate for himself in the space. And because that's what we were teaching hem is how to advocate for yourself, and not to let anyone else to make your disability a martyr or something to joke about.

>> Ida: Yes, so I started talking to my youngest son about his disability early on, like I knew that something was different about him. He just hadn't had a name or a diagnosis or a label for anything. And we summed it up because -- because the kids thought that he was weird and he thought that he knew anything. And it was like don't talk to us, you think that you know everything.

And he just would say, my brain just processes things differently from others. And he walked on about his way. And after I had done enough research and I looked up things and I think that you have autism. No, don't believe everything that you see on TV. It doesn't look like that and we talked over it and he's the kind -- when he's kind of on the spectrum to the point where -- when he gets into something, he really gets into it. So he did his research. And it's funny when you are looking and you have this seven or an eight year old doing research but he's doing his research and he is like, yeah, I can agree this is me. So it was a conversation that he did his research, and now he's a junior in high school and he has other kids, like, hey, I have a brother who has autism. Or I know a kid who has autism. But their autism is not like yours and they're asking for advice and they're, like, more accepting. And it's kind of, like, I'm pushing him, like, you know, that there's always space in the disability world for young advocates because this -- I mean, accepting and normalizing -- this is -- this is our world. And let people know that it's not what you see on TV. And like Felicia said it's not looking to be a martyr and letting people know that we're human too.

>> Elaina: Does anyone else have something to say on that question or should I move on? Okay. We'll keep going then. Did any of you have experience with disability or health advocacy before you had to advocate for your children? And what do you credit as being the source of learning for you and your family?

>> Felicia: So I have a cousin who is very close to age to me, she's 36. And she was diagnosed with

cerebral palsy. She's been in a wheelchair her entire life. She is non-verbal. And that was my first experience with disability. And one that was, right, a physical disability where her Mom had to do everything for her. And so we -- we at some point we ended up in school at the same time together, and it was always a thing of what's wrong with her. And for me she's a non-verbal person but she understands completely what you are saying because she laughs when something is funny. Yes, she wears a towel around her because, you know, her spit does protrude but she's a human being. So for me early on, it was utilizing, right, my experience with my cousin that made me aware of there's differences in people. And they all look different. Just because they may not be able to verbalize our speak, or, you know, they can't walk, that doesn't mean that they're not human. So that was my space with it. And then I think that the other part would be credited as a source of learning -- that was just going through the experience. I don't think that there's anything outside of the lived experience that can prepare you for what you're dealing with, because like Ida said earlier -- what we see on TV -- it is completely different than actually what most of -- at least our children -- what their disability looks like. We see a lot of the completely negative aspects of having or being a person with a disability. Versus you can have a self-fulfilling thriving life as a person with a disability. And so I think that just that lived experience and your family dynamic really makes up the best learning sources. Education can't prepare you for what lived experience looks like.

>> Ida: So for me, um, I had experience with disability prior to my children. For myself. And I didn't advocate for myself. My Mother, she didn't advocate for me either. You know, my grandparents were born in 1924, and it was kind of like and in our culture, you're lazy, get up and do whatever. So that was kind of the thing, and nothing was wrong with me and I'm young and the doctor kept telling my Mother she's young and get up and do whatever. So that's what I'm doing. And so I didn't advocate for myself, I just kept trying to do things. And when I wasn't able to do for myself, I just got more and more depressed because I'm young -- I should be able to get up and do things. But once I had my children, that's what changed. And I'm like, no, I see the way that he can't move or he's in pain or he just can't grasp this concept or his fine motor

skills just aren't there. I can see this. And I'm like, no -- and then I'm starting to look into things and talking to people and I'm like, no, this -- this has to be more to this. It's not just laziness. Because I see that he wants to button his shirts like everybody else wants to button their shirts. I see him staring at the group of people, and I see him on the sidelines laughing as if he's interacting with the other kids, but he can't do it. He's just stuck. And I'm like, that's not laziness. So it's like the learning -- I had to talk to other people, and look into other things, to learn about advocacy, because I'm just, like -- sometimes you do have to make noise, you might not want to make noise or rock the boat, but sometimes you have to make noise in order to get the things that you need.

