**Interview with Eliza Hull and Liz Wright**

Liz

This is a Women with Disabilities Victoria podcast.

We acknowledge that these podcasts were recorded on the traditional lands of the First Nations Peoples of this country. We acknowledge their Elders, past, present, and emerging. We acknowledge that sovereignty has never been ceded, and that this is, and always will be, Aboriginal land.

From the Outskirts is a series of podcasts featuring women with disabilities who live and work in regional Victoria.

I’m Liz Wright, a disability activist and advocate. I’m also the Manager of Community Inclusion and Women’s Empowerment at Women with Disabilities Victoria.

All the interviews were recorded in each person’s home or workplace, so from time to time there is unexpected background noise.

Musician, writer, speaker and disability advocate, Eliza Hull wants to change the way the world views disability.

She is honest, interesting and talented, enjoy Eliza’s story.

During this episode you will hear the sound of heavy rain as there was a massive downpour during the interview.

Eliza

My name is Eliza Hull, and I live on Jarrah country. I'd like to pay my respects to the Dja Dja Wurrung people. The elders past, present and emerging.

Liz

I'm really curious to know how with your creative career, you know, writing, singing, how you manage to live and work rurally whilst you're trying to be on the main stage because, you know, literature and singing, you know, that kind of stuff needs a broad audience. So how does that work for you?

Eliza

I think there's real benefits of living regionally. And those are that you, you almost have more, I guess, space mentally to be able to create.

So, you know, being able to be around more nature and things just to be far easier in many ways. For instance, you know, as soon as you go out in your car, you're not stuck in traffic for hours. You generally, it takes about five minutes to get anywhere really in Castlemaine.

But there's also barriers that come with living regionally and that is that you're just not really amongst it. And what I mean by that is that, you know, especially in the music industry, it's really part of your career to really go out and network or go and see other artists to be more inspired by those artists and build connections and community, and that's definitely something that since moving regionally, I feel like I've lacked.

It also means a lot, a lot more travel and I've realised just how much of a toll that's taken that, that constant traveling down the Calder to Melbourne. It takes a while and it's… it is exhausting in the car and then also flying, and I think that is only exaggerated because I have a disability.

Liz

What sort of disability do you have?

Eliza

I have a Charcot-Marie-Tooth, so I've had it since I was five years old and it's a neurological condition and it means that the messages aren't reaching certain parts of my body, especially the, you know, extremities.

So, my feet, my legs, my hands, and arms. I think a lot of people think that it only affects my legs, but because of the way that I walk, I think that's the most visible part of my disability. But it's actually a whole body, a disability that affects everything.

Liz

So that would add to fatigue with lots of traveling as well and managing new environments.

So, if you a sussing out going somewhere to play or needing assistance to get on and off stage, things like that, often those environments are kind of hostile to musicians with disability because a lot of infrastructure is not there. It's better than it was, but it's still not great.

Eliza

Yeah, absolutely. That's why I really am advocating more and more for venues to list how accessible their venue is. And I've even asked them…if even…if it's not accessible, can you list that on your website? Can you state if there's a step up into your venue or, you know, two steps to the toilet or…? So, I have that knowledge before I come to the venue, and it's not up to me to constantly get on the phone and ask.

But you are right, a lot of venues are very, very inaccessible. And when I think about venues that I want to perform in that are accessible, it's very hard to count them on even, you know, one hand, to be honest, isn't just such a shortage in that space, but you're right, it's changing.

Liz

It's slowly changing. Some venues have been more forthcoming in wanting to learn more.

Like if you look at the Corner Hotel website, I mean, they have a great accessibility kind of legend there that lets you know what functions they've got there. Northcote Social Club is another place that you can get in and participate in and has an accessible bathroom and things like that. But a lot of places just don't.

Eliza

Absolutely.

Liz

And it's difficult.

Eliza

Yeah. Northcott Social and Corner Hotel are run by the same people so that's why you would find there…they have a very incredible person spearheading that. Anyway, she's fantastic and she really wants to make sure that the venue’s accessible and I just love the way they've set that out with photos and descriptions and really detailed information.

