

00:00:06:24 - 00:00:37:24

Bernard Namok

Hi and welcome to Yarning Disability, the FPDN Podcast, I'm your host, Bernard Namok Junior. I'm a proud, St Paul, Badu and Erubean man from Torres Strait. And I'm also the son of the designer of the Torres Strait Islander flag. Bernard Namok senior and an advocate for the First Peoples Disability Network. Join me now on Yarning Disability as we showcase First Nations people living with a disability, as well as their families and carers and other industry professionals.

00:00:44:15 - 00:01:13:17

Carly Wallace

Aboriginal and Torres Strait Islander people are warned that the following podcast may contain the voices and names of people who are deceased. The First Peoples Disability Network and the producers of this podcast recognize the traditional custodians of the land on which this podcast is recorded. They pay respect to the Aboriginal and Torres Strait Islander elders past, present and the future leaders of tomorrow.

00:01:13:17 - 00:01:47:00

Carly Wallace

FPDN would like to acknowledge our founding elders and their lasting legacy, Uncle Lester Bostock and Aunty Gayle Rankin and acknowledge all first peoples living with a disability. Hi and welcome to another episode of Yarning Disability. I'm Carly Wallace. I'm the National Training and engagement manager at FPDN and a regular contributor to this podcast. FPDN as an organization supports the cultural model of disability and inclusion, so what does that mean exactly?

00:01:47:11 - 00:02:13:24

Carly Wallace

Well, it means that First Nations people with disability are participating meaningfully in their families, in their communities, and in their culture. To quote Dr. Scott Avery from the publication, "Culture is inclusion and narrative of Aboriginal and Torres Strait Islander people with disability". It may take ten, 20 or even 100 years to understand the phenomena of culture using the language of Western science.

00:02:14:04 - 00:02:44:03

Carly Wallace

It may also be that we are never meant to know. But in looking at the current state of the evidence, connecting people with their first peoples culture is most likely to rapidly improve their quality of life. On today's episode of Yarning Disability, we meet Noongar and Wiradjuri man Clinton Bennell, who has innately lived the very concept of culture is inclusion, as a brother of someone with an intellectual disability and the father of a little boy named Theo living with multiple disabilities.

00:02:44:22 - 00:03:10:08

Clinton Bennell

So my name is Clinton Bennell, I'm a Noongar and Wiradjuri man I live in Adelaide, which is Kurna country. So I've got two boys. My eldest is Duane is six tomorrow and my youngest, Theo, he's, he's, I'm going to

say 18, 19 months now. And he was born with hearing loss. We're still looking at the severity of that loss, but we're looking at it's looking like that the current testing is like moderate to severe hearing loss.

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Clinton Bennell

So he's got hearing aids at the moment and we've just found out through DNA testing that he's got a thing called Noonan syndrome, which is developmental delays and things like that. It's multiple different, a whole bunch of signs and symptoms that have affected him.

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Carly Wallace

Yeah, right. I've personally never heard of it before and probably like a lot of our other mob wouldn't probably know about it either. Like what I guess are some of the signs and stuff of that disability.

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Clinton Bennell

Yeah. So I'm like you said, like not a lot of our mob have heard of it. I haven't heard of it until we got a phone call recently. So we've got an appointment to go see the specialist and now discuss what what it actually means. But basically some of the some of the signs, he's actually quite small for his size.

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Clinton Bennell

So he's even though he's 18 months, he's still not walking by himself, his face. There's some development things with his face. So it's more squashed and more more flat than what a usual. What was considered normal I guess a face should look like. So those are some of the physical tells but there's some developmental delays as well. So he's not speaking at the level he should be as well.

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Clinton Bennell

So I think that with the mixture of his hearing loss has put him back a little bit, but he's still a happy and thriving boy for sure.

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Carly Wallace

So, like, how did you obviously, besides the physical signs that you just spoke of, like how I guess, did you get to the point where you're like, Oh, my little fella might be a little bit different and I'll have to maybe getting checked out.

