

We Need Better Employment Options for Our Kids With Disabilities

Transcript of Episode 39

Ellen Stumbo 0:00

Hello and welcome to Episode 39 of the "Unexceptional Moms" podcast. I'm Ellen Stumbo, from ellenstumbo.com. And today I am talking to Meriah Nichols from "Unpacking Disability with MeriahNichols," about why we need better employment training for our kids with disabilities.

Now, this is what we talked about during the interview, because this all has to do with employment training and our kids' future. First, we talked about ableism, how it affects our kids. And we also addressed the ableism that we may experience as parents. And by that I mean, before our kids were born, chances are we had some ableist beliefs and how we as parents we have to undo all of that in order to really be the best advocates we can be for our kids. We talked about grief, and how most parents experience some degree of grief when their child is diagnosed with a disability. And then we talked about finding empowerment in disability. Basically, what disability brings to the table and how amazing it would be if some of these employment training programs, transition programs, really focused on what disability brings to our kids, the positives, the empowering side of it. We talked about inclusion and the education system, the positive and the downfalls, and how nobody is really doing inclusion, right. So when we talk about inclusion, what's happening right now is not really translating into the future, into the jobs our kids are going to have one day, we did talk about those transition programs. We talked about how they kind of box in our kids, especially for those with intellectual disabilities. And finally, we talked about community and how important it is for our kids. And I'm not talking about community as a whole, we talked about the disability community. So it is a great conversation that Meriah and I had, I really hope you enjoy it. Now before I share that interview with you. Just a reminder that the transcript is available on my website, ellenstumbo.com. And for those who have asked how can you support the podcast, the best way to do it is to leave a review on iTunes. So we would love to get your review. And here is the interview with Meriah, enjoy.

Hello, Meriah and welcome to the "Unexceptional Moms" podcast and why don't you tell our listeners a little bit about yourself.

Meriah Nichols 2:39

Thank you, Ellen. Well, my name is Meriah Nichols and I am a mom to three. I'm a single mom to three. One of my children has Down syndrome. One is on the autism spectrum. And my third is actually currently getting tested for auditory processing disorder and maybe hearing impairments. And I myself am little D deaf. I was raised oral and I have C PTSD and TBI as traumatic brain injury from going through the windshield of a car.

And I'm a self-professed gardening nerd. And I'm really into Star Trek and cats and I'm a one-time career counselor. And I'm currently going in for my second Master's in counseling psychology. And thanks for having me.

Ellen Stumbo 3:37

Yes. And she also has a really incredible blog.

Meriah Nichols 3:44

I've been online for years. Thank you. So my blog I actually started, I started it 14 years ago, 13 years ago as to chronicle my dating stories. And it was called, "Finding Ruby's Father." And because I was convinced I was going to have a daughter she was going to be named Ruby and I was looking for her dad. Mm hmm. And then it went its way into, "With a Little Moxie." And then now it is it's all morphed into, "Unpacking Disability with Meriah Nichols," and it's at meriahnichols.com.

Ellen Stumbo 4:27

Meriah and I met through the blogging world. Meriah was pretty well known and somehow she found my blog. I'm not even sure how it happened. But Meriah was the first person to reach out to me and challenged me in some of my views and to point out my ableism. And when Meriah and I were talking before, I was telling her nobody had really challenged me and at first I felt very defensive. I felt like, "I can't have any ableism because I parent two children with disabilities, so how could I possibly have any ableism in me," and I think thankfully Meriah stuck with me when necessary. She pointed other things out. And of course, I followed her blog. And I think, as other voices of disabled individuals started speaking into my writing, challenging some of my views, really, that's when I realized, "Well, Meriah definitely has something to say". And I do need to, you know, because before I wanted to dismiss anything that could have potentially made me look bad. And I had to realize that you did have good points, and there were good reasons, and I had to face my own ableism. And it's probably the hardest thing I've done as a parent of disabled kids, yet the best thing I have ever done as a parent of disabled kids. And while I like to believe that, I get it, most of the time, I know, I still don't

always get it. So, um, as we get to talking about the future for kids, our disabled kids and what happens after they graduate from high school, and they go through that transition program, which makes us super overwhelmed. And we wanted to address maybe the parent piece because sometimes as parents, I would say most of us deal with grief at some point. And now I recognize that so much of the grief is that ableism that is so ingrained in our society, and that is so ingrained in us. So, therefore, our first response is grief. So let's talk a little bit about those parents beliefs, and maybe the acceptance piece.

