

**Unexceptional Moms Podcast**  
**Episode 41**  
**Let's Talk About Disability Culture and Identity Part 2**

Ellen Stumbo 0:08

Welcome back to another episode of unexceptional moms I'm Ellen,

Erin Loraine 0:12

and I'm Erin and we are on part two of our podcast with Marin today. If you did not listen to the last one, make sure you listen to that because I feel like my mind was blown. Quite a few times. When we left the last podcast we started a discussion about physical therapy, and as parents wanting our children to -- what's the best way to say this -- up here like everyone else. A couple of things that came to my mind was walking is one thing, but it was beyond that, it was walking with the proper gait. It was walking so that it looked normal. And in our experience, Oksana was very, very...things were moving forward in that direction. And then it all stopped, and we even started to see some regression. Number of factors, some that we might never understand some that we think we do. And the shift in my brain was very difficult to realize that my goal had to change to giving Oksana what she needed to be able to move through the world and not be exhausted and not be unsteady and nervous. And I remember the first time I heard someone say, It's okay that your child uses a wheelchair, even if they can walk. And it was so freeing. And I bet it was for Oksana too, so freeing to go, "It's okay for you to use that wheelchair because that's gonna maximize the strength that you have right now." Why would I want you worn out 10 steps through this museum when you can enjoy the whole thing in a wheelchair. It was, it was very freeing, very freeing. But I gotta tell you as a parent now, I struggle with the balance between giving up too much of that and feeling like I'm not doing enough for her. And giving myself, and her, the freedom to say, this is what's... this is okay. Do you understand what I'm saying?

Marin Hann 3:02

I do. Are you asking me or Ellen.

Erin Loraine 3:04

Either one of you. Does anyone understand what I'm saying?

Marin Hann 3:08

Does anyone out there understand me? Yeah, no I totally understand what you're saying because it's wanting to encourage them to continue living life and the best way, and the most full way that they can. And the most true way that they can. And like with the most accessibility. And so I can definitely see that. And it's a... that's hard, especially when you're raising a child, because there's, like, I mean there's school pushing for PT there's doctors pushing per PT. And like, as an adult, I have, I've had moments where I'm like, I would like to sign up for rec, physical therapy myself that I will go sign myself up for it. Not because I'm like, oh, I have this like high goal of changing the way my disability works but like, I'm feeling a little bit more sore or a little weaker, I would like to feel more in shape, and I feel like that is, maybe,

I don't know, maybe what non-disabled people feel when they want to join a workout place. For me that's like my, "I'm joining the gym." Because I want to join the gym because I want to feel good. But when you're a kid, it's, you don't have those goals of like, "I'm an adult going to join a gym membership and I want to have a healthy lifestyle." And as a kid what you remember is constantly going to physical therapy -- if physical therapy is a therapy you go to, -- or maybe constantly going to speech therapy or constantly going to occupational, whichever one it is.

Ellen Stumbo 5:08

Man, I feel like you just pointed out the huge difference between being a non-disabled person approaching physical therapy, and the disabled person approaching therapy, like those are very different models. And for those of us as parents we only have the voices of those professionals. The last time that I took my daughter to the cerebral palsy clinic at Mayo Clinic it's, "If you don't walk better in six months, there's going to be surgery," and it's almost like your punishment for not walking different, and by that last meeting we had I was a little bit more informed and I was able to say, "No. Like that's not the reason we do surgery," unless there's a real need for her body like if it's affecting her body a certain way, but if it's just for her to walk more like a non-disabled person, we're not going to put her body through that. And one of her main doctors asked her how much she walked at school and she said, "I use my chair."

Erin Loraine 6:20

I hear all the time.

