

What's Wrong With You?

A podcast about disability and navigating a world that's not designed for you

Episode title: Unapologetically me: Disability and self-image

Episode synopsis: Olivia and Becs hear from guests who are smashing perceptions of disability - from having to prove your intelligence when you are non-verbal, to redefining masculinity as a bloke in a wheelchair. They also find out how much money you should spend on shoes when you can't even walk.

Guests: Mamie Rose McDonald, Geneva Hakaraia-Tino, Chelsea Pita and Shakti Krishnan

Photos: Olivia, Becs, Mamie, Chelsea, Geneva and Shakti



Olivia = Olivia's narrated voice over

Becs = Becs' narrated voice over

Olivia/Becs/guest = interview in studio

Episode begins

Opening sting: Stuff podcasts

Olivia Shivas: Just a heads up this episode has a little bit of swearing in it.

Olivia: This episode of What's Wrong With You? is sponsored by EveryHuman - an online platform selling life-changing adaptive clothing, footwear and lifestyle products. It's the home of the ultimate shopping experience for people with disabilities. Shop the range at EveryHuman.com.au

[punching bag sounds]

Boxing trainer: One, two, slip, slip, two, three, two

[boxing sound continues underneath narration]

Olivia: Sometimes I kinda forget that I'm disabled – I'll just be going about my day. But then something will happen and I stop and think: this wouldn't happen to me if I didn't use a wheelchair. I was at a boxing class at the gym recently; I usually go three or four times a week and the trainers are great, they adapt the class so I can join in just like anyone else. But a few weeks ago, this lady came up to me... She said how cool it was to see me boxing and that I was really inspirational. Now, I know she meant well and had probably been wondering during the class 'do I say something or do I not?'. But me? I was just thinking: hey, it's early on a Saturday morning, I think *everyone* here is inspirational. It made me wonder how my experience in the world would be different if I wasn't a wheelchair-user. Would I get approached by so many random strangers? And when people praised me for something trivial – would I feel patronised? Or would I just feel appreciated?

[Theme music begins: Feel good catchy funk pop song]

Olivia: I'm Olivia Shivas

Becs: And I'm Rebecca Dubber

Olivia: And you're listening to What's Wrong With You? Stuff's podcast about disability and what it's like living in a world that's not designed for you

Becs: In this show we cover everything: childhood and parenting, religion and culture, dating and sex – all from the perspective of disabled people, like us.

Olivia: Plus we're determined to solve some of the big mysteries of living with disability: like – Why people get sooo angsty about mobility car parks.

[Theme music ends: Feel good catchy funk pop song]

Olivia: So Becs, I hope you are feeling inspired, sitting next to me. I am, after all, an inspirational boxer.

Becs: *[sarcastic]* Olivia, you have always been my role model.

Olivia: Well thank you! Actually, I have another inspirational story for you, again from the gym. Just a few days ago, I finished a boxing class and was getting into my car. I'd closed up the ramp and back door with my remote control, I was sitting in the driver's seat about to drive off when this couple come up to my window and waved. They had these really cheesy smiles on their face and literally gave me a big thumbs up! Like eeeee!

Becs: Uhhh that's cringe

Olivia: I just laughed! Though they probably didn't realise I was kinda laughing at them rather than with them. I suppose they meant well.

Becs: Isn't it funny how people don't realise that the wrong kind of encouragement can actually make us feel worse. Being pigeonholed all the time starts to chip away at your own self-image. The way other people look at you, starts to affect the way you look at yourself.

Olivia: Yeah. So that's what this episode is about: Identity and self-image.

Becs: It's a big, complicated subject;

Olivia: Yeah we're going to look at – the labels that get attached to us. We hear about what masculinity means when you're a wheelchair user.

Becs: We find out what it's like to learn Te Reo when your voice synthesiser has an *Astraaaayan* accent!

Olivia: And we debate just how much money you should be spending on shoes - when you can't even walk.

Becs: So much interesting material!

Olivia: Actually we found this topic so interesting that we interviewed four guests instead of our usual one or two. Editing it down to a sensible length is gonna be a nightmare. So let's just get on with it.

