

Unexceptional Moms Podcast
Episode 40
Let's Talk About Disability Culture and Identity

Ellen Stumbo 0:00

Hello, this is Ellen.

Erin Loraine 0:03

And this is Erin and today we are joined by our friend Marin. Marin, why don't you tell us a little about yourself?

Marin Hann 0:10

Hi, everyone. Um, so my name is Marin, I am, have been friends with Erin and Ellen and not new, we have been friends for a few years and known each other for much longer. And I, during the day work as a licensed professional counselor. And I also am someone who is a wheelchair user, I have disability called arthrogyrosis. And then profound hypotonia, which is a lack of muscle tone. So that kind of stuff.

Ellen Stumbo 0:44

And we wanted Marian to come so that we could talk about what it's like to grow up as a disabled child being raised by non-disabled parents.

Marin Hann 0:54

Yep.

Ellen Stumbo 0:56

And we were we were talking, I loved what Marian said, like, I don't know any other way to be.

Marin Hann 1:04

I don't know any other life. I don't know what it would be like to be a disabled child and grow up with disabled parents. I also don't know what it's like to be a non-disabled child and grow up with disabled parents, or to be a non-disabled child and grow up with non-disabled parents. So yeah.

Ellen Stumbo 1:22

So, for you, Marin. What, what sticks to your mind the most, I guess about that difference, I guess, of being disabled and your parents not.

Marin Hann 1:39

Um, gosh, what sticks to my mind the most. I think as a child, it was just like, noticing that we had to figure out a lot of different ways to do things. And they were like, trying to figure it out, like actively trying to figure out how they were going to make it work. And then, as an adult, it's more looking back that like, I have now as an adult, I've developed a very different cultural and

historical understanding than they have. So, I think that now that would be our biggest difference.

Ellen Stumbo 2:19

Okay, let's talk about that.

Marin Hann 2:21

Okay. Sounds good.

Ellen Stumbo 2:25

Yes. Because I, I do feel that that cultural piece, for me, as a parent, I feel like for a long time, I was not aware that there was such a thing as a disability culture.

Erin Loraine 2:40

Ditto.

Ellen Stumbo 2:42

And I can't say that I know a lot about it, or I'm an expert, part of it because I can't be a part of a culture that I don't belong to, and I am not disabled.

Marin Hann 2:55

Right.

Ellen Stumbo 2:56

So, I guess for you in that process? How did that happen for you?

Marin Hann 3:04

Um, it happens pretty slowly. And over time, as I was probably starting to like being in my late teens, and then from then on, it's like, slowly develops. But yeah, my parents didn't know that there was a disabled culture, or what that meant, either. And it makes sense, because I don't know how they would have access to that prior. And they didn't really know anything much about raising a disabled child till I showed up. And then they were stumbling, they were busy stumbling through that and figuring out and so I can totally understand why that didn't come up when I was a child. And I was also born in the year 1990. And so that was the year of ADA. And so, there was kind of a little bit of a repression and quieting of the movement that existed that led up to the ADA. And it was kind of like, the way the majority made history sound like was kind of that like, "oh, the ADA appeared because people thought for others because non-disabled people fought for disabled people." And it suddenly appeared and there was no like, decades long battle of disabled people fighting for it. So, all my parents knew was that now their daughter had rights that she wouldn't have had if she, you know, been born earlier. So that's totally understandable to me. It just, it was strange growing up and through young adulthood trying to figure some of that out. Cuz I think a lot of it, before you can get to like your own culture as a disabled person or you're willing to... Not even willing, like you desire to look up the history, I think, if you yourself struggle with internal or lateral ableism, you have to get

over that first. And like, you have to start working through that first and figure out why you feel that way. Before I think you're like, willing to delve farther than that.

Erin Loraine 5:20

Marin for some parents, especially that might be listening to this, can you describe to me that ableism you're talking about that might be internal in a disabled person?

Marin Hann 5:33

Yeah. So, kind of the idea that your disability is the bad thing. And if you didn't have your disability, your problems that you experience in society would go away. So, you kind of, there are a lot of other people in the majority, that either consciously or unconsciously, kind of teach that the issue is your disability. And then you kind of end up separating yourself from your disability. Like sometimes you have this desire to say like, "well, I am not my disability," rather than wanting to identify with it. And I can remember experiencing some of that. But my mom in particular was really good about talking about that with me and not feeling like issues like accessibility were my faults are that it was something I had to change, but the other people around me had to make that change.