Liz

We have a program which is in hiatus at the moment because we don't have funding, which was Bandmates Victoria, and we did a lot of our meetings with Bandmates at the Northcott Social Club, and staff were so willing to learn and came to our training and so gracious about: Oh well, our job should be bigger than it is right now and we should be able to serve people who maybe lack communication skills or have literacy or cognitive issues, or we'll serve you at the table if you can't get to the bar. I mean, I think they are terrific.

Eliza

Absolutely. Yeah. And I recently played a show at the Corner Hotel, and it was show that was promoted as, and really was a great accessible show for people with disability.

And it was interesting because I think it's all well and good to say that you're an accessible venue, but how do you treat people when you're in that venue is really another way that venues sometimes miss the mark.

Liz

Yeah.

Eliza

But my experience I performed and then I went up the lift, which was so great, up to the first level and had dinner with my family and friends. And as soon as I walked in, they just straight away said to me: You know, is there anything we can do? What do you need?

Liz

Yeah.

Eliza

It was a very friendly in a way that made me feel like very included. And it was like a very safe place.

Liz

Yeah, that attitudinal change is just one aspect of the whole accessibility kind of world of training and development. And if you can't get the attitudinal change in staff, doesn't matter how brilliant the environment is as far as infrastructure, if you still feel uncomfortable or ignored, you know it's not a pleasant experience.

Eliza

True.

Liz

So, let's talk about your latest book. You've got it in front of you there. Would you be able to give us…tell us a bit about the book and also perhaps a little reading and some image description would be lovely.

Eliza

Wonderful. Yes. So, Come Over to My House, is the name of the book.

It actually… the idea…I guess it came from two parts of my life. One was that I had edited and created a book called, We've Got This, Stories by Disabled Parents, which featured 25 parents that were disabled or deaf or chronically ill.

Liz

Thanks for asking me, but you know…whatever…

(laughter)

Eliza

I know. And there's so many people that I yeah, I wish I had, you know. So, there you go.

Liz

Volume two.

Liz

You know, it could be parenting 20-year-olds.

Eliza

That could book in itself, couldn't it?

So, I guess I met so many families and I also had met so many others when I did the ABC series of the same name and going into people's homes and being a disabled parent myself, you realise that we like, we really have to be creative, don't we, in the way that we parent and the way that we live our lives, we have to problem solve and be flexible.

And I think parenting requires that no matter whether you have a disability or not. And when I went inside, each family's home, I realised just how adaptable people with disability are. And so, in the homes, this book, Come Over to My House, which is a children's picture book it shows each family in the book and adapting really, and being creative, and…

Liz

And are they all real families?

Eliza

They are…

Liz

Oh yeah great.

Eliza

Yeah, they are. Also based on my lived experience as a child as well.

So, in the first spread you see a character that is a wheelchair user but also uses a frame. And so, during my primary school and high school years, I used a wheelchair at times. So yeah, it was that was really the only character that I based on myself. And then the others were based on either friends or people that I met through, We've Got This…

Liz

Yeah.

Eliza

And I was also doing some consultation work with Playschool for a little bit and had an idea that when you go through the windows, each window, I thought: Wouldn't it be great if you went into one of the windows and a child answered the door and said: Come over to my house, and in, you know, inside my home, you know, my mother is blind and yeah, so that was that initial idea which yeah, didn't eventuate but that kind of led me to want to create a picture book and so I approached a children's author, Sally Rippin, who now lives in Castlemaine, which is wonderful.

Liz

Was she living here at the time of the writing the book?

Eliza

She was living here as well as Melbourne at the time and now she's lived here permanently and she's just such a great person and ally because she really is very hungry to learn and wants to listen and…but on top of that she just knows how to really reach and speak to children and so it was just like such a collaborative effort.

I think people go: How do you co-write a children's book? Well, you can when you when you work with someone like Sally, you truly can. And the way that we did it is we sat down, and we had cups of tea and then we bounced ideas with each other. And then she would write a bit and then I would write a bit and then we'd go back and forth, and it was a very, very joint effort.

And I guess for me what's really excited me about this book is that children are the future and I think we are seeing how, you know, maybe not quick enough, but how much change is happening and how much diversity is being more represented and celebrated. And I think the book helps that because when I've been doing book readings with kindergartens and schools, for instance, a child put their hand up and said: Oh, my mum has a disability. And I said: Oh, you know, great. And she said: Oh, she's gluten intolerant.

