Eliza Hull Episode 25

Marjorie Aunos (00:05):
We all know that parenting is hard, so how do parents with disabilities do it? With creativity and because we know of the value of interdependence! Come hear about ways experts say we can best empower these families and let’s all learn about how parenting can be done differently.

I’m your host Marjorie Aunos. And today my guest is Eliza Hull. Eliza is a musician, writer and disability advocate. She was the 8-parts-series podcast host of We've Got This and is the editor behind the book of the same title that brings forward the stories of 25 families headed by one or two parents with disabilities. I started our conversation by asking Eliza to introduce herself.

Enjoy! And don’t forget, for more information about where to find the full recording and additional resources, check out the show notes!

Eliza Hull (01:18):
I live in Australia. I live in a regional town called Castlemaine. I have two children, a little boy who's turning three tomorrow and, uh, eight year old girl who's her, her name's Isabelle, and my son's name's Archie. And, I'm a writer and a musician. I sing, have been singing since I was five years old. And, um, yeah, I'm also a disability advocate and especially within, um, the parenting space, but also in the music industry as well. And I guess that those, both those spaces, um, are due to my own lived experience and realizing that there was still so much work that needed to be done.

So when I first started to realize that I, wanted to have children with my partner, I went to someone that I really had grown to trust over the years. I've had my disability since I was five years old. And I, as a child, he became my neurologist. And so of course, you know, someone that you trust in a medical space you go to, to I guess, um, you know, seek advice, but also just to say, well, this is what I'm thinking. What do you, you know, what do you think about this? And what are some of the ways that I can adapt as a mother with a disability? And, that's when I truly noticed how much stigma and discrimination still exists when it comes to, um, parenting as a disabled person because he, but at the beginning didn't say much at all. In fact, he just was looking at his computer and, and not speaking to me and, and going through, you know, either my notes or other other notes. So I wasn't really sure what he was doing, but it definitely made me feel uncomfortable. And then he suggested that he didn't think that I could be a parent and that perhaps I should look at other alternatives or, not parent at all. And I think because I had already had my own doubts, I felt very vulnerable actually. And I felt a lot of shame and felt like maybe for a moment there I believe that he might be right. And when I went back and, and spoke to my husband he was actually not my husband at that time, but he is now. I was quite lucky in that he said, well, no, that's not the case. We'll be able to do it and we can do it and you can do it. And um, also luckily had grown up with a family who believed that I could parent and had always said that throughout my life.

And so I just, you know, went for it and decided that I wanted to do it. And realized that he had actually just been, I guess, he, he had been part of what that narrative is. He probably had been taught in the medical space that disabled people either shouldn't parent or, or can't parent adequately. So I think that that's when I was like, actually it's ingrained in society, isn't it, that, to be a disabled parent is, is potentially harmful or at risk cuz of children or, you know, just greatly stigmatized. So that was like, okay, I really need to or want to change the way that, especially in the medical space, um, how they see people when they decide to be a parent and having a disability.

Marjorie Aunos (05:00):

Yeah. Do you think that this is why you, you've become such a fervent advocate and did you plan to be an advocate? Because I'm not sure you, you did plan. I think it,

Eliza Hull (05:08):

no, I probably didn't. And I guess for me, I really like storytelling. So, um, I, that's how it kind of all began really. And that, I saw that there was a scholarship being offered with, it's what it's called the ABC here. So it's the Australian Broadcasting Corporation in Australia. And I saw they were offering us a scholarship to a disabled person who had an idea. And that was when I went to them and, and had the idea to interview, uh, disabled parents. And again, that, that from my own need. Because when I decided to become a parent, I remember searching just online. And again, it was that real narrative of it would be a burden on the child to have a disabled parent.

Uh, and that was like, okay, where, where are like first-people stories here. Why am I not, um, why isn't not a book that represents disabled parents? Because you get given so many of those books on parenting and I couldn't find anyone like me or any disabled parent out there. And so I went to the ABC on that, that idea. And that's when I got to travel around Australia and interview various families with disability. And I think the common thread I learned during that time is that like, I think that, you know, I actually really wanna push back on that idea that we don't make great parents because I was actually seeing the opposite. I think that as disabled people, we, um, all through our life have to be pretty great at, um, you know, problem solving and creative thinking and being adaptable and flexible and, you know, for instance, not knowing if you're gonna get into a building or how will I get into the building or should I, you know, can I do it this way or change the way that my body moves or, you know, all the things that we have to do as disabled people just to exist in the world, uh, means that I think what I was seeing time and time again is that we actually make really, really great parents.

