

What's Wrong With You?

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

Episode title: What if I don't want to walk anyway? Disability and childhood

Episode synopsis: Olivia Shivas and Rebecca (Beccs) Dubber take a trip down memory lane to discuss the realities of growing up disabled. They meet a mum whose son has autism but isn't "like Rain Man". And they chat to a Paralympian dad in a wheelchair about the endless intrusive questions he faces when out with his young daughter.

Episode guests: Dan Buckingham and Tiana Epati

Photos: Olivia, Beccs, Dan and Tiana



Olivia = Olivia's narrated voice over

Beccs = Beccs' narrated voice over

Olivia/Beccs/guest = interview in studio

Episode begins

Opening sting: Stuff podcasts

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

Home movie audio: *Come on Olivia, walking to daddy*

Olivia: The other day I dug out an old home video

Home movie audio: *Hehehe (clatter of crutches)*

Olivia: Yeah, that's me. Aged about three

Home movie audio: *Mummy, hold me*

Olivia: Cute, eh?

Home movie audio: *(dad) Ok one step love, do a step*

Olivia: And that's my Dad holding the camera capturing every move as I inch across the lounge.

Home movie audio: (dad) *Wow look at that good girl*

Olivia: Plenty of families have these kinds of home movies (*baby squeals*) parents capturing their kids' attempts at walking.

Home movie audio: (mum) *Go go, keep walking. Going to send this to grandma and grandad*

Olivia: You can tell that ... for my parents ... it was a big deal. But for me ...

Home movie audio: (*Olivia blows a raspberry*)

Olivia: I don't remember particularly wanting to learn to walk. It was hard work.

Home movie audio: (dad) *She's walking to the chair look at that, good girl*

Olivia: I was born with muscular dystrophy central core congenital myopathy (yeah try saying that five times really fast). This means my muscles are weak. Now those exercises I did way back then weren't a total waste of time, as it probably did help the mobility I have now, but walking was just about impossible.

[guitar, child-like music begins]

Olivia: I got my first wheelchair when I was six years old.

I do remember hating the feeling of missing out on some things, but in my mind – being able to actually walk was never the solution.

For a while at primary school I did walk some of the time, using calipers and crutches, but it was slow work. At high school I switched to using the wheelchair full-time: I was waaaaay faster on wheels than in my calipers, and I wanted to be able to keep up with my friends at lunchtime.

[guitar, child-like music ends]

Olivia: So wanting to walk? For decades now, it's been something that never even crosses my mind. But watching that old video the other day while preparing for this podcast **[home movie audio]** reminded me that for a long time it was a huuuge deal to my parents.

Because while I was blowing raspberries at the camera, **[raspberry]** they were worrying about what it would mean for their daughter if she never learnt to walk.

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

Olivia: This is *What's Wrong with You?* – Stuff's podcast about disability – and about living in a world that's not designed for you. I'm Olivia Shivas and I'm a digital producer for Stuff

Beccs: And I'm Rebecca Dubber, I'm a Paralympian and communications consultant.

Olivia: and we both use wheelchairs to navigate the world.

Beccs: Across the seven episodes of *What's Wrong with You*, we're gonna cover all sorts:

Olivia: Dating while disabled.

Beccs: Travelling when you're disabled

Olivia: Disability and religion.

Beccs: We're going to hear from guests who'll talk about fashion, sex, media representation and body image. And we'll also try to answer some of the big mysteries facing people living with disabilities, such as: *Why do so many weird things happen whenever we go to the supermarket?*

Olivia: But for this very first episode of What's Wrong With You we're going to start where all stories start: childhood.

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

Olivia: Beccs and I have been thinking a lot recently about what it's been like to grow up with a disability, and we'll talk about that. But we're also gonna look at this from the opposite direction: What's it like being that *parent who's raising* a child with a disability?