>> Cheryl: In our family situation, none of us had had any experience with disability, and so it was all fairly new. And I would say that -- in terms of learning the most, um, I'm trying to help our son to regulate. We learned a lot trying to figure out how he worked with his sensory needs and things like that. He was non-verbal for quite a long time. And so I would have to say, yes, I agree with -- I believe that it was Felicia who talked about the lived experience. I also had the benefit, however, of having a background in education and working with children. And so, unfortunately, for us all of my years as being an educator, I didn't -- I still didn't know -- I have an extensive bag of tricks when it comes to children. And I have always been pretty successful with them until it came to my son. [Chuckle] and that was the biggest lesson for me because he needed things, and I didn't know what it was. And I didn't know how to help him. So the lived experience for sure -- and reaching out -- probably having an open mind, you know, to accessing other resources like a waiver program, or therapy, things like that.

>> Elaina: Ida, you talked about the wrap around care earlier which relates to this question. When a sibling is diagnosed with a disability or a complex need, is it easy for families to shift a lot of their focus to that child? And how can that be explained to the siblings appropriately? And how can Social Workers help to support the sibling as well as the rest of the family?

>> Ida: So I'm -- that's a very complex question. So my 17-year-old he was diagnosed at three with a bleeding disorder. So at that time he had an older

brother and a younger brother. So, you know, the focus was just on him and his healthcare, even though I knew that something was going on with his younger brother. So, you know, it's like the older one I don't have to worry about. The younger one -- well, he's okay because they didn't say anything about him. So we could focus just on him. But then by the time that the younger one got into school he's having issues at school and in order for him to stay in school I had to be at school with him all day. So it's -- I'm trying to figure out how to balance that. And then my older son, when he -- I'm -- he had strep twice that was the only time that he had been sick. And for his 18th birthday he got extremely sick. And I have never had to focus on his health ever before. And it's kind of like, Covid started and he turned 18 and he's been hospitalized. And I forgot about those two. And it's kind of like after a month, when I come home finally, they're really angry because it's never been when I had to take the focus off of them. So it's very hard to shift the focus and during Covid, it's a hard time. They try in the hospital to accommodate siblings, but nobody is allowed in the hospital, so you can't do that. And family is a big part -- family and community. Which there was very little communication access to that during the time where I had to try to figure out how to restructure that. And Zoom wasn't as robust as it is now. So there's a lot there, but only good thing was that we had experienced already what it was like to have a child that had a diagnosis, and my boys are older. But when they're younger, it's harder to understand, because it's like Mom is always here, Mom can always do this or Mom can do that. And when he did come home a lot of the family could not combine the visit because now's he's doing chemotherapy and no one can come to visit and it's Covid time. So there's a lot of factors, but they feel like they're being restricted. We can't go visit family. No family can visit us. We can't do this or that. So it's a lot, but it's all in the family relationship, the family dynamics. Social Workers, a big part that was we didn't have Social Workers working with us, but my oldest son's school, they have advisors at the school, which are kind of like -- they're kind of like counselors but the school doesn't have counselors and they kept in contact with the family and they kept calling and asking us what was it that we needed. Is there something that they could do to

support the other boys. And they brought games to the house. They asked how much are -- how much is your energy bill and we could pay that. Things like that. Is it something that we can do -- they took them out for frisbee golf and they did that, small little things like that. And by this time we were out of the wrap around program, but, you know, they knew just a little gesture to give me a break was something that could help.

And sometimes it's just asking -- are you okay, do you need anything? Or sending a nice card in the mailbox. That's something that is nice. And that was just it. Sometimes how are you.

>> Cheryl: So in our family I think that what we -- we tried to do is -- my Mother and my extended family and the siblings, we were able to rely on each other. And we tried to teach our children that there's a cycle to everything. And so one child may need, you know, focus, and then another child, you know, will need their time in the light. We try to, you know, to look at it as a cyclical thing, you know, as far as like attention to different family members. Like, you know, another way of explaining it is that I have devoted quite a bit of my last few years to my Mother and my Grandmother, but they are aging issues. And so I think that it's -- you know, it's helpful to also -- we have, like, family events. And so we have events for siblings, you know, the siblings to come along. And then, you know, there's support for all of the family, like, parents get to step away for a while and talk to other parents and all of the kids get to play together. So, you know, I think that -- you know, just for us, you know, we try to explain that everyone has needs, you know, to kind of normalize that, you know? And we all have different needs, you know, at different stages within our lives. So that's something that we have tried to -- to teach all of our children actually. So -- that might be a way to look at it.