Meriah Nichols 6:59

Easy topic of conversation. Wow. huge topic. Um, but, you know, I really, first of all, I wanted to say, Ellen, how much I admire you, because I, I truly admire people who can dig deep, and really look at transforming themselves. Um, that is so not easy. I mean, and it requires so much humility, really, and just a willingness to, to really look deep, and, and hard in ways that are not comfortable. And, yeah, and to kind of walk on that bed of fire, you know, and I see so few parents willing to do that. So I truly, truly admire you. And what you've done, that's amazing.

Ellen Stumbo 8:06

You've seen the change.

Meriah Nichols 8:08

I... wow. Thank you. Um, but yeah, so for the grief, the grief, and the grief part is real. And I think, um, I'm always fascinated by parents that don't go through it, because I don't think there's that many. But I'm wondering how they get to be the way that they are, where they don't have that process of grief. I know, for me, I did when I was expecting Moxie. Because she, I knew she was coming with Down syndrome, I had had an amnio.

And, um, and I was very, very strongly encouraged to abort her, by, you know, the hospital, by the doctors, by the pediatricians by the perinatologist, by all of them. And I mean, it was meeting after meeting where all they did was tried to, to tell me how, you know, I should abort her. And it was really difficult for me because I had been through a lot growing up with disabilities, and I didn't want my child to go through what I had gone through. And it was difficult to really see the value of knowingly bringing her forth into life. But then I realized that just because I've gone through this stuff didn't mean that she would have to, you know, and that my actually having gone through a lot of things would better... I would be in a better situation to steer clear of certain things and to safeguard her and to, you know, protect her. And I'm really glad that I made that very conscious decision to keep

her you know, it's been an amazing transforming blessing in my life, but that was also a grief process. I mean, I moved through that grief. And I think that's very similar to what you went through when you were transforming your ideas about disability and reaching deep in yourself. And that is part of that transforming grief process. And I think that unless we really actively engage in that, we can't come through, you know, to the other side. I know for me, it was a process and, it's not over, it's not over. It's not like I'm, I'm, like, cured of ableism, I'm not, I'm not, I still work through this stuff. And I still have because we grow up in a culture -- and ableist culture -- we grow up in a society that does not value it. So it's ingrained in us and, and it's difficult to really completely eradicate it, you know, but it's an ongoing process.

Ellen Stumbo 11:05

Do you think that there's a difference between the natural, the grief that we can experience because we know what our children are going to have to face a world that is not going to value them, that is going to limit them? Because I feel like that's a very understanding area of grief. Do you see it different when the grief becomes I'm just sad, my child is disabled, and not being able to move past that idea of I wish my child was non disabled.

Meriah Nichols 11:48

What was the first part of that? I wish my child was non disabled. So like the grieving, moving past that idea of, of, of wanting to go to what was it Holland?

Ellen Stumbo 12:00

Oh, yes. The Welcome to Holland.

Meriah Nichols 12:05

Well, yeah, I think for a lot of people, that's, that's a big part of it. And a lot of people, they just, they want their child to have an easy life, and they would see disability as making things, you know, more complex, you know, they haven't been taught to see the value in having disability. So what is there to celebrate, you know? "Wow, yeah, my kid is gonna have a hard time getting a job, they're gonna be discriminated against, they're gonna be bullied." Like, you know, what if the parent themselves, plenty of parents of kids with disabilities were bullies when they were in school, or they would mock kids with disabilities, and then they're coming full circle into that, you know, like, "Oh, my God, my kid is gonna have to face people like me." And then feeling that you failed, maybe, as part of it, feeling that you've failed that somehow, I mean for Down syndrome, I think maybe a lot of women with kids with Down syndrome might feel like their bodies failed them. Or

that, I don't know. Just all of those things. There's so many, so many different.
Yeah,

Ellen Stumbo 13:20

I think there's a lot of, did I cause this? right? Regardless of disability? A lot of women wonder, because we carry the babies. Did I do anything to cause this. So how do we get to a point where we can find empowerment? in disability? You have much better answers than I do. And I would say as a side note, Meriah does address these things in her blogs. I'm only bringing up things you've talked about to some degree.

Meriah Nichols 14:20

Okay, so..

Unknown Speaker 14:24

What is it? What would it take to you know, what would it look like to find empowerment in disability?

Meriah Nichols 14:30

Yeah, yeah, well, okay. So I was actually right in the middle of writing a blog post about this. I swear I am. It's like, it's so long already, this blog post and it is called... It's called "passing is not the goal." That was the name of it. It's tentatively titled it's not like it and yeah, so passing is not the goal. So empowerment would be...