Beccs: And – seeing we're talking about parenting – there's one *more* angle to consider. I'm disabled – I use a wheelchair because I was born with a congenital condition called sacral agenesis, which means the bones at the base of my spine aren't fully developed. And I really want to be a mum some day. So I want to know more about the experiences of parenting when you have the disability.

Olivia: So yeah. That's how today's episode is going to work. We meet a champion wheelchair-rugby player who's recently become father to a sweet little girl

Beccs: and he tells us about some awkward chats he has with strangers at the shopping mall.

Olivia: We meet the mother of a boy who has autism

Beccs: and hear why she thought she was going to Italy, but ended up in Holland.

Olivia: Aaaand – I make a small confession about my failures as a pet-owner.

Olivia: So let's meet our first guest, Dan Buckingham. I started by asking him this podcast's signature question, and yeah, we know it's a little bit rude...

Olivia: I don't know if I told you the name of the podcast?

Dan: You either did, or I've forgotten it

Olivia: The title of the podcast is: What's wrong with you?

Dan: Right, so I broke my neck over 20 years ago now, ninety nine as a first year uni student down in Otago just living the dream there of studying, surveying and playing a bit of footy and basically long, long story short, I went along to a game a rugby, put my head in the wrong place and broke my neck playing rugby. I was playing hooker at that stage, I had a prop either side of me and then this one scrums going to go down, one of my props pulled out and I should have pulled out, instead I tried to engage, got my head put in a very bad place and this weight of eight guys coming through to one side and my guys pushing behind me, which were my head and neck and something had to give, it was my sixth and seventh vertebrae, which leads me a tetraplegic so paralyzed from the chest down with some muscle function to the hands and arms. But I exhibit more like a para.

Olivia: Who's Dan Buckingham?

Dan: Where do I start? I guess the biggest thing in my life is, um, uh, my husband now as of a few weeks ago and a father of a gorgeous 13 month old daughter. A huge part of my life was sport, playing wheelchair rugby in New Zealand for 16 years that was all encompassing. But very much, I still miss it, loved it, um, but made that shift and realized there were some other things I wanted to do in my life. Hence married with children now. Etta was born on Auckland Anniversary day 2020, so she's- that was January 27. Just about walking, just about talking. A few words, a few steps.

Olivia: So tell us a bit about your family. What does your family life look like?

Dan: It's intense, that's been one of the biggest shifts of having a baby is life is just so full, like from through the night, doesn't just at the start of the day. And also, I think another big change I have really feel things a lot more, I think, in terms of things I read in the news or things where a child's been injured or stuff like that, I've suddenly got these, different sort of more intense feelings, to be honest it sort of a bit of a blur for the last year, but it's fantastic at the same time.

Olivia: We're talking about injuries, I mean, I've run over my cat's tail quite a few times. Have you run over Etta? Oh, had a close call?

[tape scratch sound]

Olivia: I'm just gonna interrupt the interview here, I just have to explain something - when I say 'run over', I mean in my wheelchair, *not* my car. I'm a great driver - of both cars and wheelchairs - but sometimes I don't check my wheelchair blindspot for small animals ...

[tape scratch sound]

Dan: The closest I have done I've come to with Etta, it was two nights ago. I think she's got up to the stage where she's walking by pushing my wheelchair, she'll hold the bar at the back and she managed to get her thumb caught in between my wheel and the wheel guard, just enough to cause a few tears. But yeah I think I just live in fear of dropping her, injuring her, rolling her over.

Olivia: Yeah, well, I mean, even in the supermarket, when I'm lazy and I don't have a basket, I drop the groceries and I don't want to be dropping a human baby. How do you carry her and push your chair at the same time?