I think the other kind of ableism that a disabled person can experience is what a lot of disability literature calls lateral ableism. And it's kind of like making a hierarchy of disability. So, I remember when I was a teenager, and then partially as a young adult, I struggled with that. And I... it's like, sad to look back on because I'm like, I'm so glad that I've been like, brought through a journey where it's different than that. And I'm so glad that God has brought me through that point. But I used to be... I'd get adults saying things like, "Oh, can she talk?" And like, "oh, how old is she?" Or like, they wouldn't talk to me. And so, I started thinking, "Oh, they think that I have a cognitive disability," which I would now call neurodiversity. "They think that I have that because I'm in a wheelchair. So, they think that automatically because I'm in a wheelchair, I have all the disabilities." Sometimes I would even have people like talk louder to me, which is offensive to a deaf person. But also, weird when you're not deaf. I'm like, "I don't know what's happening right now. Why are you talking louder?"

Erin Loraine 7:54

Something Ellen and I have noted with our children is people talk to them, like their babies as well.

Marin Hann 7:58

Yeah. Oh my gosh, I hate that. And I hate also, I'm sure that sadly, this has happened because I've seen it happen in places where we've been like, you know, seeing each other, but when people just like do the cute like, "Oh, I'm gonna pat you on the head." Like you're a kid. hate that. I hate head padding. Drives me wild anyway. So yeah, because of that, I would be like, "well, I don't want them to think that I have other disabilities too." So, I built like, partially, consciously and partially didn't realize how much harm that was built up like, "Oh, well, I'm going to separate myself from other disabled communities, because I'm not that community. I'm this community. I'm a wheelchair user. I'm not autistic. I'm a wheelchair user, I don't have

Down syndrome." So, I wanted a hard line drawn in the sand between us. And it took me a while to figure out how damaging that was. And I had to do a lot of spiritual work to figure out, just to realize, you're offended, that they are patronizing you thinking you have this disability, and instead, you should be offended that they would patronize someone with that disability. Like you are making a line in the sand at the expense of your fellow humans with you, that you should have solidarity with. And so, there was a whole journey of that I went through.

Ellen Stumbo 9:35

I find that really interesting. And I want to pause here, first of all to say that I am ableist. Sometimes, maybe many times. I don't want to be.

Marin Hann 9:45

I think we all are.

Ellen Stumbo 9:46

But I am non-disabled. And I feel like as parents, we are often guilty of doing that exact thing of separating our child from their disability. And I think a lot of us are familiar with maybe some parents... I hear that, especially in the autism circles, like, "I love my kid, but hate autism," Right? And then all of a sudden, we make this huge separation and one of my closest friends, he is autistic and he's like, "that is so hurtful, because you cannot separate me from my autism. That's how I experience the world. It's my brain. It's, it is who I am." And I have to really look at what I've said to my kids that maybe I haven't said those words, but I feel like I have communicated those things. And I do feel like that's a result of my ableism as a non-disabled parent who doesn't know a lot about disability culture. And like you said, even the history. When you were talking about the ADA, I think until I watched "Crip Camp," which was great documentary.

Marin Hann 11:02

Everyone listening should watch that documentary. It's excellent.

Ellen Stumbo 11:05

Yeah. And I honestly also thought that it had been parents who fought for the ADA to be passed. And no, it was these incredible disabled activists that did amazing work. I mean, some parents joined, right, parents of disabled kids, but I mean, that was led and that was fought by disabled people. And when I watched it, I was like, I need my kids to watch it, because this is part of their history. So, for me, when did the documentary come out?

Erin Loraine 11:38

Recently.

Ellen Stumbo 11:40

Yeah. In 2020. So, for me, honestly, as a parent, that was the first time that I thought I know nothing about the history of disabled people. I really don't. And it's part of two of my kids' history, right? And their culture. So, for me, because I have disabled friends, I've been a little bit

more aware of those things. So, for you as a teenager, did you meet disabled people that you started thinking about that? Or was that just the, you know, the normal way of when it's your...

Erin Loraine 12:17
Like progression?

Ellen Stumbo 12:19
Yeah, norm, what led you to want to learn?

Marin Hann 12:25
Oh yeah, as a kid, I knew other disabled kids, and I met some disabled adults, but I didn't really spend a lot of time with them. So, we never had those conversations. And I think what drove me to learn after coming to terms with recognizing that... I think we all are either that you have to be either the same that they say with Ibram X. Kendi, who wrote, "How to Be an Antiracist." He said that we're all either racist or antiracist in any given moment. And I think that that's true with ableism. You're either ableist or you're anti-ableist. And the goal is to have more anti-ableist moments than ableist moments, but not that you're ever going to stop being like someone who never has an ableist moment, because that's just kind of the way our, our, our broken state of humanity works. But I think after starting to recognize that in myself, I wanted to learn more because I started being around more disabled adults. And that made me want to learn more.