Olivia: Geneva Hakaraia-Tino is a disability advocate and communications consultant. And she's another person who ends up having to explain herself to people who've jumped to some wrong conclusions. For this interview, we sent Geneva some of the questions in advance to give her time to prepare. Have a listen, and you'll see why ...

Geneva [voice synthesiser]: My name is Geneva Hakaraia-Tino, my iwi is Ngā puhi and Te Aupōuri. I am 28 and I have lived in West Auckland all my life.

Olivia: It's interesting listening to it pronounce te reo words, it still hasn't quite gotten there yet, but we'll ask you about that a bit later. So I think I've told you the name of our podcast, so we'll ask you that interesting question. What's wrong with you?

Geneva: At birth, I was diagnosed with athetoid cerebral palsy, which affected my limb movements and my ability to verbally articulate words. I am able to vocalise. But I cannot form words that are easy enough to be understood. So I use the communication device to communicate. This method of communication has been so beneficial in my life in terms of providing me a voice in society. Ironically, it has helped me attain a communications degree and now I am pursuing a master's in education.

Geneva: I used a tablet that has a specialised software installed on it. This system uses a symbol based keyboard, making it easier for me to communicate efficiently. To be honest, I unconsciously chose to voice when I was given my first device 15 years ago. Over the years it has just become part of my identity.

Olivia: So you're clicking a fast forward button to do that.

Becs: That's pretty cool. Does it have rewind? [laughter]

Olivia: I wish I could rewind what I say sometimes.

Becs: I'd take that back. [laughter]

Becs: Can you tell us about some of the misconceptions about being non-verbal?

Geneva: Many people make an assumption that because I am non-verbal I must be mentally disabled. There has been numerous situations where people have spoken to me as if I am a child and as a 28 year old woman, it is incredibly frustrating and belittling.

Olivia: I think it is quite funny some of the interactions you have with people who, and I'll have a conversation with someone and they'll be so surprised that I can drive or something like that, and it's like, wow, have you met anyone in a wheelchair before?

Olivia: So how do you learn te reo while being non-verbal?

Geneva: Currently, I have phonetically spelled te reo words into my device and attempt to make the words sound as close to its pronunciation as possible. However, the current voices

that are available on speech generated devices doing an extremely poor job of converting te reo into intelligible speech.

Becs: Can imagine that would be so frustrating as well

Olivia: What's a Māori approach to disability?

Geneva: This is going to be a bit controversial. And I know some people are going to disagree with me. Historically, how people with disabilities were viewed in Māori society was portrayed in myths and legends, it was only natural for Māori to embrace and include individuals with disabilities without hesitation or question, it is said that since the arrival of Europeans the holistic thinking of Māori was challenged to the Westernised approach of disability was based on individualistic ideologies. Unfortunately, this is still the case in today's society. One of the main values, the Māori culture, is inclusiveness

Olivia: One thing I want to ask. Sorry, this is not a preplanned question I just thought of because I just remember at uni when we had marae trips and we made sure we went to a marae that was accessible or they put in a ramp or something like that. And it's customary to take your shoes off. As a wheelchair user, should you take your shoes off? [laughter] Does that matter? Because I think I remember someone at the marae being like, oh, no, don't worry, you don't need to worry about it. But I was like, oh, but I want to because everyone else is doing it.

Becs: Yeah

Geneva: [typing sounds on communication device]

Geneva: That's an interesting question. I think it's up to the individuals themselves, but I always take off my shoes out of respect.

Olivia: Can I ask how long did it take you to type the answers out?

Geneva: It took me a couple of hours, but I typed everything on my laptop and transferred it onto my device.

Becs: That's pretty cool.

Geneva: If I was to type everything directly on my device, it would probably take me all day. [laughter]

Olivia: That's a very long podcast episode

MUSIC BREAK

Olivia: Our next guest is Shakti Krishnan. He was born in Malaysia, grew up in Hamilton and now lives in Auckland. He has some really interesting things to say about how disability forced him to think about how society defines masculinity. Because it turns out that you don't have to be six foot tall – and muscly – and in possession of two fully-functioning legs, to be a real man!