Dan: The biggest, coolest device I have is made by a guy here in Auckland Chris Hanley who made it for himself with three kids, had he had another kid before his injury, but he's had three boys since. And he gave me two actually, one is like an old school bouncer, if you imagine, that was designed to slide into the front of your wheelchair. So we got two little slots that have been added to my wheelchair, this is just basically as, when you see it, it's really simple design, it's one piece of tubing that goes up and around with a canvas layer on it, so typical classic old school bouncer and that just slides in and out of my wheelchair. And from the youngest of ages, she's slept on that. I've been trapped under it for hours. Where she's just slept, trying to get her to sleep and I can rock her back at night and watch movies on my phone and read a book. But that's been magic from, I can change on it and, uh, I'm just dreading the day where she's too big for it, she's already a bit too big for it, um, but she still falls asleep on it, uh, to get to sleep at night. But she's also at this stage now where she just sits on my lap really easily. Her balance is phenomenal. Yeah. So she's going to be a surfer or skater or something. So, yeah, we actually got her a skateboard for her first Christmas, skateboard and a pack of band aids, really good balance.

Olivia: I guess what's kind of deemed to be like a traditional father role, doing kind of like the more active things, like kicking the ball around and you're talking about, playing on a skateboard and things like that. Like, have you thought about how that might look differently, being a dad in a wheelchair?

Dan: Yeah I think to a large degree, we're just rolling with things as and when they come up. Uh. But yeah, we do think about that, and I think Sam takes on a lot more than she would if I was able-bodied. Loading the car it's always her and I'm jumping in the front putting my wheelchair in, and she loads everything in the back, the pram and gets Etta in and that sort of stuff. When we go for walks, if Etta's in the pram it's Sam pushing her. And then looking to the future, yeah, I think there's going to be some hard times, I think I want to see, I want her to see me as someone who is very active and this last year I've been very sedentary. So I've just really tried to turn a corner on that, I think, between Etta and work. And that is just

basically anything like the gym when out the door. And before that obviously work wasn't sport was such a big part of my life, wheelchair rugby then I got into track racing. So I'm really keen to bring that back in so that she can see me in that active role of getting back into a bit of wheelchair rugby, I mean, just locally and socially.

Dan: I'm not sure how it's going to play out. I'll be in there as much as I can, at the moment it's rolling and throwing a red ball up and down the hallway which she loves.

Becs: As wheelchair-users, we sometimes get a lot of intrusive questions from random strangers. Um, and have you had any of those kind of comments made while you've been out in public with Sam and Etta?

Dan: Yep constantly. Sam notices that more than me, I had 20 odd years of it before they were around. You know, we call them the backslappers, the people that say good for you for being out and all that. It's not always bad. I think there's a lot of people genuinely intrigued. We had that situation in the mall. And we just had a few chores to do at the mall, Etta was, uh, sitting on my lap in this little carrier that we have. And someone came out just genuinely intrigued and lovely about it, like, this is amazing, tell us more and that. And that was a really cool conversation. Yeah. Other times it would be totally patronising and and I get a bit antsy, shut them down pretty quick. Mm constantly is the short answer, it's always there, but I think I try to bring it back to a place where people are genuinely intrigued, if they spin it that way, then it's good.

Olivia: Etta is probably too young to know that, oh, my dad's in a wheelchair. Have you thought about her understanding of that when she gets older?

Dan: Yeah, we have. We have talked about that. I think it's going to be challenging for her at times, I think she'll have to cover some questions and probably some taunts from other kids. We're doing our best to raise a strong, confident woman. Um, and also, I think ultimately she will have more fuller, wider view of the world, because she has a father with a disability.

Becs: Well a big thanks to Dan Buckingham, it's great to hear how he's getting on as a parent who uses a wheelchair.

Olivia: So now let's look at this from another direction. I know a lot of parents of disabled kids go through a grieving process – when they realise life will look different to how they planned. So we wanted to get a parent's side of the story. Which is why we asked Tiana Epati if she'd come into the studio. But before we hear from Tiana - a quick word about our sponsor. Oooh! I've always wanted to say that...