(laughter)

And I thought: Oh, OK. And then I actually thought about I thought, you know, this is so wonderful, because actually what this child is saying is it would be, you know, it's great, like disability is not something to be feared. Disability is a wonderful part of life. And I don't fear it. In fact, my you know, my mother is….is disabled.

Liz

Obviously, also, you know, the gluten intolerance is something that the family is all aware of. And it's not like an invisible secret thing. Mum makes just dinner for herself and doesn't talk about it.

Eliza

Yes.

Liz

And you know, that's great. That would have made me laugh.

Eliza

Yeah.

(laughter)

Eliza

It was really funny. But I think yeah, ultimately what I've seen is just the children are just like they are very, very, very inclusive, and excited by the book and ask lots and lots of questions and...

Liz

Of you as well as the book?

Eliza

Yeah.

Liz

Like, like how do you walk?

Eliza

Or why do you walk like that? And wanting to learn. And I've also been…when I've been talking about the book, I've been describing the social model of disability as well.

Liz

Brilliant.

Eliza

When I talk about the book because I'll read the first page, it’s:

Come over to my house.

Come over and play.

I'll show you around. You can stay the whole day.

We’ll swing on the swing set and splash in the pool,

and then I'll race you inside, where my bedroom is cool.

And on the page, you see a wheelchair user who is splashing in the pool with their friend and then using a walking frame to join their friend on the swing. And then they're racing up a ramp into the house.

Liz

Great.

Eliza

And I just spoke to the kids when I went and spoke on that page around the difference if that house didn't have that ramp and what that would look like and how that would then affect that person with disability.

And it's, I think it's a great way to show that it's not the person that needs to change, it's the world. And if that house didn't have a ramp, that person would not feel as included.

Liz

It's really good to get kids at a young age. And it's really good to get them thinking about how things are and noticing things so that they can bring it up, because it has that flow up effect as well as the flow down effect, if you’re talking about the social model.

Eliza

I often tell the story of going to my family for Christmas and it was extended family and I didn't expect that they would be having the Christmas get together up four steps right at the back of the yard.

And I couldn't get up those steps and I'd either have to crawl or get someone to help me. And I got very emotional because I guess I was thinking: Oh, this is my family. Like, this is not where I thought I would feel excluded.

And it just showed me that the difference of… what that would look like if we had have had it, you know, on the entry level part where I didn't have to navigate steps, I wouldn't have had that experience. I would have just been able to join my family and sit down and have a glass of wine.

Liz

Well, let's talk about that emotional experience, because I'm pretty sure all of us with disability have had that at times where the simplest thing becomes the hardest thing. Four steps is four steps, and other people just don't even notice it, or the tiniest writing or holding up something for someone that's vision impaired far out of their range of vision, can sometimes just bring this well of…it's not grief, but it's like…oh not even resentment…I don't know what it is, but it's like: what about me?

Eliza

Yeah, I'm like, how can we name that word? You’re right, it’s not grief? It's almost something deeper than that, isn't it?

Liz

Yeah. It's like. Well, it's like being invisible and dismissed or diminishing.

Eliza

Yeah. Like it hurts actually, doesn't it?

Liz

Yeah.

Eliza

I think that's the way I would describe it. It hurts especially when I guess that probably hurt more because those people were my family and they know me so well, they’ve known me all my life.

Liz

Yeah.

Eliza

But I just feel like, and this is what I've been thinking about more and more, is around that, this is a tricky thing to navigate, is around it not being accessible.

If you need someone to, you know… is it? I'm asking…I think it's a really interesting thing to talk about, like around for instance, I was at an event ceremony, and I was nominated for an award. They only had five steps that I knew I couldn't navigate to get up onto the stage, but they also had a wheelchair lift. But the wheelchair lift for me is really tricky because when it wobbles and moves.

Liz

Is this at the museum?

Eliza

No, this was somewhere else.

Liz

OK.

Eliza

Yeah. And I, you know, didn't know whether I'd be able to navigate that. So, in a way, those access…it didn't meet my access requirements at that point. But also, when a wheelchair user did use the lift up and had someone you know…

Liz

Spotting them?