00:04:47:06 - 00:05:15:08

Clinton Bennell

Mm Yeah. So definitely from when he was born I did the hearing test in the hospital was really good. They identified in the early stages. They definitely failed his right ear hearing test, so which required more follow up. And as as he grew, the more testing they did, they definitely found out that, um you know he was hearing impaired. So we've been on a journey of discovering how much that's going to be.

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Clinton Bennell

So it's a progressive hearing loss. What are the supports? Because early on they were talking about Cochlear implant. So it's kind of just been a rollercoaster of emotions. How severe is it? And you know, What is it going to impact in terms of his his life and what, you know, what are the outcomes and what what are his needs going to be going forward really in terms of the.

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Clinton Bennell

Noonan syndrome, it's really new. So we knew he was small, but his mum's small as well. So we just kind of originally thought maybe it's just he's taking up after her her size, but it was just kind of because they did the DNA testing for his hearing loss, they were able to find that and the other contributing factors that once we were told that was what what it was, it kind of like just it was like a bit of relief, you know, in terms of we found and finally found something that all it all seemed like all these random things were happening to him.

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Clinton Bennell

And once we got that diagnosis, the first thing you know, the worst thing and best thing, jump on Google, see what it's all about and kind of just made sense for us and was like, well, you know, this kind of places him and you can kind of see a way forward if that makes sense.

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Carly Wallace

Yeah, a lot of people, you know, I am we don't always see disability unless it's a physical disability. You know, we're very inclusive. Hey, you know, we just take our mob for who they are and how they come, I guess. So to have a label or or diagnosis sometimes can be stigmatizing. Did you feel any of that? Like you said, it was a relief, but did you feel any kind of stigmatization from that?

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Clinton Bennell

No, not to be honest. Not really, because I have a brother with an intellectual disability. So disability for me is just normalized in my life and my family. So I don't get caught up on labels of disability impairments, whatever it is. It's just that's like you said, that's just the individual and that's just who they are and that's whether it's considered a strength or weakness.

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Clinton Bennell

We don't see that. You know, that's just their identity for me. No, it wasn't really. Even when we were told early stages that our kid would have hearing loss. I kind of just thought, I don't want to pity him, you know, because that's just not what I got told growing up, you know, it was just about, okay, well, how do I support him?

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Clinton Bennell

What does he need? And just to meet the need. And, you know, he's not going to he's not feeling sorry for himself now. So why am I going to put that on him? So that was my sort of mindset going for it.

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Carly Wallace

Yeah, I love that. And you said that, you know, with your brother as well, like tell me about growing up with your brother with an intellectual disability you talked about, you know, it's very normalized for you. How was it normalized? Like, tell me about that.

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Clinton Bennell

Yeah, I think to kind of build on what you was talking about, you know, my dad didn't treat him any different for good and for bad you know, I definitely feel like he probably could have needed some more support. But he was treated just like I've got two other three other sisters, I should say, and he wasn't treated any different.

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Clinton Bennell

And, you know, the expectations that he would he would contribute to the family because his disability has he's got that mind of a teenager. He does have some independence. He's capable of going out and go to the movies and all that kind of stuff. But in terms of living independently, he doesn't have that capacity. So growing up with that, you know, he was 30 when I was when I was born.

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Clinton Bennell

So there was it was almost like a relationship of, yes, he's my brother. But, you know, unofficially, he's kind of like my second dad as well. So it was kind of like a beautiful relationship. And it just as we've grown, our relationships changed as well. So as I'm maturing and grow up, you know, in my maturing, nah haha, I'm maturing, you know, I've got more of a protective factor over him.

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Clinton Bennell

And so it's kind of like I understand his brain as a child, like in as a child or adolescence. So I've got a very protective and almost it's coming 360 where I'm his protector now where whereas he was mine, you know, so it was beautiful being his best friend, being almost like a son to him and then growing up and then now it's is reversing.

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Clinton Bennell

So it's it's been beautiful.

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Carly Wallace

Do you think that's like culture plays a part in that as well like that reversed role? Like as we, you know, we have those different roles in our community as we get older and you know, there's elders and there's there's senior women and men and things. And then I guess with disability disability in our family members, that might look a little bit different, right?