[Soft guitar music starts]

Olivia: When we cast our minds back to primary school, we can't help but think of the dreaded 'school run'. I'll always remember the busyness of a school day morning with parents running around getting my brother and I ready - helping us get dressed, packing our lunch boxes, making sure my physio appointments were booked in and that I had my togs for swimming lessons after school - and all before 8.30 in the morning. Then, we'd get to the school gate, ready to take on the day. With EveryHuman, the morning rush is now a little bit easier with their adaptive clothing, footwear and lifestyle products. Instead of fighting to get shoes on over orthotics, wrangling into hard to maneuver buttons, or fighting through those dreaded inaccessible morning tasks, getting ready can now be a little bit easier. The kids in your life will feel more independent and confident, and with EveryHuman's lifestyle products, you'll be better equipped to win your day and out the door in no time. We remember as children wanting to do parts of the morning routine independently and while we've learnt that asking for help is how you gain independence, EveryHuman helps disabled people do the

things they can in the morning with their universally designed options. We love that, and the young people in your life might too! Shop the range at EveryHuman.com.au

[Soft guitar music ends]

Olivia: Tiana Epati is a mother and a lawyer. She's also the president of the New Zealand Law Society. She lives on the East Coast in Gisborne with her family. She has three kids; her eldest son Umuariki is 13 and has autism.

Becs: Not long after Umuariki was diagnosed, someone handed Tiana a copy of a short essay that's become kinda famous among parents of disabled kids. It's called *Welcome to Holland*, and it has a really interesting perspective on what it's like raising a child with a disability. Getting a copy of *Welcome to Holland* is almost like part of the initiation process.

Olivia: So we'll get to Holland later on in the interview, but first – we asked Tiana about her son.

Tiana: Umuariki is my eldest child. I've got three. Um, he is, I suppose, what you call classically autistic. He's not high functioning. He's someone who has a lot of, um, challenges in his communication with neurotypical people, um, and he yeah, he is obviously a big part of my life, but not something that I've um, openly spoken about.

Olivia: Back in the early days, you know, you're talking about when you when he first got diagnosed, well, what's that process of being diagnosed with autism?

Tiana: It can be very different for different people. For me, um, I think it was actually quite good because I'm a lawyer, because I demanded answers and when I didn't get them, I kept going. Um, and when they said things like, well, there's a six to nine month waiting list, I have to see the child development team. I didn't accept that and wrote a letter and we were seen within six weeks. Um, and I just kept pushing for them to have a look at him and they put a team together, um, so it was relatively quick from the moment I started asking questions about why he wasn't speaking and why he wasn't like other children to the point where we got a unanimous positive diagnosis from a team. Um, that was I mean, that was within a year, whereas other parents I know will go for years and years and years, and it really will be the result of a teacher at school saying, look this, you've got to do something. But I think for a lot of parents, if they get you know, they get told, oh, well, you going to have to wait or do this.

Olivia: Was there anything that you needed to particularly campaign for or, you know, your parents would like to advocate, Becs?

Becs: I can remember, um, because I was a swimmer and I got to a point in my swimming, where going to swim schools wasn't enough. I wanted to pursue competitive swimming and to do that to the ability that I wanted to I needed to join a swim club. So my mum just called up and arranged, um, an assessment but didn't tell them about my disability. And she took me along and the coach that was doing the assessment didn't want to let me in the pool. And mum just went over there and she just talked to him for a while. I could see you getting quite frustrated about it. And I think she was just kind of pleading with him to be like, just watch her swim, like she can swim. She's capable of joining this club. And I think in the end, he gave in and he let me swim. But, you know, that was kind of a memory that I have of actually seeing my mom go into bat for me. Um, and that was the start of a very long and successful swimming career for me.

Tiana: Yeah, I enrolled Umuariki in swimming lessons for children who are Deaf because they didn't have any classes for autistic children. They kept saying to me, oh, we don't we don't do anything for children on the spectrum. But I thought, well, all he's lacking is

language. So we'll just enroll him in this class. I was like, oh, it'll work, it'll be fine. And I fronted up with him and, you know, go for it. He can swim. He's a fantastic swimmer. He can swim out in the surf and you can surf uh.