>> Felicia: For me, this was a huge struggle in my family. My son, of course, was the oldest, and two years after him was my daughter, who was born without any type of disabilities. And so as I said, we were -- we were there from Mississippi, where I spent pretty much all of my childhood. So when we moved here to Wisconsin, we didn't have much support. And so it was really hard for me to explain to my daughter who just always wanted the Mommy/daughter time, right, that my son required a

bit more attention than her, because of the type of seizures, disorder that he had. Like I said, he had absent seizures so he would sometimes be there staring and sitting there for hours and watching him and not wanting anyone else to watch him. My Mother-in-law and my ex-husband's siblings, they really didn't know what to look for, so those Mommy/daughter dates looked like Mommy/daughter/son dates that we always -- and it was me and my daughter would be there as well. So she didn't really grasp -- we were going to get our nails painted and your brother has to go with us. And so it was really hard in this space. As I said, I wasn't aware that anything such as the Waisman Center or even it existed in my area because no one talked about those services to me. I didn't hear about them in the school and being that -- the neighborhood that we lived in predominantly white, the teachers or the Social Workers, no one really so shared about those things to us. And so for us it was really, really hard. You know, she began to -- to be in the space where as she grew older, she understood, right, that, wait, my brother has a disability and it's nothing that he did to cause it. And it doesn't mean, you know, that Mom doesn't love me anymore. As she -- she was about 14 or 15 when she finally had that conversation with me that it was even hard for her, right, being a sibling, and not having, you know, the things that she felt like she wanted or needed from me, or us having those private and intimate moments. So it's so vital and important that -- that we -- we are letting them know, right. In a panel that I heard -- and much like my daughter brought me to tears because it was really her in spaces where she had to advocate for her brother when she would see him walking to the office because they just thought that he was, you know, being rude or being disrespectful and things like that. Where she's like, no, you know -- so much so that she has run up against teachers at the school. Like, no, my brother has epilepsy and you don't handle him and don't touch his head. So those types of things where -- they get so much more concerned about their sibling than themselves, that they end up having to show up for their siblings. Which sometimes feels like it takes away from them enjoying their childhood.

>> Elaina: Thank you for sharing that, Felicia. We have a couple of comments about sib shops, the Wisconsin program for siblings of children with

disabilities. Have any of your kids participated in SIB shops? So we have had a lot of difficult questions come up during this and I think that I personally would love to hear one story that just brings you a lot of joy with your children.

Especially your child with a disability. So maybe before -- because we're coming up on the end of time, but could all of you give a story that just really, like, highlights the fun times? Or something that brings a smile to your face?

>> Felicia: I think of when -- when Jamarius -- when he first went to the UW hospital to the neurology clinic. And Dr. Shaw walked in and he says, whoa, you're brown like me! [Laughter] and -- and as he's like talking to us and telling him what he's going to be doing and so he's like I get to get this jelly on my head again, right, and you will do all of this stuff that they have already done in Mississippi to me and he is like, yeah, except we're going to allow -- we're going to find out the main issues and

the main causes, basically. And as he's -- he's telling him these things, I could sense from my son just we're going to get the answer to how I can actually be supported, right. Because I have been hearing my Mom go off on my doctor in Mississippi who was just a pediatrician and never referred to me to a neurology clinic.

And it's almost like he sensed the sigh of relief that I had that we now have a doctor that actually gives a hoot. And he developed his own relationship with Dr. Shaw, he was like, Mom, I got this. I can have these conversations. And so, you know, even when he had to do blood draws he is like, I'm only doing this for you, Dr. Shaw, because I hate to have my blood drawn. It hurts! And Dr. Shaw told him, well, if you do this for me, then the outcome that you're going to have on the other side is going to be so great -- and I promise you that you're going to do the things that you want to do. And that ended up looking like as me and Ida talked about football and wrestling.

And so he got what he wanted. And I -- I could literally have a sigh, right, to say, okay, he's safe, he's okay.

but I'm going to every single game -- whether it's home or away, and I'm going to be present, right. And I will let the coaches know so they were 100% aware and once he felt like -- I think that he was in a place to not only advocate for himself as a little boy, but it created this man who now

advocates for his daughter, right.
And still advocates for himself. As it even relates to other things in the world and not just his disability, right? So through all of that and through the doctor, looking at a child and taking them under his wing, definitely my child, taking him under his wing to address to take time to address his questions and concerns, to let him feel that the needle, so to speak -- that they were putting the little jelly in his hair, that it wasn't going to actually hurt him. Those things are needed and necessary for him. I mean, even for me. Because, like Ida said earlier, we're more afraid than the children are, right. They're the resilient ones and we're the ones who are scared.

