

00:00:06:24 - 00:00:38:04

Bernard Namok

Hi, and welcome to 'Yarning Disability', THE FPDN Podcast. I'm your host, Bernard Namok jrn. I'm a proud St Paul, Badu and Eurubian Man from the Torres Strait. And I'm also the son of the designer of the Torres Strait Islander Flag, Bernard Namok Snr, and an Advocate for the First Peoples Disability Network. Join me now on Yarning Disability, as we showcase First Nations peoples living with a disability, as well as their families and carers and other industry professionals.

00:00:43:03 - 00:01:12:05

Carly Wallace

Aboriginal and Torres Strait Islander people. I warn 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.

00:01:12:05 - 00:01:33:24

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. Listeners are advised that the following podcast contains references to suicide.

00:01:33:24 - 00:01:40:18

Yarraka Bayles

And this is the impact bullying has on a nine year old kid that just wants to go to school, get an education, and have fun.

00:01:41:03 - 00:01:45:21

Yarraka Bayles

But every single frickin day something happens.

00:01:45:21 - 00:01:51:07

Yarraka Bayles

Another episode, another bullying, another taunt, another name calling. And I want people to know.

00:01:52:02 - 00:02:26:01

Yarraka Bayles

How much it is hurting us as a family of people to educate their children. The whole anti-bullying isn't the working. And I've got a son that is suicidal almost every single day. And this is the side that I don't choose to share. I choose to keep this private, but we can't do it anymore. We try to be as strong and positive as possible, and I only share the highlights.

00:02:26:01 - 00:02:33:10

Yarraka Bayles

But this is how bullying affects a nine year old kid.

00:02:36:24 - 00:03:02:11

Carly Wallace

The clip you just heard was a snippet of a heartbreaking video that was shared online in 2020. From this week's guests on Yarning, Disability, Yarraka Bayles and her son, Quaden Bayles. I'm Carly Wallace. I'm an advocate at FPDN and a contributor to this podcast. In early 2020, Yarraka posted a video of Quaden on her social media accounts that went viral with millions of views around the world.

00:03:03:05 - 00:03:33:04

Carly Wallace

The video showed Quaden who has achondroplasia, A form of dwarfism expressing his upset over being bullied for his disability at school. The video was shared far and wide, and the Bayles family went on to experience extreme cyberbullying and trolling from strangers online. But they also received immense support nationally from the Aboriginal and Torres Strait Islander community, the wider community from sporting stars and even celebrities who all sent their love to Quaden and his family.

00:03:33:18 - 00:03:57:02

Carly Wallace

In today's episode, we flash forward to 2023 and see how quite in and Yarraka are doing now. I spoke to Yarraka about what it's been like to be a mother of a child with a disability and having to navigate systems like the health system, the education system and others. The Bayles family have lived with immense adversity in the past few years, yet they've been able to draw on their culture and family for strength.

00:03:57:05 - 00:04:05:14

Carly Wallace

And now one of the most recognizable First Nations families in this country and in the disability community. So how old are you now Quaden?

00:04:05:23 - 00:04:09:18

Quaden Bayles

12... if you go to the American news, i'll be 18

00:04:10:02 - 00:04:18:11

Carly Wallace

I know, right? Everyone thought you were this big, grown up person. That was a crazy little lie, wasn't it?

00:04:19:06 - 00:04:20:09

Quaden Bayles

Look at my fingers, they're not even adult fingers.

00:04:22:01 - 00:04:22:11

Yarraka Bayles

inaudible

00:04:22:11 - 00:04:26:21

Carly Wallace

And I don't even listen to all these Internet trolls a bit crazy.

00:04:27:00 - 00:04:28:04

Quaden Bayles
I'm in grade 7

00:04:28:13 - 00:04:33:20

Carly Wallace

You're in grade 7 now hey. And how are you finding high school? First year of high school.

00:04:34:00 - 00:04:41:24

Quaden Bayles

Um it's going good, I'm at a flexi school

00:04:42:09 - 00:04:42:22

Yarraka Bayles

Flexi.

00:04:43:07 - 00:04:50:01

Quaden Bayles

Yeah a flexi school, they take us fishing, they take us to beaches, take us for feeds

00:04:50:07 - 00:04:56:19

Carly Wallace

How cool is that? Is that. That must be a better way to learn hey.?Than just sitting in a classroom all day.

00:04:57:03 - 00:05:02:23

Quaden Bayles

Yeah. Yeah. I can't sit in the classroom all day just staring at the teaching watching what she says.