Becs: What you also need to know about Shakti, though, is that he came into the studio wearing a woolly teddy-bear jacket, like a big fluffy thing – a pretty bold fashion choice.

Olivia: Which quickly led us onto the very important topic of – footwear ...

[laughter]

Olivia: Your shoes are like way too expensive for someone who doesn't even walk. I can't spend money on expensive shoes

Shakti: That's the point

Olivia: Like the irony. Yes, OK.

Shakti: No, it's actually because then you don't damage them, right?

Olivia: They last longer

Shakti: To everyone else they're a dispensable item.

Becs: No I feel like that's a myth. I buy white sneakers and I cannot keep them white.

Olivia: What kind of shoes- what kind of shoes are you actually wearing?

Shakti: I don't want to- is this like a fashion...?

Olivia: Yeah. I want to know because people can't see them on the podcast. They look cool.

Shakti: Yeezy 380s.

Olivia: I don't know, I'm not really a shoe person, but sounds fancy

Shakti: They're like socks dude, and they got like big soles, so when I like kind of drag my feet all over the place, like they don't get hurt, which is quite nice.

Olivia: Yeah.

Shakti: Thank you.

Olivia: They're very cool, but glittery or something.

Shakti: Thanks, eyes up here.

[laughter]

Olivia: What's wrong with you, Shakti?

Shakti: What's wrong with me? How much time do you have? I've got a list. What's wrong with me? So I have spina bifida. I was born with it. Um, I use a wheelchair to get around.

Olivia: So how has your disability shaped your identity?

Shakti: It's hard to identify something like that because every single experience is like kind of affected by your disability, you know, even from driving here, I've got to plan my time out a little better, so screw up and, you know, like leave my wheelchair somewhere silly or something like that. You only really notice it when you compare it to other people or other able bodied people, people with different abilities you don't, like, you're fine if you're just by yourself. But I think you only notice it when you're like around it lots of other people. Yeah.

Becs: I think as well, because the three of us were born with our disabilities, everything we've ever known.

Shakti: And in a vacuum that's like you don't even know that's like something different. You know, I think

Becs: You're right, it's when you start talking to people who are able bodied and they're like, oh that's not normal. Yeah. That's not how we do things.

Shakti: Uh totally. And I'll just yeah, you kind of you have to conform socially. I think a lot that affects your identity. I think I think because I struggle with it when I was younger, you know, in my more formative years. But, yeah, it takes a lot of, um, like growth and understanding to, like, get to a place where I think you are OK identifying that way and then showing that to everyone else.

Olivia: For me, I mean, it's something I don't like to admit, but I think I probably still have a little bit of insecurity of fact that I use a wheelchair because I'm super self aware of stereotypes associated with disability and being a wheelchair-user and the stories we see about them. And so I think I probably that's probably one of the reasons maybe I'm a bit of an overachiever and a bit of a perfectionist because I am so aware. So I try to compensate for what people assume is my lack, in a way. As a young woman, I've never felt like being in a wheelchair is super feminine because you've got, like, all this metal around you. And, you know, traditionally women have it to be like graceful and elegant. And I feel like a wheelchair is the furthestest away from that. I guess when it comes to, like you, Shakti, and masculinity - what are your thoughts around that?

Shakti: I think it can be really hard to be like a masculine person, like disabled person in like ableist society. I think traditionally and I'm not saying this is the right way for it to be, but men are seen as like dominant, women are seen as submissive. Unfortunately, when you're in a wheelchair, you are always playing a submissive role, you are always going to be passive. It

doesn't matter what situation you're in, you're in like a social group you're always going to have to play a passive role. And that sucks. And as a man, it can be very emasculating to never have an opportunity to be seen as dominant or masculine in a traditional sense.

Olivia: So how do you like come to terms with that?

Shakti: Oh it's tough. I think I noticed it a lot when I went on dates in uni. And you know, you're playing this like theatre of like dating and you have to like, you know, you're checking each other around, you're trying to figure things out. And it's very hard to come across as like a manly man. You know, you go up to the checkout counter, you know, to go buy your drinks or something. You can't reach the counter, you look so silly and small. You don't feel like a man who can take care of a woman, which is what we are sold to in this, like, traditional thing.