And then I started to build some disability pride. Like I started to define myself as a disabled person. And I loved that part of me. And so, I wanted to understand why other, like why the world didn't love disability pride, like I wanted to figure that out, like what was happening. And then I remember in grad school, I wrote a research paper on the history of social trauma and disability. And that is when I ran into the American Eugenics Program and started seeing a ton of disability injustice throughout American history, and then expanded more to World History of all of the injustices that had occurred that I didn't really know about. I may have heard like little tidbits here and there, but I didn't understand the extent of what had happened. So, after reading that, I then wanted to learn more and more history of like, well, what else don't I know and just wanted to figure that out, I guess.

Ellen Stumbo 15:03
I mean, you and I were talking a couple weeks ago, and I said, "Okay, do give me some books for me to read so that I can learn about this." Because I feel like as a parent of disabled kids, one, I should be informed. And I should know about it, especially if I want to be a good ally, which I want to be a good ally. And I really want my kids to have that disability pride, which you are not the first disabled guest that we've had who uses that term. So, it is a thing.

Marin Hann 15:35
Yeah, disability pride, for sure. There's a, I haven't ever been to it, but there is a Chicago Disability Pride. That's the biggest pride events for disability that I know of, and I haven't been to Chicago. But yep.

Erin Loraine 15:51

That's amazing. So, Ellen brought up a really good point, actually, there's probably a lot of parents listening right now, who are thinking, where do I even start to help my child? And myself, learn more about these things. So, Marin, what resources, what starting points, what suggestions would you have?

Marin Hann 16:17

Oh, um, I would, I guess a good starting points would be to look up -- and this is where I started building my reading list, actually -- one starting point would be to look up lists of disability history and culture literature, that are made by other disabled people, like forming lists of like, these books are good and like doing this, and also just to start getting to know adults that are in the disability community, and more adults that have a similar disability to the disability or child has, and then just allowing your kid and the adult to, like, hang out more. Because they just need to, they need to see that from somebody.

And I think the big gift that parents can give, it's not like, "Oh, I wish I could give my kid that." And, yes, there's a culture disparity there. And so, it's hard to be able to you yourself, not being part of that culture, to give that. But it's like the parent is the bridge between, I know where to get that for you. So, let's find someone who can mentor that and help you develop that disability pride. And then I'm really excited to learn. So, if you're hanging out with that friend that I've introduced you to, and you guys had a good conversation, or had questions like, let me in on it. Tell me like what you're thinking about stuff, and learning. And I think that can open up a lot of good conversation for that child and that parent, too.

Ellen Stumbo 18:01

I know, for my daughter with cerebral palsy, one of the best things that I've done for her is connect her to adults with cerebral palsy, and now she's connected with some kids her age, some other teen girls, which has been really great. But I wanted to say that Marin sent me a list of books, I will have that on the blog. So, I will have links to all of those. And Marin, don't you have a list? Like an Amazon list of books? I don't know if it's public or not.

Marin Hann 18:30

It is public. Yeah. I put it on there, too. So, I had a place to like store the list of the books. So, if anyone wants to go on that list, just to see what they are, so that they can look into them too.

Ellen Stumbo 18:44

So, I will have that. I will have that linked on the episode notes and with the transcript and everything so that people can have those resources. So, I guess this is a good time to talk about that there is a gap between parents of disabled kids and actually disabled adults. It's this great divide. My public page on Facebook has been very interesting in the last eight months or so. And I think it's because I have really tried to be a better ally. And I'm discovering that it's really hard sometimes to have those hard conversations with other parents. Like I have gone through the pain, right? I have gone through some of the transformation, again, not completely. So, I

feel like I've learned all these things and I want to share them, and it makes other parents very uncomfortable. And then I see the direct fighting and I don't like to use that word, but the direct disconnect between parents of disabled adults and the actual disabled adults.

Marin Hann 19:57

Yeah, there's conflict there.