00:05:02:23 - 00:05:07:14

Carly Wallace

And what what cultural stuff do you like doing? Rather you like fishing. What do you like?

00:05:07:19 - 00:05:09:05

Quaden Bayles

Fishing? Hunting.

00:05:09:11 - 00:05:14:07

Carly Wallace

What kind of fish? And you catch crab yet? Or what? I want some mud crabs. Can you catch me some?

00:05:14:08 - 00:05:31:20

Quaden Bayles

Nah but i was holding a crab yesterday. yeah and as I was holding it, it was moving around and felt all weird

00:05:31:20 - 00:05:41:07

Carly Wallace

Everyone out of FPDN and wants to know and community. What have you been up to because you've been a big superstar on the TV. and on the movies. Tell me about that.

00:05:41:17 - 00:05:49:05

Quaden Bayles

Oh, this got some surprises going on. Mad Max movie coming out next year

00:05:49:10 - 00:05:50:16

Carly Wallace

What was it like filming Mad Max?

00:05:50:23 - 00:06:03:05

Quaden Bayles

It was amazing, like you see all these different things and big big cameras around and producers telling me 'Say this, say that, say this'

00:06:04:05 - 00:06:06:15

Carly Wallace

Yeah. Did you have to learn any lines or anything?

00:06:07:03 - 00:06:07:14

Quaden Bayles

Yeah.

00:06:08:03 - 00:06:13:12

Carly Wallace

Really? Was that hard to do? Because I can't remember now that the really bad memory. How did you do that?

00:06:13:21 - 00:06:16:18

Quaden Bayles

Nah, whats that word mum? I just...

00:06:16:22 - 00:06:21:18

Yarraka Bayles

You have a photographic memory. Yeah

00:06:22:14 - 00:06:34:05

Carly Wallace

You've got a photographic memory. So that means that anything you kind of read or look at, you can just remember straight away. And that's a skill. I wish I had that skill. What's your character's name?

00:06:34:18 - 00:06:35:18

Quaden Bayles

I can't tell

00:06:36:01 - 00:06:45:17

Carly Wallace

Ohhhh you can't tell? Come one, I want the scoop, i wanna know wow. Nah That's deadly. What was it like working with all those different directors and camera people.

00:06:47:14 - 00:06:58:17

Quaden Bayles

Nah they were real nice, taking good care of me., an showing me support and I had my own trailer.

00:06:59:10 - 00:07:10:11

Carly Wallace

You had your own trailer? Yeah, I. What did they bring in the trailer? Good, chocolate, drinks. Did you have my X-Box or PlayStation in there?

00:07:11:01 - 00:07:16:02

Quaden Bayles

I woulda brang one but I couldn't, i woulda been on the play station too much

00:07:16:08 - 00:07:22:05

Carly Wallace

Yeah. See, that's. You wouldn't have been in the concentration mode to be in the movie. You would have been playing game too much.

00:07:22:22 - 00:07:23:09

Quaden Bayles

Yeah.

00:07:23:22 - 00:07:28:10

Carly Wallace

And what other movies have you been in? Movies? I think I've seen you in another movie.

00:07:28:14 - 00:07:33:00

Quaden Bayles

3000 Years of longing. What culture was that mum?

00:07:33:12 - 00:07:35:20

Yarraka Bayles

It was a middle East and it was a Turkish setting.

00:07:36:07 - 00:07:58:05

Quaden Bayles

And I done my little magic trick. And then when did that come out? Last year, right? Yeah last year? Oh, it was dris Elba Elba was in in that movie. I was one of the little little persons with the gold boots and i done a magic trick

00:07:58:15 - 00:08:11:21

Carly Wallace

Yeah, I seen ya and i was like 'ay look there, that looks like Quaden and that I was like 'nah, i swear that was him', I was star struck then, it was good, I loved the movie. It was really awesome. Where did they film that scene with you? Was it here in Australia?

00:08:12:06 - 00:08:18:18

Quaden Bayles

Yeah in Australia, i haven't done any movies out of the country yet, but one day that will happen.

00:08:19:00 - 00:08:24:21

Carly Wallace

Yeah, for sure. That's so deadly. Where do you want to go with your acting? What do you want to do with it?

00:08:25:07 - 00:08:33:08

Quaden Bayles

I just want to be a really good actor in every movie ever in the universe

00:08:33:21 - 00:08:37:16

Carly Wallace

yeah hey every movie in the universe. You might have to write your own movie, make your own.