Becs: Amazing.

[uplifting music begins]

Becs: Recently Tiana made a post on Instagram that both Olivia and I found kind of amazing. In fact, this post was part of the reason we asked her on the show in the first place. There's a photo: it's of Umuariki standing in a field and patting a white horse. Umuariki is wearing a helmet and has the biggest smile on his face. And then there's the text that goes with it.

Olivia: Um, do you mind reading what you wrote on Instagram? I've got it written here

Tiana: Sure yeah, yeah, yeah. I still remember the day a team of child development experts told me my son was autistic and took a long time to process the grief, which comes with knowing life is going to be very different from what I had imagined. And yes, it has been very different and difficult at times. But then a day like today comes when his beloved Whangara School wraps nothing but aroha and acceptance around him. Days like today fill me with so much hope. For him. For all of us.

[uplifting music ends]

Tiana [voice breaks]: I did warn you, this is a new subject, I suppose.

Tiana: It's really important to understand that the grief isn't about your child, it's about the world. And I think when you're a parent, all you do is worry about your children. That's all you do. Um, and we know that your child will have challenges that other children won't. That just makes you worry even more so. So it's not about the child. It's not about you. It's about how hard the world can be out there. And that's what you grieve about.

Olivia: I had a similar conversation with my mom just this week, and I was asking her like, was there like a particular point in my life where you thought, "oh, yeah, Olivia's life is going to be all good", she was saying she described it like a puzzle. How, you know, it was we don't know what my child with a disabilities life is going to look like, but OK, Olivia graduated high school. That's a piece of the puzzle. Yeah. Olivia learned to drive. She can drive a car independently. That's another piece of the puzzle. When I went abroad and traveled by myself, that was like another piece of the puzzle on, you know, how success can look like with a disability.

Olivia: And I guess comparing like, how did you get to that point of acceptance and things like that?

Tiana: I don't there was there was no point at which I woke up and thought, yes, no, I've accepted this. I think it was a gradual, it almost came over in waves. If that makes sense, so some days it would be, um, really challenging and you lost hope and other days you would there'd be a few more words that he would say or he'd be able to do something. All I know is that it took a quite a long time, I'd say probably years. And then and then you just I think there was a it must have been the way I handled someone's reaction to him, where I was, um, I didn't get upset. I didn't fall apart. I just was quite upfront and said, well, he's autistic and and then moved on and didn't hang onto it. And that's how I knew that. That there had been a change or a shift in my thinking. I just stopped caring about other people's reaction when they stared, I just didn't bother me anymore. I was able to move on.

Olivia: And in those earlier days, how did you used to react to those types of situations where people would stare or say, comments.

Tiana: Terribly upset, terribly. There was someone complaining in the Koru lounge because he was stimming and making his noises. So stimming is essentially a way of coping with the anxiety that a person with autism spectrum disorder will have because the world doesn't make any sense. And so it's like a can be rocking back and forth, that's a very common one for him. He jumps up and down and he makes a noise [*makes 'eeeeee' noise*] and that's that's a way of calming himself down when, when there's a lot going on because the world is built very different from his sensory abilities, he'll have to do that everyday to cope with the anxiety. He was making his noises and they were sort of saying, oh, I you know, "I'm trying to work here" and he said it like that. And instead of just being quite resilient and up front with the person, I started to cry and left. My husband didn't and he sort of stayed and wanted to give him a hiding, but it was when those sorts of things didn't get to me as much that I knew that sort of was a shift inside of me.