Shakti: Why tall- why does everyone listen it to tall dudes, what is up with that?

Olivia: Listen to tall people?

Shakti: Yeah, man, I'm always looking up at people. I hate it.

Olivia: So do you prefer a standing person to - this sounds awful - come down to the same level?

Shakti: To bow for me? [laughter] No, because in a social context, that's kind of weird, right? Ideally, you would want to be talking to someone at eye level sitting down at a table or something like that where it's socially appropriate in our current climate. So there needs to be like, I don't know, some social accessibility to be around it. And I think that's why I'm super loud. I got to project my voice. I want those guys in the clouds to hear me. You know, it's real hard, but I'm very social and I like engaging with people. So it can really upset me when I can't physically engage with people. I never got to play things like touch rugby or like contact sports. And like, I guess a part of me thought that sucked because people always saw me as, like fragile or like, you know, incapable, very delicate and gentle. So people would like I wanted I wanted some of that, like rough and tumble, I guess, you know, like I wanted to be treated like other people. I don't like being coddled. I remember I went on a school trip and like the older boys like hazing all the younger boys and they didn't haze me, I got real upset about it. [laughter]

Olivia: You wanted to be hazed.

Shakti: I wanted to be hazed like everyone else! But I didn't get hazed because they're too scared of like beating up the disabled guy, which I get like fair.

Olivia: Yeah, it looks really bad.

[laughter]

Shakti: Come on. Like, yeah, but I guess-

Olivia: They could have adapted it for you.

Shakti: Yeah. Accessible hazing. [laughter] But I think what it comes down to it, it's just like really being a part of that social group and like feeling like you are, you are included in all aspects of it socially, not like physically. Doesn't matter if you're just there like. You've got to be like with everyone,

Olivia: So how have you redefined masculinity for you and your identity and living with a disability?

Shakti: Movements within feminism that have made us start talking about toxic masculinity have really helped redefine masculinity in general because we can understand like the toxic traits of masculinity that are more or less bad for everyone. I think lad culture in New Zealand has a lot of that toxic masculinity and that sucks. And when you want to conform to it, it can suck a lot. So I think understanding that masculinity doesn't have to have a lot of the toxic traits that you'd usually associate with it has really helped me as a disabled person

understand that I'm not less of a man because I don't like be aggressive with people. Like I'm not less of a man because I don't physically take up so much space. You know, there are other ways to, I don't know, prove your masculinity or feel comfortable within your masculinity. There are so many ways of expressing yourself. And yeah, that's basically what helped me redefine it.

Olivia: One thing I wanted to talk about is the comment of: You're too pretty or young to be disabled.

Shakti: What the heck? I've never hear that

Becs: Those situations where I've had the comment of you're you're too young or you're ready to be disabled, have often come from people trying to harass me for parking in a mobility park. You can't see my wheelchair because it's sitting on my passenger seat. So people just like they look at me and they're like, she can't be disabled. So they come up and they will knock on the window or they will death stare you, you're too pretty-

Shakti: I've never heard those things. I'm exactly as disabled as people think I should be.

Olivia: So how do you look, how do we look more disabled?

Shakti: Well, I just I think I'm very confident when I'm parking a disabled place.

Olivia: This has happened to me. I'm just going about my day, going to the supermarket, parked in a disabled car park and I had two police officers-

Shakti: What?!

Olivia: -knock on my window. Yeah. Two police officers tell me that I was parked in a disabled car park and I was like, yeah, I know

Shakti: Do I just look more disabled than you guys? [laughter] What is going on?

Olivia: But I was like, like look in the window, like there's a wheelchair, like sitting there. I mean, they looked on the windscreen and saw my mobility permit like, oh, OK. But it takes me like five minutes to get out of my car. So they had walked away by then. Yeah. But you know?

Becs: But not as bad as the police officer is, but I was in a mall car park once parked in mobility park. I was like five minutes early so I was just like quickly clearing some emails before I got out, had my permit up and everything, and this parking warden comes over and knocks on my window. So I open up my door and I'm like, can I help you? And he's like, this is a mobility park. And I'm like, Yeah, I know. And I pointed to my sticker and he goes, But this park is for disabled people. And I'm like, yeah, I am disabled. And he's like, are you?