00:08:38:07 - 00:08:42:15

Quaden Bayles

That's what i wanna do, i think its called a producer

00:08:42:19 - 00:09:00:24

Carly Wallace

How deadly is that? And I seen you been getting around because, you know, a couple of years ago, we all, you know, we had to see you getting bullied. And that was not good, you know, and that was not good for your family and you hey and I remember speaking to you about that. And now you you've how you been going since then after all of that stuff happened.

00:09:01:08 - 00:09:09:24

Quaden Bayles

Better than ever and all the haters can lose their shit and be bored cause they got nothing else to do

00:09:10:16 - 00:09:16:14

Carly Wallace

That's right. You just got a brush em off hey bruss,. You'll always have haters, all of us do hey but you just gotta brush them off.

00:09:17:05 - 00:09:17:16

Quaden Bayles

Yeah.

00:09:18:03 - 00:09:30:10

Carly Wallace

And you know what? I reckon the best. The best weapon to getting back at bullies is, You know what I reckon it is? I reckon it's success when you really deadly and when you're doing really well hey

00:09:30:23 - 00:09:35:14

Quaden Bayles

Just don't let them get you ya, or let them get to your head.

00:09:35:24 - 00:09:44:16

Carly Wallace

How do you deal with fame now because you know everyone kind of knows your face these days like how do you how do you deal with it? Is it a good thing or is it a bad thing? Tell me about that.

00:09:45:03 - 00:10:24:18

Quaden Bayles

Well, to me, I think that's a bit of both because like at the same time, nothing changes, I'm still gonna be the same person who you are, to this day, like everyone wants to be famous. but sometimes when you're famous, you do all these good things, but then you also get death threats, and people calling you names. Like sometimes when i get bored, I play games online and people will be like 'ah you're the quaden, you're that famous kid' or have or have had an installment plan how are you going to primary.

00:10:25:06 - 00:10:51:09

Carly Wallace

Because you guys got a big go fund me and then you ended up giving it and all away didn't you. Yeah. And that, that helped other people and you know that what's, that's what it wasn't about at the end of the day, was about you sharing your story. And I think a lot of young people that might be listening to you now speaking, what would you say to any of them that it that had gone through and getting haters or you know some bullies what would you tell other kids.

00:10:52:08 - 00:11:14:22

Quaden Bayles

Just don't think about it, don't let them get to you, and if they're bullies, Stand up for yourself and don't let them call you names you can't let them get away with that cause it's not good, always use self defence, you don't have to act mad and show off and say ah look at me bra i'm fighting

00:11:15:06 - 00:11:20:17

Carly Wallace

That's it and your mum like how she helped you the last couple of years?

00:11:21:03 - 00:11:23:00

Quaden Bayles

She's helped me all my life really

00:11:23:04 - 00:11:24:18

Carly Wallace

What does mum mean to you?

00:11:25:04 - 00:11:35:10

Quaden Bayles

My world. I got a roof over my head, she puts food on the table for me, she gives me new clothes, she puts shoes on my feet.

00:11:35:12 - 00:11:41:13

Carly Wallace

Yeah. And if you want to tell your mum something, what would you want to tell your mum about being her son?

00:11:42:05 - 00:11:44:10

Yarraka Bayles

What do you want to say to me? What would you want to tell me.

00:11:45:00 - 00:11:45:10

Quaden Bayles

That I love ya

00:11:46:20 - 00:11:57:15

Carly Wallace

That's nice, well I hope you have the best year with school and you acting. I can't wait for Mad Max to come out. That's going to be deadly. We'll keep an eye out for that

00:11:57:15 - 00:11:57:22

Yarraka Bayles

00:11:58:20 - 00:12:03:23

Quaden Bayles

Yeah it's next year, make sure you go to the cinema and get tickets

00:12:04:11 - 00:12:11:07

Carly Wallace

Yeah. What about get me to the premiere. I want to be at the premiere and not. Not want to be in the cinema. Come on, get me on the red carpet, brother.

00:12:11:19 - 00:12:12:08

Quaden Bayles

Yeah.

00:12:14:07 - 00:12:17:19

Carly Wallace

You got to hook ups, you the VIP. You gotta get us all tickets.

00:12:18:09 - 00:12:20:17

Quaden Bayles

Yeah I'm actually VIP

00:12:21:13 - 00:12:33:03

Carly Wallace

Nah, that's awesome. I'm so proud of you. And I know everyone is proud of you. And we like we just so happy to see you happy. And you were such a strong little Aboriginal man, so we love to see it.