Ellen Stumbo 6:22

Yes, and he said, "you need to get up and walk sometimes," and she said, "I don't want to." And he said, "It doesn't matter if you want to or not," and she just looked at me, and it's the only time since I've known better than I've had this situation that I said to the doctor, you don't have to pay, and you know they always have. There were four of us and I said, "you don't have CP, you don't have CP, you don't have CP, I don't have CP," and I looked at her and I said, "Your feelings are valid. If you can't get up because of safety or because you don't like what kids say to you..." I think that's what she said, "kids always comment on my walking and I don't like it" and the doctor said it doesn't matter and I said, "Your feelings are valid and it does matter. And you're a teenager so school is not the time for you to have to worry about walking, and then having to worry about what kids are saying about you," like we have to respond to you as a person, that personhood. Do I want her to move? Yes, but not because I want her to walk, that's not my goal, it's just I want her body to not be tight right like to not be. I mean I wish I wasn't as tight in my muscles so for her I know it's gonna be harder. But I also feel like everybody is always asking me about her walking, people we know first thing they tell me is, "how's her walking, how's Nina" I would say, 90% of the time, but the second question they ask me, "well how is her walking?" like really out of everything in her life, that's the second most important question? But it was a big deal. Like I said, the last time, that was kind of a goal for me. Not for her, that was never her goal. It was my mother goal for her.

Marin Hann 8:12

I'm just sitting here thinking like how awesome, like, way to go for being such a great mom and a great ally to her and the both of you. Talking about that struggle and being really honest about that. I just think it's really beautiful and really cool. I was really... I told my mom I'm very proud of her for doing this for me as a child, because with arthrogryposis my hands... see how do I give a visual when we're on a podcast and the auditory description? So my hands are at a 90 degree angle with my arm. So it's like my wrist is at 90 degrees. And so my hands look different, and I can't bend my fingers, they're stuck in like a straight out position unless I use my other fingers from my other hand to bend them. I can't bend them by themselves. And I remember growing up and people would kind of like...so I remember I was in elementary school, and my teachers at parent-teacher conferences would always make like a huge deal out of, "Marin's handwriting is just incredible. She has the best handwriting in the class." I don't think that I did, I think I just had like good handwriting. I think because my hands looked so different, it was so shocking to them that I had good handwriting. But my mom could see that I was using my hands perfectly fine like that. I figured out how to do everything that I needed to do with the way my hands were, and I did it a little bit differently than people did with their hands, but I still did the thing. And when I was really little, I wasn't using my hands, I was using my feet for everything, and she told my physiatrist, who also agreed with her, that he told her, "it's okay if she uses her feet for the rest of her life." He was like, "but we can also in therapy work on some exercises for her hands, maybe it'll give her some options," and my mom's like, "well she can eat with her feet, she can write with her feet, I think she's fine. She could just use her feet for the rest of her life," and I ended up using my hands instead, as they were like giving me options. And then the physiatrist who's known me since like six months old when I was -- all through my pediatric years -- is a fantastic person, and like the least ableist doctor I've ever met in my life. So he was fantastic and it's such a blessing to have him. But I remember conversations with other doctors that it was constantly them telling my mom, "Well, she could have surgery on her wrist, and we could correct the curvature." And my mom said, why. And they were like well, "so her hands are so they, they look like typical, they look normal," and my mom's like, "but she has function of her hands right now." And they're like, yeah, and then she's like, "well if she had the surgery, wouldn't she lose function in her hands?" and they're like, "yeah, she would have to work to gain that back," and then she's like, "why would we do that to her. Why wouldn't we give her more work, taking away function that she has in order for her to get the function back?" And it was just they wanted my hands to look like theirs and my mom was like, "No," and I am so glad that my mom did that for me because I think about the surgery they do, I know I would have had less function in my hands than I do today. It's such a hard thing though because there are so many parents that are making these really difficult decisions. And the medical community only gives you one track usually of what you should do. And they don't... it's like you don't have options. it's like they don't think that there's another solution to help your child.