Shakti: Oh, that's wild. Did you not have the card there?

Becs: The card was up!

Olivia: He didn't believe you.

Becs: He did not believe that I was disabled

Shakti: But the general consensus now is that people have invisible disabilities. But usually don't ask anyway.

Becs: So I pointed to the wheelchair in the back and was like, there's a f....ing wheelchair in the back, go away.

[bass hip hop music starts]

Shakti: I've got a good story. I remember I was driving back from my mate's house once, and it's kind of late at night. And I was by myself driving back was on my restricted still probably, naughty. But I remember some guy was like behind me and I was like turning left in the intersection or something like that and he kind of just got like, really weird. I mean, I remember like, looking back, I was-

Olivia: Like tailgating you?

Shakti: Yeah, yeah. And like, I think like it's like a weird intersection then like I had to wait till I turn and stuff and he just wasn't happy with me waiting. So you freaking saw swerve the middle of the road like, like blocking my car. And it was the first time as a as a man that I was in fear for my life because I was like, oh s..t, I don't have a friend next to me, I just-

Olivia: You can't run!

Shakti: I'm like, I'm fully f....d. So he gets out of the car like he walks up to me. He's a very intimidating large looking guy. And I'm like, Oh, I'm dying tonight. And I roll- I don't know why I rolled my window down, so stupid right?. And he's just like, what the f..k did you do, you know? And just going at me like he was like, you know, pretty methed up or something. And I remember I was just I was just like I was just looking at it with my hands at the wheel. Oh, my God. Oh, my God. Oh, my God. I was just like, hope- my wheelchair was in the passenger seat, just hoping, I'm just waiting for him to see the wheelchair.

Olivia: To give you some sympathy?

Shakti: To understand that I'm not an able bodied guy who can get up and have a fight with you right now? Right. And he does. He looks at the wheelchair. He says, f..k you and walks off. Oh, say, oh, my God,

Olivia: Because you use a wheelchair.

Shakti: Because of my wheelchair. Was like bless the Lord. Thank you. But it was really scary as like a guy, I guess. Yeah, because. He doesn't know that I'm disabled at the moment, and he was going to fight me use like get his hands, like you was coming up to my window with his hand on the handle. Far out, terrifying man.

[Soft guitar music starts]

Olivia: Everyone has days when they struggle to fully embrace their body, it's totally normal to feel just a little bit out of place sometimes. Style is something that has always helped me gain back my confidence, but sometimes, the jeans that make you feel great, or the smoky eye look that makes you feel fierce, are tricky to pull off. Brushes are sometimes hard to grip, and buttons on denim jeans can be like a fight to the last woman standing! Or sitting in our case. This is where EveryHuman comes in and saves the day. By giving you access to accessible lifestyle products and making sure the outfits that give you confidence, are also functional for your needs. Everyone deserves to get dressed and live life with dignity and it shouldn't feel like a hassle to get ready. Nobody should feel bad about asking for help when they need it, but there are also times when you want to get dressed or do a task yourself. EveryHuman helps you grasp a hold of your independence, whatever that looks like for you, with their range of accessible garments, footwear and lifestyle products. If you give someone the right pair of shoes, they can conquer the world. In a disabled person's case, when we are equipped with clothing, shoes, gadgets and lifestyle products designed for our success, disabled people are able to conquer the daily barriers of navigating a world not designed for us. With EveryHuman, you can do life and style in a way that works for your needs.

[Soft guitar music ends]

Becs: Now, most of our podcast guests are born disabled, and like us, Olivia, it's all we've ever known.

Olivia: But it's not like that for our next guest. Chelsea Pita is 21 and she's studying business. She was born and raised in Rotorua and her whakapapa links back to Ngāti

Tūwharetoa and Ngāti Rangitihi. Three years ago, she had an accident; she's now paralysed from the waist down. So walking is something that she was still doing, really quite recently. That sudden shift from non-disabled person to disabled person forced Chelsea to reassess who she was - and even what words to use to describe herself. But I started off by asking her a question that, to be honest, I've been putting off asking a non-disabled person. Because sometimes, it's hard to be confronted with the reality of what you're supposedly missing out on as a disabled person ...