I'm gonna backtrack just a little bit here, because this is mostly talking from my own experience of growing up with disabilities and growing up oral, and oral means that even though I couldn't hear I was supposed to always lip read, and just, you know, having massive hearing aids on and not being able to, to understand what was going on in class most of the time, and so I would just catch up on everything through reading and when I was, in many classes, like, when I went to college, my brother was in almost every single one of my classes with me, and he would tell me what was going on. So he was sort of like my de facto translator. And, um, and then I, you know, I also have brain injury, and I have the complex PTSD, but the C PTSD came on later, but the brain injury didn't and, like growing up without accommodations, and the message that was consistently layered on my, my whole life, was that I needed to overcome my disabilities, and I needed to be someone that I wasn't, I needed to somehow be hearing, I needed to pass, I needed to, to be, like everyone else was, let's see, the thing is, is that there's no way I could do that, I can't do that, I can't, you know, do that. So, I was trying to make myself

into somebody that I could never be, never. And when we have kids with disabilities, you know, Down syndrome, or autism, or cerebral palsy, or you name it, when we try to ask our kids to squeeze into this box, by way of therapy, by way of pushing them to strive to be like the mainstream, and pushing them to strive to be like non disabled people, then we're pushing them to get into a box that they will never be able to fit into. And when we do that, we're also, we sort of, like, we're cutting off the bits of them, that are what make them really unique, that are their contribution to the world, that are the aspects of themselves that frame the platform by which they live. So when I finally realized that my hearing wasn't this horrible thing, and that, you know, my brain injury too wasn't this horrible thing, but they were aspects upon which I was experiencing my world, then everything really shifted. And I also saw things. And this was also because I spent a lot of time abroad. So because I traveled so much abroad internationally, I really saw that my hearing was great. Because I was so tuned in to nonverbals, that when I was traveling it didn't matter if I spoke the language or not, I could always get around, I could always get back and always make friends, always, always easily. And that was a real gift. Like, you know, I'd be traveling and in rural China and with people that's beautiful Chinese, you know, Westerners beautiful Chinese and, and yet the only people that the Chinese wanted to communicate with would be me, because I'd be so tuned into them and so aware of them, that it didn't matter, language didn't matter. And I just saw that as a real asset. After a while I was like, "Oh, I see, like not being able really does give me an edge here, you know, like, it gives me something. Wow, that's cool. I never thought of that," you know? And then when I was teaching English as a second language. Um, that was also very helpful because I was so tuned in, and I'm so aware of like, how to enunciate, how to move, how to do all that. So it really gave me an edge when I was teaching. What I'm just saying is that my own personal experience got me to the point where I was able to step back and look at my disabilities from a different vantage point and see the benefit of them. And that's something that I don't think that has happened yet in our Western culture. It just hasn't happened yet. It's not if your disabled, or you're non disabled, if you're a parent, if you're not a parent, it just hasn't happened, where we're really looking to see the benefit of different types of disabilities in and of themselves, like what do these disabilities bring to the person who's experiencing them, not to the family members? Not what does my deafness do for my mom, like? What made her really frustrated?

Unknown Speaker 20:01

Cuz she'd be yelling at me, and I just turn off my hearing aids and she was like, but yeah, but no, no, no, no, not not for my mom. But for me, you know, and like my son's autism, like, what is that doing for him? Like, not for me, but for him? Like,

what is it giving him? And same thing with with, you know my daughter Down syndrome? It's like what does Down syndrome give her? You know, and that's a real question because we, one, we hesitate to layer on stereotypes you know, and I agree with that. I mean, we do need to be really careful about that, especially with down syndrome because of the intellectual disability. But really thinking about different disabilities, and what they bring to the table, and how they augment your own personal experience, you know, as a person with disability who's living them. Am I often say, because we're talking about empowerment? Right?

Ellen Stumbo 21:02

Yes, no, you, you keep talking because you're so eloquent. And I'm even thinking about myself, "Am I? Am I doing things for me?" you know, because I'm good at them?

Nevermind, my kids, I don't even know how to do it.

Meriah Nichols 21:30

Well, the thing is, is that the more that we do this, the more we're ultimately helping everybody. And this is the thing that I would love for people to really understand, is that it's like, it's the same thing with women's equality, you know, when you're helping women become equal to men. It's not like you're doing women a favor, you're doing men a favor too, you know, with two wings, the bird can fly, right? So bird can't fly with just one wing, you get two of them, you fly. And it's the same thing for racial equity. You know, when you're saying Black Lives Matter, you're saying that, like people of color matter, it's not like you're doing them a favor only, no, you're doing everyone a favor, because all of us need to rise up. And we need, we need to really see the integral value of all of us as human beings. And the same thing applies for disability.