00:12:33:17 - 00:12:41:15

Quaden Bayles

Thank you

00:12:41:15 - 00:13:05:19

Yarraka Bayles

I think that systemic racism is so ingrained in the health system now that I have been able to navigate my way through it, I'm now having to help advocate for other families, including families that have had their kids taken. I've had kids know brought back to their families when they were wrongfully taken, like it's just been a nightmare.

00:13:05:19 - 00:13:34:04

Yarraka Bayles

And the fact that, you know, I'm the first generation on my mom's side not to be stolen. So we go back. Five generations of stolen children on mum's side. From New South Wales. And when I got a letter saying that, you know, from child safety with all of these allegations and even just coming to my home when I wasn't there interviewing my twin daughters, like it was just it was very retraumatizing.

00:13:34:04 - 00:13:58:20

Yarraka Bayles

You know, the PTSD, Quaden refuses to go to hospital he will not. So I bust my boonty so that I can afford private health. Otherwise it would just be continuous drama headaches that I'm PTSD and re-traumatizing and so triggering. Just going to try and take him to an appointment because he thinks docs are there waiting to take him.

00:13:59:01 - 00:14:18:24

Yarraka Bayles

So it's just it's horrific, you know, I don't know. I've been a foster carer since I was 19 years old. When my mom passed away, I looked after the kids that were in her care. So, you know, working in partnership with child safety, being a foster carer, kinship care after more than half of my life. Yet we still live in fear of having our kids taken away.

00:14:19:11 - 00:14:41:13

Yarraka Bayles

It's disgusting, you know? And yeah, I'm always just clashing with the health system of child safety with authorities because they just have very little cultural understanding at all, you know, the way that we operate when navigating all of these worlds and it's just, yeah, the discrimination is disgusting.

00:14:42:03 - 00:14:53:16

Carly Wallace

So child safety like take me back so is this when quite in was younger because of his disability, was it linked to his disability, tell me about that.

00:14:54:09 - 00:15:21:04

Yarraka Bayles

Yes. So he was diagnosed at three days old. I was offered no support, nothing at all. Just it was disgusting the way the whole diagnosis, you know, I just the way that we were treated. And it wasn't much different when I had the twins, you know, I was a single 17 year old mother of twins and having both of my pregnancies at the model mothers may very well known it hasn't improved.

00:15:21:04 - 00:15:46:17

Yarraka Bayles

I will give them that. They have been engaging and consulting with cultural capability facilitators. But yeah, it's, it's started when I was 17 I noticed that, ah, my dad made a complaint when he saw how I was treated as a young, vulnerable person back then. That was in 1999. Fast forward to 2023, there's been little improvements, but it's like they take one step forward.

00:15:46:17 - 00:16:06:03

Yarraka Bayles

They were dragged ten steps back and yeah with Quaden, I was really struggling. I wasn't in a good place and there was just no support offered and that's why we started Dwarfism Awareness Australia to be able to, you know, be that support that I needed now that I'm able to pay it forward and help others go through.

00:16:06:03 - 00:16:22:15

Yarraka Bayles

And you know, I regularly we get contacted about people that have just received the diagnosis. So there's still lots of gaps within the health system, within the education system, too many in prison systems. Yeah, I think this country's just got a long way to go.

00:16:22:24 - 00:16:27:16

Carly Wallace

How do you think the Health System views Disability for our mob in our community?

00:16:28:00 - 00:16:53:12

Yarraka Bayles

Well, it's like they already look down on us anyway. And I there's always an exception to the rule. We've had some amazing nurses, doctors and specialists, so it's not, you know, one fits all. I'm not calling them all out, but I've made several complaints and it's like a double edged sword. You know, if you're a minority of a minority, it's extremely hard.

00:16:53:12 - 00:17:17:01

Yarraka Bayles

It's so much more difficult trying to navigate when you already feel and not even behind the weight or off the whole pool table to begin with. You know, I being a young black single mum, then having a child with a disability, you know, it's just it has been the probably the one thing that has caused me the most stress and anxiety out of everything I've gone through in my life.

00:17:17:10 - 00:18:00:22

Yarraka Bayles

You know, overcoming Childhood trauma. DV, Drugs and alcoholism, being homeless, dragging my kids around from state to state. It applies. Then it's something that I really dread. Just going back to the hospital for an appointment. I could just even just get on a letter in the mail. And I hope that they understand the impact that they have on people, especially

with the increasing rates of self-harm and what's going on within our communities and the fact that we're twice as likely to, you know, have a diagnosis and you look at the right, the increasing right and the statistics of, you know, mob with disabilities, yet there's very little support in mainstream.