Olivia: I think it is interesting when you do grow up with a disability, success can look a bit different. It's not, you know, and like I never hit those regular milestones of taking my first steps. I still haven't guys [*laughs*] way behind on that side of things. But, um, but yeah, like, I was drawing this kind of puzzle analogy before. Like, it's interesting when you do, I think, like, my mom is also my one of my biggest advocates. And when she has conversations with other people about. About about me, she almost has to- I mean, she's not a lawyer, but even she will defend me. She'll be like, Oh OK, you might feel sorry for me, but they'll say, but mum will be oh, you know, she can actually drive. And her friends her age or who are older will be so surprised, like, oh well the eyes widened and so even for me, like, you know, success is not being able you know, it's not necessarily hitting those regular milestones, but when you still hit them, um, like you're saying, everyone else celebrates with you.

Tiana: They're better because it's about it's about starting point and the realities of the world. The world isn't built for you. It isn't built for my son. It's built for neurotypical, able-bodied, white men mainly. [*laughing*]

Becs: Just an FYI - we're laughing at the one neurotypical, able-bodied, white man in the room here, that's Adam Dudding, Stuff's podcast director.

Tiana: I mean, we know it's just about starting point, and when your starting point is different, it hits different when you do things.

Olivia: What could be better done in terms of design to help your son thrive

Tiana: Probably better understanding around autistic spectrum disorder. The number of times that people say, oh, but he must have this really he must be able to play concertos and he's a savant or Rain Man [*laughs*] can I take him to the casino, and it's like, wow, no, he doesn't have any of these things. So I've just got one of those really average autistic children, which I know there's this idea that somehow they have to meet these some other worldly thing. Um, yeah. Just a fundamental understanding that it's just different. Early in the journey, I had a lot of parents saying, oh, but, you know, I'm really grateful for my child because they make me a better person. I see the world differently, you know, and that is true. And that is a benefit. But it's not about you. They're not they're not there to enlighten you. They're there to be in the world as their own person and your job as a parent is to guide them and equip them to be in the world without you. So it's all about your child. It's not about your journey and what you've learned, although you do learn a lot, this is about them. The grief can overtake parents and that's how they deal with it, because I've become this really amazing person with this new diverse you know, world view but it's not about you, it's about your children. Put it this way, I think if he- because he loves stacking things, if he got a job at

Countdown, lining up all the bread and the soaps, that would just be wonderful because I know how much he'd loved that. It is the greatest joy ever that he finds something that he loves. It's not about what I want for him. What about my expectations? It's about, as I said, that is my fundamental job as parents for any parent, your children will one day be in the world without you. And so your job is to make sure that they can be that and be happy.

Becs: I love that. It's so beautiful. Yeah, and I think that that is I you know, I think the world would be a much better place if everyone had that philosophy.

[Warm guitar music begins]

Tiana: In Samoa, community and family is everything. Absolutely everything it it supersedes and goes beyond the individual every time. And so when you have someone who is different, who has a disability, who is you know, transgender or all that is built in to the way that we operate and look after each other. They don't have any, uh, particular understanding around autistic spectrum disorder, but that's kind of irrelevant.

[Warm guitar music ends]

Tiana: I remember telling some of my Samoan relatives quite tearfully that Umuariki was autistic and my Samoan aunty went, oh yeah? Still the same child though yeah? Yeah, yeah, but he's still the same child as yesterday. All that's happened is that we're going to get some money, yeah? [laughs] But darling, don't worry. He's beautiful. Oh, I went to church today, saw the other kids and they're yuck. So just very, you know, direct and it's just it's fine. And you look after each other, you know, there are no rest homes in Samoa and no special schools in Samoa, and of that, you look you you always look after your family. Um, so. Yeah, it is different, and that's part of the reason why I love Gisborne so much is because the demographic is quite different. Fifty percent of the population is Māori, um, and my son, being Ngāti Porou that are affiliating to Ngāti kōhi, which is Whangara school, all the children look at each other as whanau, you look after whanau, you look after each other. So manakitanga, aroha, those are those are foundational principles of this small country school. they're struggling with him, leaving this to go. It's not going to it's not going to be pretty. The grief is already sitting in. Letting go is always hard for a parent. Yeah, but at times it becomes harder when you fret about, I don't think the world is going to be kind enough to my baby.