Let alone the fact that it's self serving. I mean, because, you know, you know, it's the only minority group that anybody can join at any time. And the older I get, the more friends I have that become disabled. And then I like all of a sudden am really popular. "Oh, hey, Meriah, how do I...?" So yeah, but it's really true. So when you make it equitable for everybody, and you see the value in everybody, you're helping everybody. And that includes people without disabilities.

Ellen Stumbo 22:56

Yeah. So let's talk a little bit about the idea of inclusion, and specifically to what that looks like for our kids just because we briefly talked about like, mainstream and all of that. So thinking about the future for our kids, right, thinking about

building upon the things that they're good at for themselves. When we think about inclusion... before we get there, so let's... let's say inclusion during school. How does it need to be done to actually be done well?

Meriah Nichols 23:34

Oh, my God. Yeah, it that's such a tough question. I think it really depends on the disability as well. You know, when I was invited over to the deaf program here, and I went there, and I saw a roomful of deaf kids. And they were being visited by hearing kids who had sort of learned some ASL as part of their project. And I saw the deaf kids really swarming, you know, and just being uncomfortable with this whole "otherness," you know. And I saw some deaf kids like really trying to pretend that they were not deaf, that they could hear, and they couldn't. And it was... it kind of made my heart break a little bit, because I remember being one of those kids. And I feel like, that's one example. And then you have another example, like my daughter in her class, and she goes to a local school, and she is in an integrated local school. So she's in the general studies room, and then she gets pulled out for certain subjects and she gets this more intensive help with the areas that she needs. And the older that she gets, I'm sure you've seen this Ellen, I'm sure you've seen it, but the older she gets, the worse it gets. Because she doesn't keep up with her general class. Or classmates, you know.

Ellen Stumbo 25:02

Can I interrupt you for a moment?

Meriah Nichols 25:02

Yes, please.

Ellen Stumbo 25:03

I just, I did want to talk about that. Because when Nicole started Middle School, that's when we really started looking at, how much do we push this inclusion. And I find myself feeling trapped in that, if we decided not to do enough, what's considered a mainstream class, we were going to have other parents of kids with Down syndrome judging me saying, "that's not the best thing for your kid, you need to have a full inclusion and all of that". But I was thinking, "Okay, these are the, these are the main classes: math, science, history and English. Is it fair to have my daughter with an intellectual disability taking a math class? That is years beyond what she can understand?" I don't think it's fair. I don't even know that that could be good for her self-esteem because she can't keep up. She doesn't understand what's happening. She's not getting the same handout. And being in the corner with a paraprofessional, how is that now inclusive? Now, she's the kid in the

corner with the paraprofessional that all the other students are seeing as not part of the group.

Meriah Nichols 26:13

Yeah.

Ellen Stumbo 26:14

So, I feel like the older she gets, the more I wrestle with preserving her dignity.

Meriah Nichols 26:23

Yes, yes. Yes.

Ellen Stumbo 26:25

Above everything else, regardless of what the huge advocates for inclusion are saying, or regardless of what the people who might believe she should only be in a self contained classroom, because I don't agree with that either.

Meriah Nichols 26:38

Right.

Ellen Stumbo 26:38

Um, so. So that part is really tricky. And I think throwing kids together in a classroom is not inclusion. I do not consider that to be inclusion.

Meriah Nichols 26:51

I agree. I agree. You know what this reminds me of all of a sudden when you were saying that I had this flashback. When I was, I was sent to Japan when I was 15. And I was sent there because I was caught in a party that I wasn't supposed to be at. I lied, and I went to a party. And my parents were really conservative and religious. So man, did I get it? Right? And I got sent to Japan. Yeah. And so I was in this all Japanese High School. And I was sitting in this classroom for like, eight hours a day, regular Japanese classroom.

And they were talking about like trigonometry. You know, in Japanese. I didn't speak any Japanese. And I'm hearing impaired. And so I slept. Because I didn't understand anything. So I just put my head on the desk, and I just slept. Because I did not understand anything. It was full on Japanese class. No, like, nothing. I got nothing, right. So finally, I went to this teacher and I said, "You know, I love sleeping. I do. But this is too much. I'm getting headaches now from sleeping too much in school. So can I please have something different?" And they said,

"Oh, Okay, how about art?" And I said, "Okay, that'd be great. Yeah, thanks." So I went to art class, for most of the day, while my classmates were studying trigonometry in Japanese. But you know what, Ellen, I think this is the same thing we're talking about. It's like we're talking about why should our kids sit down in a trigonometry class in Japanese when they don't speak Japanese?

Ellen Stumbo 28:20

Yeah, yeah. Right.