Ellen Stumbo 12:16

I'm thinking that there's people listening, thinking, "I've had surgeries for my kids, based on some recommendation that maybe it was not necessary," because honestly, one of the surgeries that my daughter has had for cerebral palsy, that surgery took her back to where she was in strength. And I look back and like, what was the reason? And I think it was to improve

her gait, it's always been about that, and I mean I know there's gonna be another parent like me who's probably now thinking, "Oh my goodness. Have I done this?" And I think unfortunately we... I don't want to say that we're victims of the medical community, but if we're not experts, so often we rely on their expertise of these professionals and we do try to make the best, most informed decisions for our kids. But honestly, I never made those informed decisions talking to other disabled people, or other people with cerebral palsy to ask and say, "Hey, did you ever have that surgery? Does it even help? Does it even work?" Because, overwhelmingly, I'm hearing adults with CP who really wish their bodies had not been subjected to so many surgeries. And as the parent, I mean I feel... I feel guilty.

Marin Hann 13:45

I did have one of those surgeries that you said, the strength set her back. I had bilateral clubfoot surgery... I had hip surgery when I was really young and then the bilateral clubfeet and then I had, I have scoliosis, so I had scoliosis surgery when I was 11. But the foot surgery in particular, they did it... I think the reasoning -- and my mom and I talked about it because like we had conversations, even though I was a child, about what the surgery was and what it may or may not help me do. And so I did understand at the time that they wanted me to be able to bear weight, and with my feet being clubbed feet, I couldn't, because it was hurting my ankles too much, so they wanted them straight so I could bear weight and like a standing frame and gain muscle tone, which logically makes perfect sense. I totally get that. What we didn't know is that my feet being in casting for that long and the cast being so heavy, is that I would lose so much strength in my lower body, and then my hips, that were way looser before the contractures of my arthrogryposis tightened over them over that period of recovery time, and we never were able to undo those contractures, and no one knew that was coming, no one knew that "Marin's feet are going to freeze shut if we have bilateral clubfoot surgery." And that's just how it happens. And so there were a lot of things that I used to be able to do that I couldn't do after that surgery. And that's the thing though, like, even if it's a surgery where a parent's like, "I'm gonna have... I feel bad that I had my kid had the surgery" like listening to this episode, even if they feel that way, I think in any surgery, like any surgery that we have, we don't ultimately know how good the outcome is going to be. And so sometimes it's going to help and sometimes it's not going to. I think ultimately with the thing with my hands with my mom saying no, she didn't see any benefit to that, that would help me. But what I'm more grateful for more than anything was just hearing my mom say that it was okay that I didn't look like somebody else, and not so much that she chose or didn't choose to do the surgery. And so, yeah. I don't want parents to think, "oh my gosh I'm such a terrible parent because I've had my child go through all these surgeries."

Erin Loraine 16:33

Oh no, parents make those decisions with the deepest of love for their children and their desire to do the absolute best for their children, so I don't think there should be guilt there. But as we learn more, we can put that in our, our toolbox of resources as we get decisions in the future.

Ellen Stumbo 16:54

Yeah. Yeah. And, I mean so many mind blowing moments right as we're talking with you Marin, because I'm also thinking about... the things that I say about disability in front of my kids. What am I communicating to my kids about their disability? I asked Nina one time, she has cerebral palsy, "What how do you think I feel about your disability?" And she said, "I think you don't like it and I think you wish I was not disabled" and I was like, Oh, what have I done? And again, we're, I'm having those conversations not because I'm like super enlightened, but because I have disabled friends, so then I'm talking to my friends about these things, which then made me think I should probably ask. And I don't think that she could pin-point and say, "when you said this," and maybe she could but she didn't tell me. Actually, I'm sure that she can probably think of certain things I've said. But yeah, I mean even with my typical child I probably said things that hurt her, and that were not very positive and that made her feel maybe bad, just because it's the reality of parenting, you say great things to your kids, you build them up and then you make really not very nice choices as a parent to or you say things that you don't mean to say or whatever but..

Erin Loraine 18:31

There is no perfect parent.

Ellen Stumbo 18:33

There is no perfect parent.

Erin Loraine 18:34

What?!?!

Ellen Stumbo 18:35

I'm sorry Erin, I know you thought it was you but...

Erin Loraine 18:40

I've been trying so hard to get there.