>> Ida: I just think about what is something that's really -- I think about -- so basically my sons, they've had the same pediatrician basically since birth. And I think about the relationship we've built with the pediatrician for the number of years. And we have children-led appointments. Yes, I call in and I schedule the appointments and I tell them what the topic will be of the appointment and why we're calling, but when we go in my children lead the visits. The pediatrician learned early on that I'm an only parent so every appointment that every child is coming, so she knows every child's file. And even if she comes in the room, she's going to see at least one of the other ones toes or ears or whatever, but she never complained about that. And every time that, you know, she's examining one, and even now with them being big boys, she's asking when I come in with one -- how is the other boys. And she still calls and asks, you know, when she hasn't seen us for a while she calls and checks at home to see, you know, how we're doing. But, like myself son, he doesn't like people touching him. But he's okay with her touching and she's like, Oh, hi, Brian, and how are you and he's like fine. And she's like, is it okay if I touch you today? And he is like, you can touch me but the other doctors can't touch me or the nurse can't touch me. And, you know, that's the thing. And he has a thick where at school a lot of meltdowns because the teacher puts their hand on his shoulder and she asked him about that. And he's like, personal space. And he's like well, you have been touching me for a long time and I am like Brian you can't tell people that she's been touching you. That doesn't sound really good. But he's like she

touches me all the time. So, you know, he says things and they're minced in a different way but he says them and they're kind of funny. But that is just him.

>> Cheryl: I think for our son, the last time or the most recent time that he says quite a few things throughout the years. And he's like one of our relatives who kind of surprises us. And so we had a family event, and our son is compassionate, and -- and we don't always realize the extent of that. And he had the opportunity to kind of talk to the other youngsters in our family group, and it was of his

own doing and we were kind of in awe of that. And for us, that's being a good relative, and that's one of the things that we aspire to. So we are pretty happy with a lot of the pulling together of the work that we do with him. And for him.

>> Elaina: Then we're coming up on the ten-minute mark. So, maybe for the couple of last questions or for the time that we have left, one question was, do you all have a mantra that helps you when you are

care giving or gives you strength in the times that you need it?

>> Felicia: Mine is -- it's just words, not really a pact. And each divine day creates divine intervention. That is -- everything happens for a reason. If we -- if we come to it, it's one of our feats that we have to defeat. And as I think about intervention, right, and where that piece comes in -- we can intervene on behalf, right, of our children, or we can intervene with our children, right? And that goes back to one of the -- I think one of the biggest sayings that everyone has, where two or more are gathered. So if I'm intervening for my child, what we can get out of that together in timing creates a better outcome than me going in and just advocating on my own, because he's the person who lives with this each day. I'm just affected by his circumstance.

>> Ida: For me, I think that I want to -- I want to be the person that I wish that I would have had, that I needed going along my journey. And I also think that if no one does it, will it ever get done? Somebody has to start it.

>> Cheryl: No mantra for me. It's something that I'm still learning to work on and been a quite a bit of worry throughout the years. And so for me, the thing that I'm working on is to breathe, not to

anxiety breathing, but calm breathing. So that would be my mantra -- breathe.

>> Elaina: Yeah, we do have one question that is very important. So we're going to probably end with this one. But just want to recognize that this is also challenging topic I think -- so I'm going to put it in the chat for Cheryl, and everyone else to read. But the question is -- a lot of social work students are going to be connected to either CPS or schools, where mandated reporting of concerns about the special needs children often brings down the power and control of the CPS and legal system onto the families

What recommendations do you have to encourage those new Social Workers to not become the power brokers and harm agents, but supporters of the children and families that they're trying to serve?

>> Felicia: I'm going to absolutely say first and foremost -- don't assume. Do not assume. Every family and every household looks differently. I know that in my family, my Grandmother raised me and five cousins. And none of us have a disability. My Grandmother didn't clean up every single day. She cleaned up on Saturdays because she worked Monday through Friday to provide, you know, a stable household for us all to be in. And so thinking about several of my friends who are parents of autistic children, some of them one, some of them two to three -- um, man -- like, you can't have the expectation just because you walk in a person's house on a Tuesday at 10:00 o'clock A.M. that this is the way that it should look. What you should ask is there anything that I could help you with? Do you see that child is physically harmed or not? Right, you can ask the children, like, how are you? And sometimes they can't respond to you, but absolutely, have a conversation with Mom. What is your day look like, right? And that often comes up because I hear so many times, even from Ida and other women who I'm connected to, today may -- Friday may look completely different than Saturday. It's going to look completely different than Monday. And so when you think about that, and just because on Tuesday you had a successful journey of getting your autistic child out of the house earlier, and it could be that you don't on another day get out until 10:00 o'clock because that child had a meltdown and they damaged things in the house and here you are expected to be at Mom's house at tens can thirty, and oftentimes as Mothers, right, it's a fine line