Marjorie Aunos (07:13):

Yes. I second that <laugh>. Yeah, I agree. And so you did a podcast series, um, of eight episode, I think, right?

Eliza Hull (07:20):

Yeah, that's right. And so that was called, We've Got This and it was yet featured various families, parents with intellectual disability, parents that were deaf, parents that were blind.

And I traveled all around Australia interviewing those various families that then became a podcast series and digital articles and a, and a little video as well. And to be honest, I was like, I was very shocked at how, well it went I guess like how how much people really responded to it and how, how many emails that I got from people saying that they had held onto these misconceptions that they didn't think that disabled people could parent as well, especially parents with intellectual disability. And so when I saw that those emails come through, that representation like this was changing people's minds that really was like, wow, this is storytelling is very, very powerful and hearing from people's lived experience is very powerful.

And so then I went to a publisher and and said, I really think this, you know, should be a book cuz I'd always wanted to be a book even before the ABC series. And luckily they said yes. And so it became an Australian book. um, which was an anthology of all various families with disability. and then now it's an international book, so, which you're part of, which is fantastic. that pictures parents from the United Kingdom, Canada. And America. And that one's going to come out, you know, very soon.

Marjorie Aunos (08:57):

Yes. That's also why I am like super excited to be speaking to you because the Australian version was very hard for me to get a copy. And so I had to use my contacts in Australia, for it to be there. And then when you told, you told me that you were doing a similar book, but for UK and US, or American, audience, I was really, really excited because people do need to read these stories. There are stories that are powerful, but they're true. So it's not about sort of inspiring people. That's not, I think, the goal of any of us. It's just to show like, this is what it looks like and it's beautiful just the way that it is. <Um> and so I find that, so useful and so necessary and I thank you for leading those, those projects and making sure that there's representation because like you said, one thing that has been lacking is, is representation. And so being able to, to say, and I'm not the only one and, there are others and we are all struggling and making it work all at the same time cuz that's what parenthood is. <Exactly.> and so we do the best that we can and we, we raise our, our little people, with all the love that we have.

Eliza Hull (10;23):

Yeah, exactly. I think you, you have spot on in that it's not, sugar coated, it's just like real stories, real human stories. And I think it's been really great when non-disabled people have read the book and saying, you know, I just found the stories really powerful and interesting and I, no, I'm not a parent and I don't have a disability, but I still really enjoyed the book. So that was, I think, really great as well. And also just as you were saying, having disabled people reach out saying that they have been told that they shouldn't be a parent and this book is, you know, really affirming that they can and or they've just had a baby and they just, you know, listening to the audio book cuz they're looking after their newborn. I think yeah, they're really incredible stories that, um, yeah, make it all that bit, you know, more worthwhile.

Marjorie Aunos (11:13):

Yeah. And one thing that I found also like in talking with you, interesting is that when I started working in the field about 25 years ago, there was this notion of sort of like an hierarchy amongst disabled communities, you know, with people with intellectual disabilities sometimes being seen as like the, the poorer or the poorest. And yet in all your projects you, like, when we talk about representation, all of your projects really look at representation. Like you could have just done a book on parents with a physical disability mm-hmm. <affirmative> or a neurological disorder, but no, you went, you wanted to, to represent all forms of disabilities. And in a way the disability itself does not really matter, does it?

Eliza Hull (12:08):

Yeah, I think that's a good question. Yeah, I think you're right. I think I, you know, in terms of We've Got This and also I've, I've put out a children's book called Come Over to My House that represents in a way a lot of the families that you meet in We've Got This, and I did that. I guess for me the more cross section you can have, the more you can reduce stigma. That's kind, that's really what I think the more, and also especially for parents with intellectual disability, I feel like they're the stories that we don't hear enough.

And, I hadn't heard stories by parents with intellectual disability ever actually at that point. and I think they're also the spaces that really need the most changing in the, in the parenting space. And, uh, there's a, you know, a high, very high percentage of parents with intellectual disability as you know, that have their children taken, have their children removed and be not given any adequate support and education to parent.