Ellen Stumbo 18:44

Aren't we all right? Anyway, I don't think I have anything to say I'm just thinking through, in my own mind, just because our kids are more vulnerable and I feel like what they get from society and from the world -- that having a disability is bad -- and home should be the one safe place where those are not the messages they are getting. Yet as parents we are a part of this world and unfortunately we were taught those negative things, and unfortunately we do hold some ableist attitudes, even if we really don't want to. And we make mistakes. So,

Erin Loraine 19:26

I'm excited for that list of books [made in reference to a list of books mentioned in Part 1].

Ellen Stumbo 19:29

I am too. I'm really excited for it.

Marin Hann 19:33

I'm working through it myself, so I'm okay to be on that journey of working through the list and building it as I go.

Ellen Stumbo 19:39

Yes, and for people listening, Marin, has a list of books recommended for History of Disability and Disability Culture that we can read as parents to learn about the culture that our kids belong to. So let me ask you something Marin, sometimes as parents we maybe don't make those negative comments about our child's disability in front of them, but maybe we make them in front of like, you, and you are disabled. So tell me about what it's like for you as a disabled woman to hear non-disabled parents talking or saying very hurtful things about disability.

Marin Hann 20:22

Yeah, it's... it doesn't feel good. Yeah, sometimes I wonder in the conversations when parents with disabled children have shared around me negative thoughts about that if they've forgot that I was disabled for a second, or like, they... they do that whole like... kind of how many of us struggle with racism, and we used to, white people used to have that slogan of, "well I don't see color" and we thought that wasn't racist when actually it's super racist? I wonder if they are just like, "oh I don't see you as disabled." But I am. I am definitely disabled. And I know that, you know, sometimes you're having conversations with other adults in you're like... you just get on there like this venting, like I need to blow off some steam place, not in like an angry way but you're just like, "Oh man, I've been around kids all day and like my kids are driving me crazy and so I need to say something." But sometimes for me, it's hard to...feel... It's gonna sound bad and I don't mean it to, it's hard for me to feel a lot of sympathy or empathy when people talk about how hard it is to be a caregiver. Because as a caree I don't get a lot of sympathy. And there's no caree support group, where we can go and complain about our caregivers.

Mind blowing again.

Ellen Stumbo 22:07

Wow!

Erin Loraine 22:13

Marin this stuff that you say.

Ellen Stumbo 22:15

Yeah....

Erin Loraine 22:17

Wow!

Unknown Speaker 22:20

I know that caregiving is a challenge, like I know that it is, but to hear about it, as someone who is cared for, then it's like the kind of reminder of like, oh, there, there is the whole burden complex thing again. There it is, you're a burden, you're a drain on society, people's lives would be easier if you weren't disabled. And it starts this whole spiral thing downwards just because you're like, "I know this person is just telling me they're tired, but that's not what I picked up from that conversation. And so, yeah, I've been trying to figure out a better way to be able to like exist around those conversations and not go into that spiral. I just haven't figured it out yet, I don't think. But talking about caregiving for your children that are disabled is one of the things that I think people say or don't say or just implicitly it's brought up somehow.

Marin Hann 23:21

And also when parents use language, that's, "oh my child's going to overcome this!" I know where they're at in that journey, and like I used to think that way too, but now that I think differently about that it's like this thing of, it's gonna take that kid a while to get there by themselves. This is what they hear at home. And so, yeah, and I don't know how to reach into that place with the parents to meet them where they're at, to have a helpful conversation about that. I don't know if I'm the best person for that, when I haven't figured out how to take the sting out yet.

Ellen Stumbo 24:10

Which I think that contributes to the divide between disabled adults and parents of disabled kids, Because I, I think you're right that there's... we are creating pain for the disabled community. As parents, although we love and adore our kids I wonder if it's because we tried to separate their condition from our child, if that's why in a way we reject the voices of other disabled individuals, because we don't see our kid as belonging to this other community, with their own culture, with their own history, with their own pride. Because we don't belong to that culture if we're not disabled that we, we make that divide inside of us when we look at our kids, which is not the right way to love our kids because then we're not loving them fully. They're disabled. That may be not quite what defines them, but very much a part of their identity and how they experience the world, and how they relate to the world, and even how they relate to us.