Eliza

Yeah, and pushing the button for them and it broke halfway up, and people were waiting on stage. And I think, you know, that's not really access.

Liz

No.

Eliza

Like, access is when we all can be together and we can, you know, roll, or walk or move however we do together, in one way. Instead of it being segregated where you have someone off that way, someone off that way, you know, that to me doesn’t feel like access.

Liz

Yeah. And long pauses while someone is scrutinised by an audience because the inadequate, you know, access machinery is not working like that. The scrutiny is very hard to, you know, have everybody's gaze on you while you're stuck somewhere.

Eliza

Mmmm.

(Music playing)

When you go and do your readings with kids and classes, do adults interact and talk to you about the book as well? Like particularly if you're selling books or is it mainly the children who interact with you?

Eliza

I think, you know, parents do as well, and I like hearing parents stories about how their children are interacting with the book. For instance, there's a mother that reaches out to me quite a bit and says that her autistic son loves to read the book to the class.

Liz

Oh, that's great.

Eliza

I also wrote a song, a children's song for the book that I sing using AUSLAN at the events. And he then sang the song to his class as well. So yeah…

Liz

Oh god, that’s great.

Eliza

Yeah, it's nice hearing the parents’ experiences of the book and also parents saying that it's been wonderful to have a book, that they can have the conversations with their children about things that they might not have even known how to bring up or how to explain.

Liz

I think it looks like a beautiful book, but I also see it as a beautiful educative tool. And I don't mean to diminish that from the creativity and the beautiful side of it, but just informing kids at such a young age is so, so great.

Eliza

I think that was the main aim of it. Yeah. I think it was just lucky that it reads really well. But also, you know, the illustrations are really colourful and vibrant and beautiful, but ultimately the idea was to, to make it be a conversation starter.

Liz

How did you find your illustrator?

Eliza

We wanted to make sure that we had someone from a diverse background, so that was definitely a priority. And that didn't, it didn't necessarily mean a disabled illustrator, which would have been wonderful and had been planning for future too. I’ve broadened my network in that space which is great. But this particular illustrator lives in Tasmania and his name's Daniel Gray-Barnett and he's a person of colour and also in a same sex relationship.

Liz

Right, OK, so your ticking, ticking some boxes (laughter).

Eliza

Yeah. You know, he said that he hadn't really thought about all of these things himself, about disability…

Liz

That’s great.

Eliza

But he was just so open to taking on all my ideas and he was very like, you know, wanted to as much as I did, make sure that it was as authentic as we could make it.

And so, there was a lot of back and forth between Daniel and I on how, how do you draw certain people or certain houses or using certain, like for instance, as a parent that uses several prosthetic attachments in the book. And so, making sure that that's done in an accurate way.

Liz

That's fantastic. I'm going to move on to music now, so you've you're working on an album for release next year. How are you going with it?

Eliza

It's been a really long process of like, let's get in the studio for two days and not see each other for a month and then come back again. And but it was really the only way because the producer I'm working with is quite busy. And also, I'm juggling all my advocacy work, putting out a children's book, putting out We've Got This, and having a family and living regionally. So, living away from where the studio is in Melbourne. But it's coming to a close and the aim is that it's finished by the end of the year and is released next year.

We've actually completed one of the music videos for the first song that will be released, which is a song that I wrote called Running Underwater, and I performed that on ABC Q&A. And it's a song about being disabled and I guess accepting that identity that I feared for so long growing up. It's about self-acceptance and it's a real…like it feels like a proud song. Like I think that a lot of people with disability have reached out saying that they can really relate to it. It feels kind of like an anthem almost. And I worked with a great dancer. Her name name's Roya, and she goes under Roya the Destroya. And she's a great disabled dancer and she has one leg and like can move like I've never seen before, like somersaults and, you know, a lot of floor work, handstands with one arm and just an incredible person. And so, she's yeah, she's an exciting person.

Liz

So, she's in your film clip?

Eliza

Yeah. So, she, her and I work together and choreographed that whole dance piece to the song and at the beginning of the clip, I walk in singing live, the song and sit at the piano, and then she walks in, into the huge, kind of like a warehouse space. But I don't notice her because in a way, she's not real. She's kind of like the alter ego, the version of myself that is.