Ellen Stumbo 19:59

A lot of conflict. And I did a podcast with my friend Carlyle. We talked about this great divide, and I do I call it the great divide. I feel like it's -- it's just a great divide. And I know that as parents, it's hard sometimes to hear someone say things about our kids when they don't know our kid. And they don't know what it is like at home, but maybe they do know, because they have the same disability. But... there is a lot of validity to what someone who has a disability has to say, such as, "hey, don't share private information." "Well, my kid is not going to understand," is like no, but others do. So, you're not really protecting their dignity, right. Or it could be other things. And I'm not asking for a solution because we could talk about this for years, and we're never going to find a solution. But I mean, what do you think about that gap?

Marin Hann 21:06

I think... I think that gap is there. I've tried as well, as a disabled person, tried to as truthfully, but as gently as I could like reply online to like different things. I'm part of Facebook groups for my own disability, arthrogryposis, and we realized in the arthrogryposis group that it was necessary to have an arthrogryposis group that was for everyone who knew anybody with arthrogryposis. And then a different arthrogryposis group that only allowed adults with arthrogryposis. And because we realized there were conversations we couldn't have if we were all together without it getting very confrontational.

And I still try to start conversations gently on the mixed group but I find like, if I bring up like, systemic discrimination issues, and like the historical issues and the macro level of what discrimination is, there are some parents I've gotten pushback from, like "my kid is not a victim, my kid is strong, their disability doesn't weigh them down," kind of responses. And those are kind of like a wall that it's like stops the conversation. There's no, there's no moving from there. And so that makes it... I haven't figured out how to get over that, well, I haven't figured out how to like, meet halfway on that conversation. And I understand what... I understand that they love their child, and I can tell that, I'm like, "I understand that you love your child very fiercely." It's just that right now, for them that love is like, "I love my child. And I think my child is not their disability. I think that I can separate those two things." And that's a hard point to be in for any of us. And so, I think that person... that's like a journey that I guess everyone has to go through to try to figure that out.

But I wonder too, as you were talking about the disparity, if it's kind of like if you adopt a child from another culture, or race or country, and then you have other people from that country and maybe try to tell you something about your kids culture, and you're kind of offended because they're not raising the child. And that's hard, because I think that's easy to understand

how that would happen if we're thinking about race. But if you are, if you look like your child racially, but your child has a disability, you think that there's not a cultural difference between the two of you, you think that you're from the same culture.

Ellen Stumbo 24:17

I did.

Marin Hann 24:18

Yeah. I did, too. I thought I was from my parents' culture as well.

Erin Loraine 24:24

That's really profound Marin and I think a lot of parents listening are gonna go, "Wow."

Marin Hann 24:32

I mean, it's so tough because it's, it's been hidden from history and society so much. It's been... the Disability Pride movement is now starting to become a less quieted thing. And so, even though it's been there for a really long time, the awareness of it to the majority at large is kind of new and so it's hard for people to come to terms with that, like, "What do you mean? This seems like a brand-new thing?" And I know now, and I didn't know before, well, it's always been there. But it was just closed out from the majority. And like media didn't give the disabled people a voice to talk about it. And now that we're starting to get a small amounts of media time, I think now, maybe in another number of years, the culture will start, being something that's like, realized, but right now, it's kind of weird to think, even for me, if I imagine if I were to have children in the future, and I had a non-disabled child, for me to remember that we're not from the same culture. Like, because we wouldn't be from the same culture. And that's like a very new concept.

Ellen Stumbo 26:03

Yet, at the same time, because you were kind of raised in that non-disabled culture. And you I mean, I think about me, right? I'm Mexican and I assimilated to the American culture in order to survive and to fit in. And I feel like the older I get, the more I unpack what assimilation did to me and what that means, the more I have returned to my roots into my culture, that I can say, you know, I'm not American, and I don't have to follow these expectations, even within our Christian circles and our faith circles. But to just be me. However, because I was so assimilated to the American culture, I actually feel like I have, like two different personas, right, like the American, quote, unquote, Ellen, and then the real Ellen, and..

Marin Hann 27:00

You know the culture, right?

Ellen Stumbo 27:01

Right. So, I feel like I do know the American culture because I had to assimilate to it and I don't know, I mean, do you feel... I mean, it's not assimilation, maybe when you're disabled, but

maybe that is the right word. Did you feel like you had to fit this non-disabled culture in order to be accepted?

Marin Hann 27:23

Yeah, I would say, I don't know if I would have been able to put that into words. But I would say I felt like I had to... I felt like I always knew the pressure was, you need to accommodate the world, because the world's not going to accommodate to you. And I don't know if I would have called it assimilation. But now that you're talking about, like, realizing what assimilation did to you, and then owning back your own culture, I feel like that's the experience that I'm starting as an adult of like, "Oh, I feel like I didn't have this my whole life" because I was, told that I, I mean, there were adaptations made and things like that. But it, it was like in a smaller bubble. And I felt like the world at large was not going to adapt to who I was as a person. And I needed to act more like they did or look more like they did.