Meriah Nichols 28:22

Let's let them do art. And then they can learn some Japanese, like, while they're doing art, like, you know, yeah, friendly art practitioners.

Ellen Stumbo 28:30

I feel like sometimes we think about inclusion, throwing the kids together. And, and then there's this idea that it will magically become inclusion in the future once our kids are looking for a job and the future employees. And the reality is that we are doing inclusion so wrong in schools, that what we're hoping it accomplishes, it's not like I said, it's throwing the kids together, that is not inclusion, and you do have the kids who are nice, and people say, "oh, my children, or my son, my daughter, they have friends who are non disabled," and they think how often are they calling them? How often are they inviting them to hang out? How often are you seeing them in your home? Because that's a real true friendship. And while it does happen, I don't know that it happens for most disabled students

Meriah Nichols 29:27

No, also when they're just thrown together like that. So I guess the answer there would be very carefully, like really good inclusion would be done very carefully and it would be done with regard to true education and you know, peer mentoring and peer development, but this is where it gets like really, really tricky I think because the education systems overall. How could... I don't even see how parents could do that, how parents and teachers could do that in the current system, like where it's teaching to the test, you know, where it's so like, focused on certain areas of academic success that it's... I just don't see. And I see now, I can see like, some of my daughter's classmates, like their faces tightening a little bit in frustration, if they have to, like go through another explanation, or she messes up, you know, in some way that they're working on something and, and... that is the part that makes me very tense, because she's gonna pick up on that, she's gonna pick up on those nonverbals, you know, and that is the stuff that's gonna bring her down. And I don't want that to happen, because that's, that's not going to do her any good.

Ellen Stumbo 30:54

I like what you're saying about the peer mentoring. And I think that applies to the non disabled students as well, because they also need to learn the skills to interact with people who are different from them. I think, with recent events in society, and everything that's happened, we're all aware that we don't know a lot of times how do we interact, respect, listen to those who are different from us.

Unknown Speaker 31:18

And until we are finally able to admit to them, to realize that we have to learn and to grow and to listen, a lot of those social interactions, I fear will continue to be the same. And we were talking a little bit before about, you know, me having to confront my ableism. And before we were recording, I was telling you about the five stages of disability attitudes. And just real quick for people who are listening, the five stages are stage one, ignorance, stage two, pity, stage three, care, stage four, friendship, and stage five, co-laboring. So stage two, pity, is the most commonly experienced disability attitude that disabled people experience. That's what I meant to say. And I think it's because it's the most common. Now when I look back on myself, I would say, that probably did fit me very well. With a very healthy dose of ignorance. And that's, I mean, those are very ableist attitudes, of course, but pity looks so much like niceness. And I feel like in a lot of systems designed to include even disabled students, they come across as really nice programs when they're really rooted in that pity. Right? And yeah, and I feel like because it's so common, it's almost like we're teaching that. And I just cringe to think about interactions that I've had with disabled adults, even when I had disabled children, how "nice" I was being and my tone was condescending. And without recognizing it, I was positioning myself as having more to offer, I was the person who had something to give, something to teach, something to do to make someone's interactions with me better, right. And I feel that in some of the programs that my daughter -- specifically my daughter with Down syndrome -- has participated in because I feel like that ableism is so much more prevalent when you have the intellectual disability, for events, targeting them because there's a lot of excuses, mainly from parents, but even from people in the professional field saying, "well, they can't speak for themselves."

Meriah Nichols 34:08

Oh, I know that one!

Ellen Stumbo 34:10

"We're gonna keep doing these events, when they come they're really happy." I mean, just because someone is going to have a good time at a certain event doesn't mean that it's not condescending and ableist and just really problematic. But again, I feel like it's because in our culture pity is so prevalent and because it comes across as niceness. And it's like we based a lot of that and I say that because there are programs in my kids schools that are meant to help my daughter interact with non disabled students, you know, their peers, but it's very much the non disabled students are going to go and be very nice to the students and then they become almost like...

Meriah Nichols 35:02

A pity party. Yeah. A pity thing.

Ellen Stumbo 35:04

Yeah, a pity thing. And it's not just about...

Meriah Nichols 35:09

It's a photo op.

that kind of drives me crazy here because they have all these like, you know, special stuff. And it's like a special surf event or specials or something. And it's like, it's like a one day thing where you get together and the kid with a disability will ride on a surfboard with a surfer and, and it's like, Great, that's awesome. You know, but tons of photos are taken right? tons. But then there's nothing ongoing. Nothing. That's it. And it's like, Whoa, you know, we could do like ongoing surf lessons. Like, you know, we could do like, something more like, yeah, we can totally do it. It doesn't have to be this one time shot, like photo op thing. But I totally hear you. It's that, that pity stuff with the, with that niceness. And, you know, the photo op.