between motherhood -- almost like a penalty in ways and for been having a child with a special healthcare need. But no one asks you what you need, right. And while people think that overstimulation isn't real -- it absolutely is. And if an autistic child is overstimulated, you know. And that's the way that it sometimes shows up -- you best believe that a Mother having two or three autistic children in the household and also having to care for herself, go to work, figure out all of these things she's absolutely 100% overstimulated and the last thing is that she needs is for child protective services to come into her home to take or remove her children when she's doing the absolute best that she can do.

>> Ida: Wow, Felicia, that's hard to follow up behind, but I totally agree.

And a lot of times it looks like we have everything put together on the outside, or whatever, and we get these calls to come in for whatever -- and it's kind of like -- learn about different cultures and learn about the family before you come in with assumptions or this report or whatever. A lot of people do mean things for mean reasons and a lot of time that -- that power -- it can break a person completely. And I tell people -- listen, my house is a mess, my car is a mess and so is my life, but tomorrow I'm going to get my life tomorrow. And I'll just end on that.

>> Cheryl: I think that I'm going to assume that most of the attendees at this conference are students. And to seek out -- I encourage you as a student to seek out internships or take courses, you know, to explore the different kinds of communities that are out there. And to do work on self-reflection, the cultural responsiveness piece, again, the anti-racism. To do -- to do the hard work of understanding, you know, your particular background and what your perceptions are of the world around us. I also think that there should be, you know, opportunity for people as professionals to reach out to colleagues, and to develop a collaborative relationships, say, with tribal, social work, I know that there's like other, um, agencies out there that, you know, that are to develop relationships with these different kinds of agencies that are out there. That work in -- you know, in diverse communities.

>> Elaina: So thank you so much to all of our panelists today for all of the insight and experiences and knowledge that you have shared.

It's very much appreciated. And I know that they gave everyone in attendance a lot that can be reflected upon and thought about, and searched further. But we are coming to an end. And I guess in the last few moments here while we're transferring to the end, is there any organizations local or state that you would like to plug?

>> Felicia: I think that for the end I would like to say here that there was one question about a parent who feels like that she's exploiting the services. There is -- there are many, many ways, right, that you can show appreciation to your doctors and providers, but to know that that is not necessary for you to do, but if you feel like that is something that you want to do, that looks like giving back, right, and giving back to other people in your community. And supporting others, providing help and to share resources. All of those different types of things. There are many in our area, I know that we have two respite services specifically that kind of work with people from -- who have different types of disabilities, all types of disabilities, and that's one. And then Geo's garden, they absolutely need people to offer respite services. And that could look different for each person. If you are receiving services, it is because you need them, so not the fact that you are exploiting any types of service. Otherwise, they wouldn't exist.

>> Ida: I want to just say a lot of times a little planning goes a long way. A lot of times parents don't feel like they're doing a good job, it doesn't look like they're doing a good job to others or sometimes just a mental thing. Just sometimes telling them that they're a good parent and they're doing a good job -- even though it doesn't look perfect, they're still doing a good job of with the resources that they have. And just letting them know that they're doing a good job or to tell them just to keep trying, keep doing what you are doing. And that little bit means a lot, because I probably quit 30 times a day, but that little bit of inspiration, it helped me so much along the way.

>> Elaina: All right, Cheryl, any last remark that you want to make or last comment?

>> Cheryl: [Chuckle] I really think that if par face pants have the avenue to look at -- participants have the avenue to look at a disability lens, to take a class, do some training in that, that I think that would be extremely helpful, because in general, disability is stigmatized in the wider society. And

just like we look at ourselves in terms of race and culture, we need to also do that when it comes to disability so that we don't inadvertently apply that kind of statement to the people that we work with.

>> Elaina: Well, that brings us to the end. Thank you all so much for your attention and for attending. And maybe Tracy can say where to go for information about CEUs. If not it's definitely on the conference website.

>> Tracy: Yes, I was going to say that I'm not the person to ask about that but I know that it's definitely on the website. And I also want to thank Ida and Cheryl and Felicia. It is such a powerful panel. Thank you so much for sharing so graciously.

>> Ida: Thank you, thank you, everybody.

>> Tracy: Okay, I will hang our webinar up, thank you!