[light, fun guitar music starts]

Tiana: I can remember riding on the school bus with him because I was determined that he was going to ride the bus. But then also at the same time, I couldn't let go. So I rode on the bus next to him and then in a seat behind him and then at the back, while he was at the front, three weeks.

Olivia: Spying in the background.

Tiana: Whereas with my daughter, I took her to the bus stop and said, oh, maybe we'll get on the bus. And she's like nah. I saw what you did with Umuariki. I'm not having that catch you later.

[light, fun guitar music ends]

Olivia: In our chats with Tiana before she came into the studio, we got talking about a famous essay that gets passed around between parents of children with disabilities. It's called Welcome to Holland and it was written by an American woman, Emily Pearl Kingsley, in 1987: she's the mother of a child with Down syndrome. Now, not everyone likes this story. But Tiana found it really helpful, and we wanted to ask her about that. It's kinda hard to "get it" without hearing it, so I just read the whole thing out.

Olivia: I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

[uplifting electric guitar music starts]

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills.... and Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

[uplifting electric guitar music ends]

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss. But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Olivia: Oh, I think we're all a little bit teary now. So why did that story resonate so much with you Tiana?

Tiana [voice breaks]: I think it just captures it. Absolutely, it's the loss of a dream, I think that in some ways you're being sold. But it's hopeful because it tells you how you look. Yeah, it's going to be different and you will grieve this idea you had about your life, but don't dwell on it because, yeah, you've got clogs and cannabis [laughs] and there are lots of things to learn. But at it, yeah, you're thinking everyone else is going to Italy and buying Prada and having this fabulous looking Instagram life. And I'm in Holland and it wasn't wasn't what I thought or pictured. It's it's light that captures the realness of how it feels. It gives you hope, because that saved me in that first year.

Beccs: Well I think when it, when it's so ingrained in our society that everything's supposed to be like living in Italy, it's really hard to get used to living in Holland.

Tiana: Yeah and at some point you gotta be like, I am not going to be Italian. I'm going to be-

Olivia: Dutch [laughter]

Tiana: I was like Holland-ish? [laughs] I'm gonna be Holland-ish, jeeze what an excellent lawyer I am. [laughs]

Olivia: For people who don't understand autism or how to act around disability, I know I've had some awkward interactions - what would you say to them?

Tiana: Don't stare. That's the one thing if you're not prepared to help in a situation where a child is having a meltdown or a parent is struggling, don't just stand there and stare because that's felt, um. Don't judge because you have no idea what's going on for that child or that parent. Um, and just keep, if you're not prepared to help, then keep moving. I think the most helpful thing that a stranger did for me was my son was having a meltdown in an airport and I was also holding my baby daughter and this lady stepped in and said can I how can I help? You want me to hold your baby while you manage him? Is there something I can do? Can I get him a drink from the vending machine? And so she was she was willing to actually physically step in and help me. What can I do with my best placed and everybody else in that particular area just, you know, didn't stare, if they did, they looked in a really compassionate way like OK, we can work this out together. And it's as simple as that I think.

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

Olivia: And that's it! Thanks for listening to the very first episode of What's Wrong With You?

Becs: There were so many great pearls of wisdom from both Dan and Tiana that I want to take on when I become a parent one day!

Becs: And if you want to watch a seriously cute video of 3-year-old Olivia blowing raspberries at her Dad instead of practising her walking, check out our showpage, www.stuff.co.nz/whatswrongwithyou - we've posted a little clip.

Olivia: In the next episode...

Air hostess: Ensure your seatbelt is fastened

Olivia: We've off on a bit of an adventure

Olivia: Ah we need to find a lift

[airplane noise]

Olivia: Oh my gosh, it's huge. Are you guys going to get into it OK?

Becs: Yeah

Grace: Why has that man got Carlberg at 10 o'clock in the morning?

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

Olivia: This podcast was made with the support of New Zealand on Air
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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