Olivia: Is walking that great?

Chelsea: Oh yeah.

Olivia: And if you could go back, what would you do?

Chelsea: Honestly, I would go back, I would take the lessons I've learnt, but I would go back just because. Yeah, miss the feeling of grass and sand and I miss taking my nieces on walks to the park and things like that. But and why I still get to do all those things, that's just different. You know, my wheelchair is now my new set of legs. So I'm not really missing out on anything

Olivia: So how did you sustain a spinal cord injury?

Chelsea: It was from a swimming accident, uh, swimming with my family. We were jumping into the lake and because of the height of the jump and the impact of the water, I ended up breaking my back and that ended up pushing into my spinal cord

Becs: That must have been pretty traumatic.

Chelsea: I remember it, but I think I was so in shock that I don't quite believe it. And because I don't quite understand it either, I was just it happened and that's it.

Olivia: When you first had your injury, was your goal to, walk again?

Chelsea: My goal was to walk again, but it's because I didn't quite understand it of like how severe my injury was that I didn't quite get that. It's not like you're going to wake up the next day and feel your legs automatically again. I think what didn't help was that I did have partial feeling. So I'm thinking, oh, maybe the rest of it will come back eventually. My goal was to walk again.

Olivia: Such like a big thing to process at such a young age.

Chelsea: Yeah, especially at 18 when you're in that transition age of like you're moving out and like your whole life is about to take on a new journey. It was really difficult to wrap my head and this is my new change and this is the new journey that I'm about to go on.

Chelsea: So my mum was a caregiver for a trust. I think I was around four and she would like take me to work with her. And so I had been exposed to that world like disability community. So for me, when I had my disability, didn't feel any different, like obviously I was the one to experience it. But because I was surrounded by the disability community at a young age, I kind of felt normal to me, seeing people with different disabilities

Becs: I find your perspective on it really refreshing because I think so often you know, the patronising comments that you get in public is like, you know, I'd rather die than, you know, I have to use a wheelchair or, you know, I would be so depressed if, you know, I had your life sort of thing. And to hear, you know, you say that, you know, it's just part of who I am. Like I roll now, I don't walk.

Chelsea: Don't get me wrong, I did have go through that phase of being, like, anxious and sad and like, I guess grieving my old life. But at the end of it, like it is what it is like, I can't change it. So you might as well just accept it and move on and, you know, just go with it.

MUSIC BREAK

Becs: So Olivia, how did you feel when Chelsea said walking was *really great*?

Olivia: It did shake me a bit because *I genuinely believe I'm living my best life* as a wheelchair-user and her answer *kinda disrupted* that and, to be honest, it did put me in a weird mood after that interview. But I'm really glad she could be honest with us.

Becs: Yeah I know what you mean, but I could relate to her too. My swimming career ended early because of an overuse injury. I mean, I love my life now - post-swimming - but if I could flick a switch and undo the damage so I could have a shot at going to the Paralympics again ... part of me would say yes to that in a heartbeat.

Olivia: Our fourth and final guest is Mamie Rose McDonald. She's 21, lives in Auckland and is studying tourism.

Becs: Two years ago she got involved with the modelling agency run by myself and our podcast producer Grace Stratton. By an amazing chain of events, her photo ended up on the Vogue Italia website.

Olivia: For someone who faces a lot of inaccurate assumptions from strangers, it was an incredible validation of the self-image Mamie had always felt: that she's beautiful and confident in who she is. When she came in for the interview, we started by asking about her disability.

Mamie: So I was born with Williams Syndrome, which means that I am also missing my seventh chromosome in my DNA and I also have some heart problems that comes along with Williams Syndrome. Yeah, and also facial features, are a very prominent thing when it comes to Williams Syndrome.

Olivia: Do you mind describing what those facial features are ...

Mamie: The cheekbones, we have a lot of teeth with sometimes people have a lot of teeth. And so our cheekbones are very sharp and also, I guess like. Yeah, just the way that the bone structure.