Ellen Stumbo 36:00

And then our kids get to the age where that even stops. That's not happening anymore. So we can kind of start talking about that, which is the whole reason I wanted you to come on the podcast. What, what happens then for kids, when they graduate from the school, and I'm going to guess that things are similar in Hawaii, then, once a kid turns 18, then they have two to three years of a transition program, which is supposed to be the time where they're doing some job teaching, life skills kind of work, maybe training for a particular job. And the reason I wanted Meriah to come is that she wrote an amazing blog about the three F's, you want to tell people that... four? The four Fs.

Do you want to tell them what they are?

Meriah Nichols 37:05

Sure, okay, four Fs of disability employment, they're food, like food preparation and service, they're filth, cleaning, janitorial service, flowers, simple landscaping, or decoration. And factories, like light assembly work. By the way, I did not come up with this. This is like a standard and in the disability community, we're talking about employment of people with intellectual disabilities being limited to these four F's. And it's like we were talking before we started this Ellen, like, everybody has their path and all work is noble. And all work can be a means of, of worshiping God, and it can be a means of becoming, you know, closer to the creator to the universe and to really strengthening our spirit and our body and our minds. And so it's not to disregard, is not to at all disrespect any of the jobs that are involved in those four F's at all. But it's that it seems to me that so many organizations and families and culture itself really push people with intellectual disabilities into one of those tracks, and saying that they can't think outside of those tracks. But you know, what if they belong outside of those tracks, or what if their calling is something that's beyond those tracks, you know, like, with Nichole and her makeup, you know, or Moxie and bodyboarding, you know, or this stuff that she really digs? It's like, if her calling is in, is in janitorial work, that's great. But if it's not a janitorial work, what then? So it's us as parents, because really, this this change, I think, is going to have to be led by us. How are we going to help broaden those fears that our kids can dive into when they are in this transition period, or even before this transition period? You know, when they're growing up? It's a huge question. And it's daunting. I mean, it's incredibly daunting. I mean, I I feel like, I feel like crying and throwing up at the same time, honestly, like when I think of all of the work that we have, I just don't even know.

Ellen Stumbo 39:39

Yeah. And I think it's the reality that anything past 21 feels so overwhelming, because there are no set paths. Now we know that even if they participate in some of those training programs and some of those transition programs, they stop after certain age. So what systems, and I think sometimes systems just don't get it right, but what do we have available for the after? So as I think about Nicole, when she finishes a 21, she's done. What job does she get to do? I mean, she probably wants to do YouTube makeup tutorials. But she also, you know, she's thinking she wants to do makeup for other people, too. So is there going to be a cosmetology school that is going to be willing to let her come in. But what if since she was in high school, right, we started talking about maybe this is something she would like to

do. So rather than focusing on some of the four F's, we're focusing on some of those strengths, and maybe, maybe she is taking more art classes, right, so that she can be practicing those fine motor skills and that creation and combining color and... and I don't know that there's any place that's doing it, right. That like you said, looking at the real strength that someone has, and I really liked what you said, the strength to come from disability, not just, "you are really good at this, but because of your disability because of how you experience the world differently, that way, this is a really great strength." So how do we make that be a possibility of fulfillment of work, of a passion, of the dignity of having a job or the dignity of having work.

Meriah Nichols

The other thing that I just wanted to just say because it flitted through my mind when you were talking is, is that too often too, we are the limiters, like our own selves are always the limitors, like we think of another example here. Sorry, I'm full of stories. Okay.

So when I was an undergrad, I loved religious studies, right, loved it. And I took almost every one of my electives was in religious studies, and I actually was one class short of a double major in religious studies and education. It was just because I ended up with all my electives. And I loved it. I love studying religion, right? More than anything, I love it. I still do every day, I study religion every single day, right? So back then, you know, my, my advisor was like, "Damn, Meriah, all your classes are Religious Studies. Like, why is it? Why don't you just major in it?" And I was like, "Oh, no, what are you gonna do with religious studies? Like, that's useless."

So fast forward, okay. And I really thought it was useless. Why get a degree in religious studies? Useless.

So, no value in it, you're not gonna get paid, and you're not gonna get a job in it. Okay. 20 years later, I'm in a career fair at UC Berkeley. And I see these agencies are specifically looking for people who have majored in religious studies. And I was like, "Huh, why?" Why, you know, still, like, stuck in like why? And they're like, "oh, because if you had a degree in religious studies, it means you understand the underlying pieces of culture. You understand why people believe the way they do why they think the way they do, you understand current affairs, you're like, Okay, well, x y and z happened in Afghanistan, people there are in this religion, this religion believes that, like, this is what is likely to happen because of that it ended up," so you see they're totally spot on. That's exactly true, it really is true.