Marin Hann 25:26

I think now that you say that, I wonder if that is a big part of the caregiving aspects of language when parents are burnt out from caregiving or they need more respite. I wonder, because... like let's say you're caregiving for an elderly parent who has dementia. Dementia is not something that you consider part of your parents identity. And so you, you separate that out and you're saying, "I'm frustrated with caregiving not because I'm frustrated with my parent, but I wish they didn't have dementia." And I wonder if that's kind of the same idea, if someone is congenitally disabled or they become disabled a little bit later in life, that like it's seen as not part of their identity, but more of a disease like dementia is, and like the disease is the enemy here, and that's why I'm so tired. Because the disease is hurting our relationship. Rather than as a disabled adult, my disability is part of my identity so when I'm hearing that, I'm hearing, "your identity is hurting our relationship," which is not what I think they're trying to say.

Erin Loraine 26:40

Nobody saw Ellen's little mind blown motion in this conversation. I've done it like five times.

Ellen Stumbo 26:48

I'm thinking I'm gonna, I'm gonna listen to this over and over and over again.

Marin Hann 26:55

I like having this conversation because as we're talking I'm having these thoughts and I was like, "Oh I wonder if it's like that. I wonder if that's where it's coming from." And, yeah, I don't, I don't think anyone means to... I'm taking it as if you're telling me my identity makes you too tired, and I don't think anyone's trying to say that at all. I think they're looking at it like, "Man, I wish people didn't have dementia, kind of thing."

Erin Loraine 27:23

And I do think you bring up a good point because we don't want parents listening to this to be like, I mean, "I feel like I'm being attacked or I'm a failure" or anything like that. This is all, how can we learn and grow? You know? So my mind has been blown by so many things you've said. And yes, I feel convicted by some of them in a good way because now I can grow from this experience.

Marin Hann 27:53

Can I ask the two of you, like, I mean a lot of this we're talking about and I'm just sharing like this is kind of difficult to hear and these things. From your perspective as parents of disabled children, and you're not disabled yourselves, what is not helpful for disabled adults to... what is not a helpful like breach into that circle, like... what, what is a better way or something that you wish disabled adults understood, for them to start that conversation.

Erin Loraine 28:27

I've got something, Ellen, do you have something?

Ellen Stumbo 28:29

I do but you can go first.

Erin Loraine 28:32

So my first thought is, as a non disabled person, I fear, I feel very fearful of saying the wrong thing, the wrong word, the wrong phrase, and I have found that often the correct terminology changes, and I think I'm still using the correct terminology and it's changed, and it's to the point where you're so afraid of offending someone that you just keep your mouth shut. And to be honest with you, I've done it about 20 times just in this podcast every time my mouth opens I go, "did I use that terminology correct? Did I?" Because people get so offended by that and I'm not saying that that's wrong in a lot of cases, but I think it keeps a lot of conversations closed because people are afraid they're going to be attacked because they use a word wrong completely unintentionally. Does that make sense?

Marin Hann 29:31

Yeah, that totally makes sense.

Ellen Stumbo 29:35

So I agree with Erin, I do. On the flipside, let's say like the words "special needs" or "disabled" right, disabled adults have been telling us now for a long time that "special needs" is an outdated term and it's ableist so please don't say it.

Erin Loraine 29:52

Yes.

Ellen Stumbo 29:54

And I feel like once we hear that, when you have a community of people saying, "this is what we want you to call us," like the only right choice for us as a community is...

Erin Loraine 30:05

To change it.

Ellen Stumbo 30:06

It is to change it.

Erin Loraine 30:07

without a doubt.

Ellen Stumbo 30:08

Yes. And I, I mean you know Erin -- because everybody knows she's my best friend so we talk about a lot of things and she knows everything about me -- but it's a real fear sometimes, like what if I say something to a friend, especially if they're disabled that is going to like, destroy this friendship.