Mamie: I guess like when you look at me, you can't go, oh, she has a disability because my disability isn't physical. It's more learning wise. so just some things of having to try extra hard to qualify and get all the things that I really want.

Olivia: Do you know where, um, Williams syndrome originated? Do you know Mr. or Mrs. Williams?

Mamie: Um, so Williams syndrome was diagnosed by Mr. Williams. And, um, odd story.

[quirky, mysterious music]

Mamie: He actually one day disappeared. Yeah, like, oddly enough, vanished.

Becs: I think I remember you telling me about this, it's like a cold case. They don't know where he is.

Mamie: It's like they're like. Think of it is a disability that wasn't supposed to be discovered, like literally. That's how I think of it because he went missing!

Becs: So he went missing after he published Williams syndrome.

Mamie: Literally-.

Becs: Someone out there did not want him-.

Mamie: To say, to literally be like, there's this disability that like- he literally his bag was left in a airport.

Olivia: Yeah, so when did he, when did this happen?

Mamie: A long time ago, I don't remember the exact year, but, um. Yeah. I'm sorry if you're still alive now, I'm sorry for exposing your secret, but, you know, I had to because it's part of who I am and yeah, and if your family is still alive, then, you know, I hope you're OK!

Olivia: So we'll get back to Mamie's interview in a second, but after what she'd told us I felt I should find out a bit more about this Mr Williams, and it turns out he's a New Zealander! Mr Williams' full name is John Cyprian Phipps Williams and he was born in 1922. While working at Auckland Hospital and Greenlane Hospital, he started taking notes on patients who had those same features Mamie talked about - such as the pixie-like face, heart problems and learning difficulties. He published a paper about it in 1961. His disappearance still remains a bit of a mystery, but according to volume 41 of the *Pediatric Radiology* journal, while in London he met up with another well-known Kiwi, the poet and author Janet Frame and they began a relationship. He proposed, but then she ran away not wanting to get married. After that little is known about Mr Williams' whereabouts. Interpol actually tried and then failed to find him and in 1988, he was declared "a missing person presumed to be dead from 1978" by the High Court of New Zealand. So yeah, we may never know what happened to Mr Williams but at least he got some important work done before disappearing. Now back to the interview with Mamie

Mamie: My dad is Māori and he grew up in Blenheim, and we have a place called the Waiau Pa, which is this beautiful lake, and we have Marae there and sometimes we go down there and we go to tangis and things. And, yeah, um, my journey to Māoridom. Um, my grandfather didn't speak Māori, so my dad didn't speak Māori. And so I grew up not speaking Māori til later in life. But, you know, I felt like a sense of like identity loss, you know, I was like, OK, so what cultures am I? So it was really so cool to find out about my culture. And with the LGBTQ, I am a member of the B and the LGBTQ. B stands for B, bisexual. So. Yeah. Oh, yeah. It's kind of a long journey because I realised, oh, I like boys but I like girls. And so, you know, um, I guess I was about 16 when I probably realised that. Oh, yeah, I mean, I'm the B in the LGBT, so, you know, it was pretty cool and then. Yeah, I guess, like, um, also with gender identity, um, gender nonconforming, so like when it comes to buying clothes, I don't care whether it's on the womens or the mens. And I love I love, I love exploring things.

Olivia: So there's another part of your culture as well, you're part Italian?

Mamie: Yes, so my great, great, great, great, great great great great grandfather came from Bardi in Italy and so. He traveled here and he had 10 children and obviously from the 10 children. I was born to the world and yeah, and so the thing with Vogue Italia. So I did a photo shoot with Karen Inderbitzen-Waller, who does photographs with Karen Walker. And so she asked me if you could achieve anything from this photo shoot, what would you like to achieve? And I was like, I would love to be in Vogue Italia. And so, you know, like and then all of a sudden during the lockdown of the middle class that day and it was lunchtime and I went online and I saw that Grace had posted the photo and it was from Vogue Italia. And I was like, oh, my goodness. Like, that is just so crazy.

Olivia: So what did that do for your confidence?