Because when you have that understanding of all of these different religions, and you really understand the way that people think and value, and that stuff that propels people, you know, the drive.

But here I get into the limiting piece, right? So back then I thought religious studies, useless. It wasn't in Newsweek, you know, what you need it for careers that are hopping popping in 1990, whatever, you know, and now we do the exact same thing, right? I do it or other people will do it be like, well, what are you going to get a job? And how are you going to get a job there? They're like, you know, what good would studying, you know, the color orange. I'm looking at my meditation piece right now. What good is studying the color orange? Like, how is that going to happen? But we don't know. Right? We don't know. And we don't know what it could lead to, or how things could evolve or what that might actually be. And we also forget that we are the ones that create culture, and we are the ones that make it happen. So if we shift ourselves, and recreate that change in ourselves, and we open our own minds up to the possibility of what could be, then we're allowing those paths to open to for our kids. So I think that's like one of the really important pieces in this, in this puzzle, is like, is being able to open up our own minds and our own hearts and realize that we have the power to shift culture. And we also don't see the end, when we're in the beginning. And we don't see what might come up our child, you know, studying XY and Z that we don't think it's gonna lead to a job. Because it's not part of our our current cultural belief in what is a profitable career. It doesn't fall into the four Fs. You know. I don't know.

Ellen Stumbo

How does community... I'm trying to think how does community enter into the picture, not just like the parent, right, because as a parent, I'm probably going to do everything in my power to try to open the doors for my kids. So where does community come in?

Meriah Nichols

Totally. For me, this is just going back on my personal experience, because I felt so incredibly isolated, growing up. Never knowing any other deaf people. I didn't know anybody until I went to to Berkeley. And when I was in Berkeley, and all these other deaf people, it was like, my head was blown open. It was like, holy cow. Like, "you guys are like me. Oh my god, I'm normal. I'm normal." Like it was so huge.

You know, and now they're moved back to the Big Island here, one of the first things I did was I connected with the deaf community here. And, and that is, it's

like this huge memory foam cushion that I can lean back on. And I know they have me, I know they get me, I know they understand. I mean, that's the minimum, but it's there's,

It's so important just to be around people that, understand, you know. And so with Down syndrome or with intellectual disability, I mean that, that it's right there with it, it's like, having that sense of community that they know that they get each other.

You know, with Moxie, when we first got here, there was nothing at all on the Big Island for community with Down syndrome. And so, you know, bit by bit, I've been trying to get that going. And Moxie has some friends with Down syndrome now, and it is really, I can see that it helps her friends and maybe even more than it helps her because they really are being pushed into these boxes, where they don't have a chance to just be who they are. And then when they come together, they're able to receive that support. And that camaraderie, and the love and the genuine unconditional acceptance, you know, that they have for one another. And that's, I think that means everything, gives them that power to like steer through what they need to steer through and a society that often doesn't value them.

Ellen Stumbo

Yes, I believe it's so important for kids to be connected to their own communities, to the disability community, which as a side note, this is why I think parents need to listen to their child's disability community, because they were their kids at some point, right? They were those children. And if we listen to what disabled people are saying, when they're saying, "this is harmful, this is the problem. Maybe don't share that personal information about your child. Maybe the language you're using is not great." I mean, there's so many things that I feel like disabled adults are very vocal about and in sharing those things that we often dismiss those voices.

However, going back to our kids having community, one of my really good friends who is autistic, he often tells me that it is exhausting to pretend, and he uses the word "masking," which I'm so excited to read your thing on passing because I feel like it's a little bit of that, you know, masking, pretending to be or almost being perceived as...

Meriah Nichols Non disabled.

Ellen Stumbo

Yes, being non disabled. And I think for my daughter with, you know, cerebral palsy, she uses a wheelchair at school. She's going to be in high school already.

But one of the first things that she asked during the transition meeting, she said, "Is there any other student who uses a wheelchair?" And they said, "Yes, um, one or two other students use a wheelchair." And she looked at me and she said, "finally!" because all her life she's been the only kid who uses a wheelchair in her school, and she feels so different from everybody else. And then if for any reason, she gets up and she walks, you know, which she can do, then it becomes a big thing, and everybody's pointing it out. And then she has all this attention. And it's not positive attention, it's attention on her body, its attention on her disability, not really of her as a person.