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Clinton Bennell

Mm. Yeah, I love that because I think what a lot of people probably I'm going to say, you know, mainstream media and mainstream Australia, they don't realize how much discipline and responsibility we as Aboriginal people have. And when we put it in that family context, absolutely, because my dad's passed now. So it's my responsibility to look after my older brother because he doesn't have capacity.

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Clinton Bennell

And you know, my mum, my mum looks after him on a day to day basis. But being the only male in the family, it's my responsibility to to have those hard, tough conversations with him and also protect him as well. So I think to some that up it's kind of like you see the need and you meet the need and that's that's just how we how we are with our families, our communities and and our culture as well.

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Carly Wallace

Yeah. Like how does culture, I guess play a role in your family unit with your brother and now now your son? How do you then, you know, you said you're the you're basically the man now in the family. How does that play a role? I guess culture.

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Clinton Bennell

It's a little bit hard for for my brother because he's his communication is, you know, it's it's not a you know, he couldn't have the conversation we're having now. I wouldn't say he's non-verbal, but he he can't pronounce some words and he has trouble communicating. So I communicate with him quite well because I've grown up with it. But and I'm a little bit off topic here, but I just want to share this because when I invite my friends over from school and he try to talk to them, they couldn't understand him, you know, whereas I was just like picking it up.

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Clinton Bennell

I knew what he wanted. I knew what his communicating and that kind of shocked me. That was kind of first time I sort of noticed that there was a little bit of a change or a little bit of difference. And I thought, why can't you understand my brother? He's telling you this this and this. But to get back to culture, I think it places him, culture places him, and it comes in his identity.

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Clinton Bennell

So, you know, we get stigma of like, I'm fair skinned, my brother's fair skinned as well, but we've got obviously Aboriginal speeches and his nose is quite wide and he's very proud of that because he said that's his Noongar nose you know. So he's got his little he's got his little bits where he holds on to and I think his culture and identity.

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Clinton Bennell

So definitely him being a Noongar man is it places him and it keeps him grounded as to who he is and where he belongs and definitely a key member of our family for sure.

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Carly Wallace

Yeah, I love that. Does he go to any like men's groups or anything like that? It's kind of taken part in any of that stuff over the years.

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Clinton Bennell

Nah, I see. My brother is really independent and he he doesn't like those kind of things. And I think I'm just I'm kind of speaking for him, but I don't think he enjoys those activities, whereas he'll go out and he'll go to the movies. Like he's got a routine, he's very, very structured. He'll catch the bus, he'll go to the shopping center, he'll go to the movies, watch his movies, he'll have his lunch, and then he'll come home.

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Clinton Bennell

And that's his routine. You know, he's got it down pat and he's just very independent. And I think that goes back to his upbringing, where I think a lot of people smothered him for support, whereas he's like, Nah, I'm independent, I can look after myself and and we appreciate that. And we I'm very proud that he can do that.

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Clinton Bennell

Sure.

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Carly Wallace

With you, your little fulla you talk about hearing loss. So that might mean a whole bunch of changes for your family, like maybe Auslan have. You guys have to think about this type of new approach I guess to your world and his

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Clinton Bennell

Definitely so we're we're involved with this program. I can't remember the name of it and they're going to kill me. But they, they come out and it really good. They come out to the house and they've got these, these cards made up for us and they've got the visual of how to do the signs for Auslan. But they come out and they do some speech work with him as well.

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Clinton Bennell

So making sounds depending on the toys and things like that. So that's really effective for him. He's really engaged in that. But yeah, absolutely. My, my mum, this is what I mean about my family particularly being exposed to disability and hearing loss in particular because my mum knows some of that from her cousin who grew up, they grew up together so she's kind of re learning how to communicate with Auslan as a little bit different I think from the eastern states to South Australia where I am.

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Clinton Bennell

So we're just doing it as one big family, you know, we're just trying to learn really basic communication and it's good to see my son Theo if I signed him something or something simple like Thank you, heâ€™ll understand what it means, and or we've got our own little, you know, blackfulla sign language where like, you know, what do you want?