Mamie: Really built it up massively.

Olivia: So I guess coming off, you having such a positive, empowering experience through Vogue Italia, Becs and I have also done some modeling at New Zealand Fashion Week, we were some of the first wheelchair users as models and the mainstream show. And I think for me, I had I think I kind of had this epiphany moment, actually, after Fashion Week, because

the whole day is very busy getting get in straight there, do hair, makeup, you're like changing outfits and it's quite overwhelming. Um, but I was looking back through my phone and some of my photos and one of the girls who was helping me dress took a photo of the back of my dress and it was like these knotted, um, a knotted design on the back of it. And then I notice my scoliosis scar. So I had scoliosis surgery when I was 13 to fix my crooked spine. And I used to be so self-conscious of that scar. And I remember thinking at this Fashion Week show, I almost forgot about the scar, but it was like fully on show, like at Fashion Week and thinking how, wow, all these aspects of me, like my scar, my wheelchair, were actually like fully embraced and seen as a point of difference is something that was desired were you don't usually normally see that in mainstream shows. So that was such an empowering experience for me.

Becs: I think for me, the scary, empowering moment for me for Fashion Week was I was involved in a runway show and I remember going to the fitting and they were picking the outfits and they decided that they wanted me to model jockey. And I was like, OK. I have a massive scar that goes from, like, halfway down my abdomen. And, you know, it's not something that you would expect to see on someone modeling underwear on the runway. And I think I just kind of pushed it all to the back of my head, but the photos pop up every now and again on social media and they get shared and I just I'm so proud of those images and I'm so proud that, you know, they gave me that opportunity and it was embraced by everyone to see a different body modeling underwear on the runway.

[Contemplative guitar music begins]

Mamie: One day I was with my mum at dinner and she said. If I gave you a million dollars and I asked you to take your disability away, would you do it? And I said I would not take it away for any money. I mean, why go through all this trouble that I've had to been through or just to get the struggle taken away from me and had to re-learn things again? You know, I think it's really important that we accept who we are.

Olivia: People have sometimes asked me, like, if you could take a pill and you wouldn't be disabled anymore, would you take it? And it's such a complex question because it's not just like, oh, yeah, I can walk now. It's like all the experiences that I've had in my life that have brought me to where I am today. Like, I wouldn't know anyone in this room if it wasn't for my disability. And I don't think I could bear the thought of not knowing you guys if that meant that I could walk. And I don't think- for me, it's not worth that pay off, just because if I could walk, life would be a bit easier. I could reach stuff on the top shelf at the supermarket and things like that, but I don't think it would make my life richer.

Becs: I think that that one comes from the misconception that disability is, you know, this burden and it's something to be pitied. And, you know, I guess there are definitely struggles with having a disability when it comes to things like medical appointments and living in a world that's not made for you. Um, but I think everyone has struggles in their life. And I think that even though my disability is something that might be looked down on by, you know, the general public and I will the able bodied people out there, to me, I think it's given me so much more than it's ever taken away.

Mamie: I know my worth and I see myself as a wonderful, amazing human being, and I think that, you know, people ask me, how do you like something in the mirror and just see me with my underwear on? And I'll go you're amazing. You know, like it's like some people actually just being in front of a mirror and go, you're amazing in your underwear and I know this

sounds odd, but like I think that when you start to feel a lot of confidence and accepting your body type and everything about you. Yeah, it just again, it comes back to acceptance.

[Theme music starts: Feel good catchy funk pop song]

Olivia: So that wraps up this episode, next week...

Olivia: I've had like a random stranger come up to me in a public bathroom asking me if I can have sex

Etta: I wish I was brave enough to be like, why are you propositioning me?

Becs: I was like, OK, is this guy coming back? Like, have I just been left at the top of these stairs? Has he realised that dating a girl in a wheelchair is too hard and he's just like, gapped it?

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[Theme music ends: Feel good catchy funk pop song]

Olivia: This episode was sponsored by EveryHuman - an online platform selling life-changing adaptive clothing, footwear and lifestyle products. It's the home of the ultimate shopping experience for people with disabilities. Shop the range at EveryHuman.com.au