And, um, I think there's just so much stigma and, um, beliefs that parents with intellectual disability are going to be harmful for their children or it's gonna be problematic. You know, I really feel that here in Australia and child protection gets called far too quickly without, you know, any support and we all know how challenging parenting is. So, having an intellectual disability on top of that without any support just to me, just feels, um, yeah, just, I just can't believe it actually. That's, I I still feel like how can, how can we be letting this happen? And so I think by, you know, showing a cross section and for me it just, again, it just, um, having that representation reduces stigma and, um, by having that representation, people feel like they begin to understand and begin to be able to step in and learn.

Marjorie Aunos (14:13):

There's one thing you said, you know, like in terms of um, sort of that parenting is hard, right? And sometimes this is used in a way against parents with disabilities in that, they'll say, well, yes, parenting is hard. So <mm-hmm.> How can you, on top of your disability now sort of bring on a, a role that requires a lot of tasks that are so difficult? What would you say to someone sort of bringing this argument or this question?

Eliza Hull (14:45):

Yeah, I think you're right, parent. That's what I'd say. Parenting is very hard for everybody, <laugh> everybody. But as I mentioned before, all through our lives we deal with hard things, like constantly. And, because of that, that skill building and knowledge, I just, and we're also really resilient and you know, even if we are just, we newly acquire a disability and then have a child, I still think that because of, then becoming a disabled person as an identity and even if that's a, a process that's happened, you know, quite quickly just before having a child, I think that really does build resilience and builds that ability to quickly adapt because you ha you have to <laugh>. <That's right.> I just think that that's why we really truly have those skills and, we also have to come up against constant discrimination out in society, in the community, in our workplaces, or lack of workplaces. You know, we are constantly having to advocate for ourselves and, uh, in my opinion that again we just build those skills, the communication skills, ability to advocate and ability to, you know, build resilience and, and problem solve.

I think that anyone that says that we don't make great parents, I think come into a house and, and see a disabled family and you'll soon see how incredibly adaptable parents and families are. And also what that then does for a child is, in my opinion, builds, you know, I've seen it, I have a physical disability, a condition that's called Charcot Marie Tooth, and it means that, you know, I fall over a lot and I find it hard to walk. And both my children, even my three-year-old is, you know, there for me, like will hold my hand and, you know, say, well, this is a, little thing about to happen in the road, maybe will just slightly turn here. Or, you know, they're always looking out for me. And, I just see how that then plays out in their lives at schools, at daycare. they've very kind children.

I think it also shows, you know, by me modeling who I am as a person, as an authentic person, as a person that identifies as disabled, who speaks about my lived experience and who also advocates for others and amplifies others. Again, that's just modeling to them, that it's okay to be different. It's okay to be who you are. And I just see so many positives out of that and I've really witnessed that with various families, how much those children grow up to be great kind children and, and then future adults. So I just see the benefits in my opinion.

Marjorie Aunos (17:43):

I love speaking to you cuz you have, you have a way with words and you're able to release or grasp, you know, an understanding and, and explain and make it very clear. as I was listening to you, I was, I was going like, oh, people are gonna ask like, how, how is that affecting the children? And yet, you know, like, um, you are bringing this notion like very fluently within sort of our conversation where you're saying, well no, it's actually skills that our children do need. And because they are, you know, with us and seeing us and they're learning from us and they are developing skills that they will require as adults and as <yeah>, the next generation that has to face a lot of changes, a lot of, you know, need for compassion for inclusivity and accessibility and and so forth. And so we are really preparing our children for their future.

Eliza Hull (18:46):

Yeah. And I think especially in the world that we live in, I think it's so right there that, especially the digital space as well, like that where everything's very image based on, on the way that we look on our social media profiles, you know, that unfortunately is the world that we live in. And, you know, I'm, for me at school there, what, there wasn't Facebook and, and Instagram thank goodness because like how, how could I had chosen as, you know, teenager what my profile picture would've been and all of those things that are just so, yeah, we live in this world of, you know, I guess a corporate, you know, world, where everything's filled on advertising and quick, everything's very quick world that we live in. And I think that, you know, being a disabled parent does push us back on those things because I, I actually see it as like slow parenting for me anyway.

Marjorie Aunos (19:41):

Me too.