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Clinton Bennell

You know? Or, you know, you want food, and we'll just point to our mouth, So we've got our own communication strategies but definitely need to learn that Auslan and you know, that's going to be a really big part of his life for sure.

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Carly Wallace

What's your brother do now? Does he work or What's he up to?

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Clinton Bennell

Nah he's at home. So my brother's nearly 60. He's old fulla but he lives with my mum and yeah, he just, he just kind of does his thing every day. So they've got a routine for him. Structured day. We do some, some housework, do some cleaning. He's got his dogs, he's got two little tiny little shitzus.

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Clinton Bennell

that he loves to death and he looks after them. And on the weekends, Saturday comes, he's out. But no matter what else is on, it could be my birthday. He'll be out in that movie, he donâ€™t care

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Carly Wallace

More social than me by the sounds of it and he's got two dogs that's a full time job I know about that. So yeah. Yeah, it's own job in itself. You know, looking back, you were saying that it was very normalised in your house. He wasn't treated any differently. Your brother, we all got we all got, you know, cousins, you know, mucking around and, you know, having boxing fights

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Carly Wallace

with each other, we didn't treat anyone any differently.

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Clinton Bennell

right? thatâ€™s right

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Carly Wallace

That was was it.

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Clinton Bennell

He roughed me up too, like growing up because I played basketball, I played rugby league but then played basketball and he would rough me up and we'd be playing and bumping into me. And yeah, no mercy is just like, that's it.

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Carly Wallace

Everyone is treated fairly then hey

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Clinton Bennell

That's right. He definitely could do with more what I would guess would be like a support worker or a residential care support worker. If you wanted to pursue that independent living, that would have been great for him at a younger age. What we're finding now, and through my experience working in health, is that he needs definitely more care coordination for himself.

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Clinton Bennell

So as he's gotten older, like most blackfullas we get diabetes, so he's got diabetes. And just managing that and explaining that to him has been a difficult process. So just those small things in terms of what everyday people could or not everyday, but you know, what would be can see considered an everyday task monitoring your blood sugar levels.

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Clinton Bennell

That's challenging for my brother and not understanding the importance of managing and maintaining that. So what we're looking at now is some support for his health needs and just that continued maintenance of his health needs as well. So I guess for me now, because when my dad was alive, I don't know if it was a pride thing or he just didn't know what to do.

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Clinton Bennell

He didn't get a lot of that support outside of you know, he did go to a special school and had a special class, but outside of that, there was no real other support sfor him. And I think he definitely could have, you know, if he grew up in today's day and age, he definitely be more supportive.

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Carly Wallace

Yeah, I think that's that thing we talk about at FPDN we talk about culture of inclusion, so we don't want to treat our mob any differently. We want them to to grow up. And we do have that pride of like, no, I can handle it, you know, especially our old people and our mums and dads like yeah, they're juggling so many things, you know, large families trying to feed the kids every week, like having a disability.

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Carly Wallace

It's like you're just another person in the family that we're catering for and we don't want to, you know, make a big fuss. Hey, like that's a big thing, we just get on with our world. but unfortunately, I think a part of that is we do like forget that you know, we could probably get some help, or my young fella might need a few extra things to help him with his care.

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Carly Wallace

So, yeah, that's that's that's understandable. I understand why your dad was coming from there, but. Yeah, so, like, does that now with you? Does that make you as a father of a young fulla with the disability, the are like, do you think about supports for him and like what you might need and want in place for him?

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Clinton Bennell

Yeah, definitely. So already we're looking at, you know, what school is he going to attend once he's of age started to plan that that process education map in terms of what primary school will he go to is it going to be continued in high school in terms of the hearing support? So we've got a few picked out in Adelaide definitely.

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Clinton Bennell

And we know people who have kids with hearing loss as well. So, you know, it's good to link in with them, you know, kind of get their experience from from the schools that they've taken their kids to as well. So I mean, you know what communities are like too tight knit. So we all we yarn, we all talk.

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Clinton Bennell

So it's good to get that firsthand experience as well.