So she is connected to the cerebral palsy community. She has some mentors. She now has a friend, actually her doctor's daughter, but anyway, you know, they're not close to us, but they FaceTime and having that connection, like you said, maybe for her realizing. "I am a type of normal."

Meriah Nichols
Yeah.

Ellen Stumbo
Right. Like maybe everybody has their own thing that they would consider normal, but these are my people. They get it and I don't have to pretend and I don't have to overcome my disability when I'm around them and I can just be me.

Meriah Nichols
It's just, it's amazing. And then you do have to slog through so much. You know, even last week, I was in class and you know, all of my classes are on zoom, and I get the captions in my classes and one of the professors had not familiarized herself with how to integrate the caption in with the zoom. And she had us all wait for half an hour while she was like, trying to figure out these pieces. And I felt like going through the floor, like I was so... and I was really trying not to go there and those feelings of shame. But it's hard, it's really hard to, to get over it, you know, especially when you're there and your classmates are just like waiting. And it's like, 'oh, there's Meriah again, she needs to have the captions," and it's like, ugh! It means a lot to be able to laugh about this later with people who understand, it means a lot to just be able to, to put it in light and to be with people who really, truly understand. And the other thing is tips, because one of my other professors who is also teaching a deaf kid, and in his undergrad class, he connected me with this kid. And now I'm this kid's mentor, you know, and it's great, because I'm like, "Hey, have you heard about like this, this and this, have you heard about, you know, these little like things that you can give to your professors and they can put

it on and then their voice can go directly into your hearing aid. And you could you know, there's all of these like, tech pieces that you can use now that really make a world of difference." But you get this from within your community, because your community are the ones who try it out and who test it and who know, like, what works and what doesn't work, and how, whatever, all of those, like quirks and pieces. And so I just feel like, it's so important for us as parents to help our kids connect with those people. And to to Oh, like Amanda Gorman says, to be the light.

Ellen Stumbo

She's amazing! Yeah, and I don't think that there is an age where community is not important. for our kids.

Meriah Nichols

And you've experienced that too! With being Latina and in the Midwest, I mean you know how important that is? You're like, yeah!

Ellen Stumbo

Before we started recording, I was telling Mariah that I've connected with the Latinx community for writers, and suddenly I'm writing fiction for children!

Meriah Nichols

Oh, great.

Ellen Stumbo

But I found my people and it only took me 22 years Meriah. So here we are, maybe some day I will do a podcast en espanol. We'll see what happens.

I have to say there are so many things that we could talk about. Because people need to find you, you are a wealth of information. I was, you know, let me go back a comment that you said because you've studied word religions, but you also know the Christian faith. And you also challenged my theology at some point, and you might not remember.

Meriah Nichols

No I don't remember.

Ellen Stumbo

Okay. But interestingly enough, now, I teach churches, theology of disability, and I'm going, oh, yes, thinking Mariah kind of set this to me. You know, and now

we've come to full circle, and now I'm sharing some of those things. But anyway, besides the point, I could come up with such a long list of things that we could talk about. Um, but so is the time for us to wrap up. So do you have any closing thoughts or remarks?

Meriah Nichols

No, but I really like talking with you. So hopefully, we can chat. Well, even though it's not podcasting, or something like that. I really, really liked talking. You're a good person to talk story with.

Ellen Stumbo

Oh, thank you. So where can people find you?

Meriah Nichols

Oh the blog, it's meriahnichols.com. It's "Unpacking Disability with Meriah Nichols."

Ellen Stumbo

And I will have links to that. I also have, every podcast has a transcript. And that's on my website, ellenstumbo.com. And are you on social media?

Meriah Nichols

Oh, yeah, I'm all over the place. So I'm on Facebook. It's just Mariah Nichols. I'm on Instagram, as unpacking disability, and Twitter, Mariah Nichols, Pinterest, Mariah Nichols. What else is there?

Ellen Stumbo

I don't know. I will have all of those links so people can find you.

Meriah Nichols

Okay, thank you.

Ellen Stumbo

I was gonna say, people if you follow my Facebook page, I have sent you all to Meriah's page at some point or shared her blog posts for sure. Okay, so I will have that there. Thank you so much for joining today Meriah.

Meriah Nichols

Thank you, Ellen. I really appreciate your having me.

Ellen Stumbo

Thank you, Meriah. And thank you, everybody for joining us today for another episode. I have show notes on the blog, ellenstumbo.com and again, if you want to support the blog, not the blog, but the podcast, the best way for you to do it is to leave a review on iTunes. And we will see you next month for the next episode of "The Unexceptional Moms" podcast.

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