Eliza Hull (19:42):

it's actually pushing back on that, that idea of that life has to be quick and that we want the next, the next, next, next, next. That actually it's really great to walk really slowly and, um, smell of flowers. And um, and also that as I was saying before, that it's, it's that it's okay to be different, you know, that they see their, their parent. I mean, I have feet that are very deformed I guess as what, you know, what you'd call it in a medical space and scars all over my feet and I have claw toes and you know, my legs move differently as I walk. And I think me being, you know, on the beach or at a swimming pool where people just stare so much there, especially when I'm not wearing, you know, when I'm wearing my bathers. I think to model that to my children and be having fun and, and saying, I, you know, I'm happy with myself again, is just that modeling of, of what it means to be authentic and okay with whoever you are.

Marjorie Aunos (20:39):

Yeah. Yeah. One of the things, you know, like I, it affected obviously my, my child, as he was 16 months old when I had the accident. But what I've noticed also is that it affected, all his friends, like, you know, and his, the parents of his friends because all of a sudden they also saw as, oh well it's possible, it's just that we have to reimagine it. Cuz in my case, I was a walking mom, who was doing so much, you know, like way too many things in her life. So maybe that was one of the lesson I needed to, to learn, which was just like slow down and smell the, the roses. <Um> but it sort of, you know, showcased those lessons for everybody. And the kids, they asked sometimes, oh, how come you're in a wheelchair or what happened? And then when you give them the answer, it's done. It’s like, can I have a coke, can I have ice cream now? Or can we go to the park and they're onto the next topic.

Eliza Hull (21:49):

Yeah. What is your feeling about children asking questions? Cuz there's um, a lot of people, um, and rightfully so, a lot of disability advocates and disabled people are feeling like they shouldn't be asked by children. I'd be curious <Yeah>, what you feel about that.

Marjorie Aunos (22:05):

It's interesting because I sometimes hear that too, just like also disability or identity. and to me it's like they wanna, they wanna know, they have a question they should ask and, um, I will answer because to me it's unfortunately not something that we've done. Like an able-bodied parent, will probably never talk about disability or most of them won't. it's not something that is necessarily taught in school either. And we could argue, you know, maybe it should and yes, I think so. And so for me it's sort of like as long as the question is respectful or comes from a kindness or from, um, a beautiful curiosity that children have. You know, all they want is an answer and then they move on. Like, it's not about like discrimination, coming from a child, I don't see that. And if this is where they get the education, quote unquote, then I'm happy to uh, to oblige. That's how I see it.

Eliza Hull (23:17):

Yep. Yeah, I see it very similar. Yeah, similar in that I think ultimately as you were saying, that education should provide that and also just, you know, good parenting and that providing books and talking about it in the home. But you're right, it doesn't often happen. And I've noticed that when parents do the opposite and get their child to look away or shh their child, to me, that just creates more stigma.

Marjorie Aunos (23:43):

Exactly. <Yeah.> A hundred percent. And I think the reason why you had, you know, the children's book made, you know, it's in a way sort of answering those questions and look, when you come to my house,

Eliza Hull (23:49):

Then do that <laugh>. Yeah.

Marjorie Aunos (23:50):

You know, when you come to my house, this is what you're gonna find and you know, my house is like yours, but different. And, they need to also sort of hear that somewhere. Professionals also need to hear that. <Uh, yes.> As you mentioned, the medical doctors, like you, um, shared with your story, most of the audience in this podcast is actually professionals from the child welfare system. And so if if there was like one thing that you could say to them or one, I don't know, maybe advice or suggestion, what would it be?

Eliza Hull (24:23):

probably as we were saying, like, you know, delve into representation. So, you know, read books, listen to audio books, watch, you know, documentary series, by disabled people so that you understand the perspectives and lived experience of disabled people. I would also say give us a chance <laugh>. I think that it can often be quickly assumed that we do not make adequate parents. And so I think that's, you know, first and foremost is, don't always go jump to that conclusion first. I think that, uh, there are times, when it will not be safe for a disabled parent to have their child, but that is also the case for non-disabled people that in around on all the spectrum. But I think that it's quickly assumed that disabled par people, uh, can't or shouldn't be a parent. And I think ultimately we not only need to be given a chance, but we also need to be given support.

We need to be provided with, ways to modify our home, support in our home, education when needed. ultimately we just need to be given fair, fair and, and the way that we're treated, um, fairly. And, um, I think that negative attitudes and assumptions and discrimination feed into our own insecurities and our own disbelief of whether we should become a parent or whether we will make a great parent. And I think that when we are given that real trust and, and fair, yeah, I guess fair ad the attitudes that we face when we go into medical spaces and when we face, um, child protection, I think that that really can feed into how that experience plays out. Uh, because we are very, I think we as to say with people, we can be pretty hard on ourselves as well, and we might have our own doubts and our own shame that we've faced potentially all through our life and to, to then have medical professionals or child protection then doubt us. I think that can really feed into those, that vulnerability and shame. So yeah, it's quite a long answer, but I think that ultimately we need to be just treated really well and provided with adequate support and education so that we can be the parents that we know deep down we can be.