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Carly Wallace

So and what about barriers so far that you've, I guess, had to come up against, whether it's in the education system, in health, in these big systems that I guess put the barriers in place from the experience of any of those. So far.

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Clinton Bennell

What I've noticed is there's a lot of early detection and then there's steps in place for that as well. So I mean, I can't really comment for barriers other than what's been, I guess, a little bit of a criticism with one of the the speech pathologist that we're working with is just how to engage with with Aboriginal families and Aboriginal people, whether they're doing that best.

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Clinton Bennell

You know, it's not our fault that they're not that is not meeting their expectations of how that how they should grow or how he should go, because it puts a lot of pressure on us. And even though we're doing all the right things, it feels like it's not good enough, you know? And that's just in terms of a being a culturally safe or culturally responsive service that didn't sit well with us.

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Clinton Bennell

And, you know, a lot of things, like when we'd go to see a dietician, they'd think that we're not feeding him or things like that. So it's always a negative. And we, we felt really defensive taking him to these appointments. So that was probably the only negative thing. But once we got that diagnosis of this Noonan syndrome, it all made sense.

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Carly Wallace

what are your hopes for firstly, your brother and you know, heâ€™s in retirement kicking back at the moment. Like how do you see you two and your relationship for the next few years?

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Clinton Bennell

I wanted to snap out of his sooky grumpy moods. haha

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Carly Wallace

But that just comes from getting older right? thatâ€™s everyone

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Clinton Bennell

Yeah, I love him because he's got no filter and he just tells you straight how it is. So if he's in a mood everyone knows about it. So I just, I just want him to keep, continue being, being him. That's that's what's given me joy. And he doesn't apologize for nothing. He's just he's who he is, regardless.

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Clinton Bennell

And I love that about him. What's really been special for me is to see how he's with my children now, seeing a lot of how he was with me to my children. That's that's been really beautiful to watch because it's a lot

of him gone back to doing the things that he did with me. So I just think it's yeah, it's great.

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Clinton Bennell

It's kind of crazy actually to see him be the same person, like he's just the same person.

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Carly Wallace

That's lovely. And what about Theo?

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Clinton Bennell

I just want Theo to be the best version of himself. And that doesn't mean he has to fit into whatever expectations or whatever standards. As long as I agree him up to be a confident and somebody who can regulate himself. And, you know, you experience highs, experience lows, but still be confident who he is. I'll be happy with that.

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Clinton Bennell

I don't have any I don't want him to live up to anything. I just want him to be himself.

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Carly Wallace

So no any messages for any parents that may have children with disability for the first time? What advice would you give them?

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Clinton Bennell

Whatever the situation is, you just got to own that and then accept it because it's not going to change. You got to put that child first. You've got to put your child first and see what are their needs and then just put everything you can in place to support them. And I think one of the big things that it came from a movie like this, so like cliché but I was watching I don't know if you seen Creed but that boxing one and his daughter's got hearing loss and then Rockyâ€™s is like are you feeling sorry for her because she's not feeling sorry for herself.

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Clinton Bennell

And that really hit me. And I was thinking that's kind of what's kept me on track this whole time. And she's hearing that because my son's not feeling sorry for himself and any child that disability doesn't feel sorry for themselves because it's normal. That's their normal. You know, we don't need to put that onto them as well and society does need to put that on to him so I think if we just grow up this next generation to be inclusive and supportive, we get rid of that stigma.

00:23:52:09 - 00:24:13:00

Carly Wallace

That was Clinton, Bennell and Noongar and Wiradjuri man sharing his story as a brother and a father of family members living with disabilities. Thanks for listening to Yarning Disability, FPDN would like to thank you for coming on this journey. As each week we hear from First Peoples living with a disability and shine a light on the issues they are facing.

00:24:13:14 - 00:24:49:23

Carly Wallace

If there's anything you heard in today's episode that raises concerns for you, there is help available. You can contact 13YARN on 13 92 76 or beyondblue on 1300 22 46 36 or lifeline on 13 11 14. Follow FPDN on our social media accounts to stay up to date with future episodes and information. You can also visit our website at www.fpdn.org.au