Liz

Moving differently…

Eliza

Yeah, moving differently and also discovering her own identity in a way. But really, it's kind of like what I'm feeling. She's kind of what I'm feeling.

And then she joins me on the piano right at the end. But again, I don't notice her much because she's like almost like a ghost. And it's really… I'm so proud of this clip.

Liz

The whole pride thing and the idea that this song is an anthem and self-acceptance and self-determination and all of those things. It's a really interesting concept because we all come to it at different times and sometimes times there's catalysts for it or sometimes there's peace, sometimes people just find peace with themselves. Sometimes people find anger is their motivator to pick up their pride or to rally against something. What do you think was your…catalyst?

Eliza

Like a mixture. I couldn't, I couldn't say it was all just one thing, but I think that one it was a mixture of feeling like in society we're seeing greater representation and people are talking about it. If people are talking about it, we're seeing more representation. I feel more safe to be me. I feel like I won't be discriminated against because I have been discriminated, discriminated against so much.

And I think it was that. And also having a family like having kids and finding a partner that I could really trust and feel accepted by, and also wanting to model that for my children and that authentic self and feeling like if I'm not myself, then what is that modelling for them? Because I really want them to be whoever they are or become. So, there was a mixture…and I'm so glad now that I don't hide it and I don't hold that weight, it’s so…

Liz

It’s so lightening, isn't it? And by lightening, I mean when it's gone or you don't feel it all the time, I mean, you know your story before about family, not paying attention to your needs for a family occasion that there's little glitches like that. But when you kind of come into your own, there's… I don't know this there is a lightness that comes with it.

Eliza

I guess for me…it was sometimes so… it felt like looking back, I realise how ridiculous it was at times where I'd be at an event and I would be standing there and, you know, for me, even standing can be hard, so I'd be holding onto a table, but as soon as someone that I really respected turned away and went to the toilet, that was when I could move.

Liz

Yeah.

Eliza

So that's how…

Liz

You were really masking…

Eliza

Yeah. And then they wouldn't see the way I walk or move. So, it would be that bad that I would have to hide that much or when I met somebody I would be seated and yeah, make sure that they didn't know.

Liz

They left first…

Eliza

Exactly…wait for that. It was all of those things, especially job interviews. I did that all the time where I would, yeah, try and find a way that they didn't see, like…sometimes so ridiculous as like, you know, almost look over there for a moment.

(laughter)

Liz

There's a spider.

Eliza

Kind of, you know, maybe not that, that…but almost.

Liz

Yeah.

Eliza

And it’s so exhausting.

Eliza

I think for me, the only place is…that I have to be completely honest, and I guess we're all on our own individual journeys, but there's still things that I hide.

Like I still feel quite sad admitting this, but I still don't go and meet friends at the pool. I don't generally go to the beach much. I wouldn't…

Liz

The beach is difficult.

Eliza

Yeah, I don't go with friends and that's because I'm still afraid. The fact that my legs and feet look very, very different. Like I've got quite what you would call, you know, in inverted commas, ‘deformed feet’. Lots of scars and clawed toes and yeah, I guess that's still something I'm kind of working on. I'd love to wear shorts I'd love to wear a skirt. And I, I'm thinking I will get there, but it takes time. I'm just…I'm not saying I've got it all yet in terms of that self-acceptance.

Liz

I think you will get there. And why I say that is because I think you're a brilliant creative woman and learning to love yourself is a continuum. And it's not like a block, you know, just happens, that kind of thing.

Eliza

Yeah, look, I'm getting there, and I guess I just wanted to say that because…all people it's a work in progress, isn't it? In a way. And we all have our things that we might feel like we need to hide or to... But yeah.

Liz

Or that are harder to accept. You know as well.

(Music playing)

Liz

To find out more about Women with Disabilities Victoria go to: wdv.org.au

Liz

I'm wondering in Castlemaine, because I've walked around Castlemaine a little bit and been here to, you know, come to gigs and go to different places. What's it like moving around a town like this that you know, doesn't necessarily have finished footpaths and or do you drive everywhere?

Eliza

I drive everywhere, but I have to get out of the car in the main street to do shopping and go into any stores around the main strip. And yeah, look, I've actually found it really hard and…

Liz

Big gutters.