Ellen Stumbo 28:18

Yeah, I've heard a lot of my disabled friends with that there was an expectation for them to be as "non-disabled" as possible. So, if they could do anything to be as non-disabled as possible, they were going to be more accepted.

Marin Hann 28:32

Yeah, I actually had experience feeling that way in physical therapy, which I had a few physical therapists that were fantastic growing up, and then I had many more that were not so fantastic. And I remember as a kid, I always liked occupational therapy more. And it wasn't until I was older that I could figure out why I really liked occupational therapy more than physical therapy. Because unless it was the really good PTs that I had, I felt like in PT, the expectation was... I had physical therapists that I would come in with my mom and right away, they would say something like, "Oh, well, I'll have her walking in six months."

Ellen Stumbo 29:25

Wow.

Marin Hann 29:25

And first of all, no, they were wrong, every single one of them. But hearing that as a kid, it felt icky. And I couldn't figure out why it felt really icky. And then, as I got older, I realized to put into words that in physical therapy, it was more about making my body work for the rest of the world and making me function more like the PT functions and in occupational therapy it was about what tools can we give this young girl that can help her accommodate a task that doesn't work for her? Like, what tools can we give her that make it work for her, instead of how can we make her body stronger so that she can act more like we do.

Ellen Stumbo 30:17

So, here is a moment of confession for me, because I have a child with a physical disability. And we did PT for a long time. And not only was the PT's goal for my kid to walk, it was my goal. So, it's like, my goal was for my kid to walk. And it took me a really, really, really long time to

recognize what... why that was important to me, and right, the ableism, like, "the right way to move is to walk" that I had to let go of that. But also, to recognize what my messages were communicating to my kid, that in order for her to be acceptable to me even, she needed to walk.

Marin Hann 31:06

Well, I hear that.

Ellen Stumbo 31:09

You don't have to be nice to me. I know!

Marin Hann 31:10

No, I hear that. And like, I appreciate that confession. Because like, as a kid, it did feel icky to hear that. But I can also think like I don't, I don't know what my mom's goal was for me in PT. I know her goal was to get me to PT constantly. But I'm not sure what the end result was. Because there were a lot of strides that happened in PT that were helpful. But they weren't strides that change the overall function of how I function as a person. But what I was going to say is that I really appreciate the confession. And you being honest about that. But I also think, well, of course, what other messages did Ellen possibly receive that would tell her that it was okay, like, when would the doctors have told you, don't try to get your child to walk.

Ellen Stumbo 32:09

Yeah, it's the medical model.

Marin Hann 32:10

Yeah. Like the guidance you had having a disabled child was the medical community, and very few people in the medical community, in the past number of years have been at the point where they don't think that way. And so if that's all you hear, "well, your child needs to be stronger at this and be stronger at this and they have to walk because life is going to be much harder for them if they don't," then, of course you want your child to walk, mainly because you don't want their life to be harder for them.

Ellen Stumbo 32:44

Right. And I think that's part of it for most of us. We don't want their life to be harder. And then the guidance, not only is the medical community, most of them are also not disabled.

Marin Hann 32:54

Yep.

Ellen Stumbo 32:56

Erin, I don't know if you have anything to add. I... this is a great conversation. So, this is going to be a two-part episode.

Erin Loraine 33:05

Okay.

Ellen Stumbo 33:05

So, we're gonna wrap up here. And then next week, people can listen to our part two. So, any closing thoughts about what we just talked about?

Erin Loraine 33:14

Like a million? So, you know...

Ellen Stumbo 33:17

We're gonna talk about all of that in the next episode.

Erin Loraine 33:20

Yeah, I'm processing a lot of what's been said and relating it to my own experiences in the last 10 years raising Oksana. Yeah.

Marin Hann 33:29

Can I just say that I know that in the next episode, like you and I, all three of us, we're all gonna keep going. So, for everyone else, they're gonna have to wait. But I just want to close with I'm so thankful that you guys invited me on as a guest and I love hanging out with you. It's super fun.

Ellen Stumbo 33:44

It was so fun to have you Marin.

Erin Loraine 33:46

I love to get to see you again.

Ellen Stumbo 33:48

Bye

Marin Hann 33:49

Bye.

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