Marjorie Aunos (26:45):

And where do you think advocacy should go?

Eliza Hull (26:50):

I think we're moving into a really great space now where we're getting to hear the lived experience of disabled people and it's moving into very mainstream areas. So I guess, you know, for me, in Australia currently we have an autistic lead in the biggest drama series called Heartbreak High that is reaching teenagers and young people and, and adults. And, um, this particular advocate is Chloe Hayden, and she's really changing the way that we see disability. Uh, we've got the Australian of the Year just recently who's a wheelchair user, Dylan Alcott. Again, he's very much in the mainstream. He's just created the biggest inclusive music festival in Australia that's just so great, but is also reaching that young audience through the major, youth sta radio stations. And we are seeing it in advertising and we are seeing it on the catwalk, you know, in modeling and advocacy is now, part of the everyday. And that's what I want to keep seeing. I wanna keep, you know, seeing it when I open up my social media when I look on a billboard. And I just, yeah, I just feel like it, it is slowly happening, it's just taking time and, I just hope that we get to continue to hear people's lived experience and that will then hopefully feed into the spaces that really need some shifting, like in the medical space, but also in the political, government spaces where we get to really change, some of the big changes that need to happen in, in terms of law and, uh, yeah. So that's what I hope, I hope advocacy, you know, feeds up to those really high end places.

Marjorie Aunos (28:44):

Yes. So in the last year you've had books, children's book, you know, several interviews in the mainstream. Are you working on something special right now or do you have plans for the next step?

Eliza Hull (28:59):

Yeah, I am. I think I'm always working on something. I think that's my nature. This year it was really, designated to my music because I've kind of put that on, on the shelf. So on May 11th, I'm going to be releasing a song that I wrote about being disabled. It's called Running Underwater. I did perform that on TV here in Australia, but I've never released it. It features at a film clip with a disabled dancer. She has one leg and she's the most incredible dancer you will ever see the way she moves. And so it's the two of us working together on this clip that will come out on May 11th. Then I'm off to the UK in May to do a tour with another disabled artist called Ruth Lyon. She's a wheelchair user. We're doing a tour and performing at the Great Escape Festival, which is a industry festival for, um, music industry delegates. And then I've got another children's book that's coming out, it's about the social model of disability. So it's kind of a, through a story, it, it explains to children and how the world needs to change, not the person.

Marjorie Aunos (30:12):

Love it. Those are awesome. Um, I also love it because, um, so all year I've met and talked to, uh, 24 other people. yeah, you are number lucky 25th and you will be the last episode before I do like a recap. And to me it was very important that you be the person to, to maybe give us the last words because of all the advocacy that you've done and, because of like this beautiful title that you have on your books and you know, We've Got This, I just wanted to finish with this. Like, "we've got this", we really do.

Eliza Hull (30:58):

Yeah, that is it. Yeah, exactly. It's such a good title, isn't it? Because it's that thing of like, yeah, we do, don't we? We've got this. And, and even though we're told that we don't and we have to push up in the medical space, the child protection space, that ultimately we are proving time and time again that we've got this.

Marjorie Aunos (31:21):

Yes. So thank you so much for the time, for today, for all that you're doing. I really do hope, and I wish that both your children's books could be available in my neck of the woods, because, I know it would change the world and I talk to a lot of kids and a lot of children need to see them and read them. And for everything else that you've done, it will be in the show notes including this beautiful that's just coming out like right now, We've Got This. you know, I just received it today actually.So

Eliza Hull (32:02):

What' strange timing!

Marjorie Aunos (32:04):

I know.

Eliza Hull (32:05):

Wow.

Marjorie Aunos (32:06):

So It was, you know, perfect timing. so now I'm gonna be reading it in the next few weeks. So I'm really excited about that.

Thank you so much, Eliza.

Eliza Hull (32:07):
Thank you.

New Speaker (32:08):
This podcast was supported in part by a grant from the Minnesota Department of Human Services, Children and Family Services Division.