Erin Loraine 30:30

Yes.

Ellen Stumbo 30:31

And that's a real fear. Now, before that, Marin, this is the reality, I don't know very many parents -- and that includes me -- when our kids are born, and even before they're born, whenever we receive a diagnosis, there's a reality of grief. And I know that that's a really really tough conversation to have between parents and disabled adults. Now I understand that a lot of grief comes from ableism, but that does not... that does not take away the fact that we do go through that. And I feel like... I don't have the solutions, but we have to figure out from the parent side and the disabled adult side how to be able to have that conversation without maybe disabled adults, feeling, you know... like what you're saying, like you feel like that's the

caregiving and I feel like a burden without... do you guys know what I'm getting at? It's even hard to describe it.

Erin Loraine 31:40

I know.

Ellen Stumbo 31:41

Because I feel like it's the... you know like... like the first block, like the first building block of so many things. And that conversation right there is the first really hard conversation to have, where I feel like it creates a lot of tension. I know, I know now that my grief was based on my ableism, but I still went through it, I can't undo that.

Marin Hann 32:08

Right, right. I think too hearing both of you say those things, one, is super super helpful, two, I think something that I miss in a sub-culture of the group of disability, is that the minority of disability is like one of the only minority groups, you can become a member of later. And I was born with my disability, I'm congenitally in the... I came in, I came in automatically, automatic in this group. And I know that for those who join this minority later, there is that grief process in a different way, but a grief process for them, because they were living one life, and now they are living a different life, and there is I think a period of people who become disabled, where those of us who have always been disabled, like, don't really know how to talk to each other very well, because like, we're feeling two different things about our bodies or our minds. And so there's there's this like grief period. That, I think those of us who are congenitally disabled need to process more, which is hard because it's like processing something you can't ever experience, but maybe imagining, "what if I was put in a different minority group suddenly and everything I knew about my life beforehand is suddenly completely colored by that, and I can't look at life the same way or, or if you have one disability and then you have another disability, like I use a wheelchair, what if suddenly I was blind. That would... there would be a grieving process and not because I think it's bad to be blind, but because I don't know how to navigate the world as a blind person in a wheelchair. And so now I have to figure out how do I navigate the world. And I think... it sounds like you're saying that as parents, you have a disabled child and you have to figure out how to navigate parenthood in a way that no one described parenthood.

Ellen Stumbo 34:40

Yeah, that's true.

Marin Hann 34:43

Oh Everyone told me, oh it's gonna be like this to be a mom or a dad and then it wasn't like that to be a mom and a dad.

Ellen Stumbo 34:50

And that's what you maybe observed, right? Most people you know got to do the traditional route.

Marin Hann 35:00

My mom read a book once, and I forget who the author is but she quoted something of like it's like having every itinerary planned out that you're going to go on this trip to Italy and you learned some Italian, and you like...

Ellen Stumbo 35:15

Oh the "Welcome to Holland" poem.

Marin Hann 35:17

Yeah and then you end up somewhere else and then you're like, well, it's not bad to be here. It's not bad to be in this different country, but I wasn't prepared for this country. So now this country is like a culture shock.

Ellen Stumbo 35:35

Marin, there's so much that we could keep talking to you about I think we need to have our back Erin.

Erin Loraine 35:40

Oh, without a doubt,

Ellen Stumbo 35:43

Because our time is up and we need to wrap up, but I... thank you so much.

Marin Hann 35:50

Thank you so much. I've loved being here with you guys, it's been wonderful to get to like see you again. And it's also, I just love having these conversations. It's so helpful to know, like the barriers of language, and word use, and then just that grief process, that that grief is real and should be cared about and acknowledged. I think that's helpful for those of us that are disabled to remember, so thank you so much for explaining that.

Ellen Stumbo 36:20

No, thank you for being here. I'm going to listen to this two episodes, a lot, so. Thank you Marin.

Erin Loraine 36:28

Thank you Marin. Bye.

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