Eliza

Big gutters.

Liz

I've noticed that because…

Eliza

Yeah, like it's one good thing that they're doing at the moment is they're putting money into like reinvigorating the town in terms of getting tourists to come and visit. So, they've kind of activated some outdoor spaces for cafes. But what that actually does is take more…

Liz

Car parks.

Eliza

Yeah, and space for like some of the paths up to the main street. And so, it's really, really tricky to navigate that. And the experience that I had about two weeks ago really highlighted that and that was that my two-year-old was able to kind of crawl up quickly up the…up to the path area.

Liz

Yes.

Eliza

And he was up there. I couldn't get up there because it's so steep to get up onto the path.

Liz

Yeah.

Eliza

And the nearest…like entry point onto those paths were too far away to leave him.

Liz

Oh, God.

Eliza

Yeah. So, I was like, OK, well what can I do? I can't get up to him. Can't leave him, because then what if he runs onto the road?

Liz

Yeah.

Eliza

So, then I had to… which is not great. Say to him: What if we go get an ice cream? Like I had to…What if we go get an ice cream? And then he's OK and come down and so then he crawled down to me.

Liz

I would have done exactly the same thing. I would have used any bribe…because the fear is awful.

Eliza

Yeah. That's another thing around, you know, talking before about the social model it's so… that they're the things that affect you, isn't it? Like the barriers that the world has created and yeah, I really wish that more access was prioritised in terms of physical access in the town.

Liz

When people activate or when local government or state government injects money into a town to activate it, they often think about bums on seats, but they don't think about access in a proactive way, and that just can really, really disrupt a local person's life.

Eliza

Yeah, it's hard, isn't it? Because they're trying to do the right thing by small business owners, but at the same time that then affects many, and a lot of disabled people.

So yeah, it’s hard and I also live on a street that's not an actual road, it's gravel. And that's again really hard because a lot of potholes and if I'm ever walking up and down that it's very easy to fall.

Liz

Do you use an aid…if you're down the street out of the car? Or like a stick or something?

Eliza

I just finally ordered a stick. So, I use walking poles. So, what I'm doing like a big…even just a big is probably not very big to some…just if I'm going for a walk with the family, I'll take the walking poles. But yeah, I’ve just ordered a walking stick mainly to get to…I was thinking it might be good in terms of balance, but also in terms of getting up stairs, I was thinking I'd try to navigate that with the stick. Haven't had a turn of it yet.

(laughter)

Eliza

Yeah, so that’s exciting.

Liz

Yeah, that will be exciting. When you've played local venues here, have they been helpful as far as getting you in and getting you out and assisting you with stuff? Because I don't imagine its great accessibility because you know, Castlemaine, like Bendigo, they’re old towns.

Eliza

Yeah, I think, yeah, they are. The venues here are really great because they're managed by great people and people that are really wanting to make sure they're more inclusive and as part of a Music Victoria initiative,

I actually spent time with each venue and spoke about ways that they can be more accessible just for…it was not probably for long, long enough…it was a couple of hours and I've sent them some material on even how to make their social media and website more accessible…

Liz

Oh, that’s great.

Eliza

And they are just really so great at taking that on. So, I think that's the benefit of living regional is that whilst the physical parts of this town is really hard for me, the actual ease and feeling of connected…connected town of like-minded people, where I feel more accepted here, I think that's probably just it. When I'm down the street, people don't stare as much and people…yeah, I just feel like it's just more inclusive and accessible in that way and that kind of attitude.

Liz

Where did you come from?

Eliza

So, I grew up in regional Victoria, Wodonga, and then moved to Melbourne when I was 18 and lived there for, I think just under ten years.

Liz

OK, so you've been here just a little while. Yeah.

Eliza

Yeah, six years now.

Liz

OK. We just worked out your age.

(laughter)

Liz

I would just like to finish today's conversation with saying that I’m really looking forward to the new album. I think that will be fantastic.

But what I'd really like to say is thank you so much. You've been very gracious letting us into your home and reading for us and showing us your beautiful book. So thanks, Eliza.

Eliza

Oh, thank you so much for thinking of me and having me today.

(Music playing)

Liz

You can find out more about Eliza at: elizahull.com