00:18:01:19 - 00:18:26:23

Yarraka Bayles

And that's what I found most difficult. The fear of the unknown. Never heard the word achondroplasia before. And yet I was left to go home with a newborn baby. It was just. Yeah. I hope no one ever has to go through that again. I know. You know, I'm not. I don't feel sorry for myself. It's not victim mentality at all because it has made me the strong black woman that I am today.

00:18:26:23 - 00:18:54:20

Yarraka Bayles

It has made me the good mum and grandmother and aunty and carer that I am today because I am so bloody strong and resilient for all that I've enjoyed. But to be honest, it nearly killed me. I sank into that deep of a big depression for the first two years of quiet as life, because I just didn't understand, you know, I had people in the medical industry that also didn't have the knowledge to be able to support me.

00:18:54:20 - 00:19:15:02

Yarraka Bayles

So can you imagine having a newborn baby, you know you're supposed to be feeling over the moon and then your world comes crashing down? And I tell you that you got to start having to think about modifications for your housing or and I'm like, I've just given birth what they so they've just Google this information printed out information about achondroplasia.

00:19:15:05 - 00:19:40:00

Yarraka Bayles

I've done that myself. I didn't want to do that. You know, I like I was in denial, shock, all of these rollercoaster brought like just a lot of the rollercoaster ride of emotions every single day. And yeah, I was just yeah. Still upsets me just to even talk about and I just think, man, how did I bloody make it out as well as I have?

00:19:40:08 - 00:20:01:02

Yarraka Bayles

And it's only because of the support of our family and community how much we stick together and support each other and back each other up. But it's not unless you speak out and you swallow your pride and ask for help. And that's the most difficult thing for a, you know, a proud mum to do. You think you know, it's it's been a week but I constantly got to remind people that it ain't weak to speak.

00:20:01:02 - 00:20:31:05

Yarraka Bayles

It is it is so courageous just to be able to stand up and speak out and just express yourself. But it's something that we find very, very difficult. And it's a trauma response. Everything comes back to trauma

and then intergenerational trauma on top of that, knowing that we've inherited, you know, centuries of intergenerational trauma and knowing that trauma is stored in our DNA up to seven generations, well, I've already inherited five generations of, you know, stolen children on mum's side.

00:20:31:17 - 00:21:00:06

Yarraka Bayles

And until I was aware of that, which unfortunately was, you know, a bit too late, Mum's already gone. Dad's gone. Great parents, grandparents, godparents. They're all passed away now. And I'm only just learning the impacts of intergenerational trauma now, but I've already passed it on to my kids and grandkids, you know, I. So to turn that around from a strength based approach is what I'm learning now with the amazing legacies of my parents and grandparents and Auntie Judy Atkinson and brother Brian.

00:21:00:06 - 00:21:29:09

Yarraka Bayles

Did this trauma informed care practice knowing that, yeah, we've inherited all of this intergenerational trauma, but we got hundreds and thousands of years of intergenerational wealth and cultural knowledge and wisdom and healing practices. So that's what I'm really trying to emphasize now, to help just to help combat and deal with that every single day, because everything I look at that I'm dealing with and I can see, you know, my own kids and siblings and family and community members, all trauma responses.

00:21:29:18 - 00:21:37:20

Yarraka Bayles

But we're not taught that. We're not aware of it. And that's why we're seeing the statistics through the roof. There's just very little understanding around it.

00:21:38:16 - 00:22:00:02

Carly Wallace

Well, you know, we like to have conversations, too, around trauma. And is it a disability? You know, will it be a disability? I don't think there's at all, you know, that much study happening on it. And I think even as our mob, we haven't had those discussions because I know even in my own family, obviously, we all were, like you said, have that intergenerational trauma.

00:22:00:10 - 00:22:06:18

Carly Wallace

And I've got family that can't function because of that, which is disabling them from their life.

00:22:06:23 - 00:22:07:17

Yarraka Bayles

Exactly.

00:22:07:23 - 00:22:08:19

Carly Wallace

What do you think?

00:22:08:19 - 00:22:36:04

Yarraka Bayles

100% it needs to be taken into consideration? And because it impacts every aspect of your life, mental, physical, spiritual, financial, when you're also trying to protect your kids from experience, seeing what you've experienced and also witnessed your parents and grandparents, it's not taken into consideration. They just blast because it doesn't get the clickbait or the shock content, all the rave reviews up, you know, and that's why they going a blast.

00:22:36:11 - 00:23:01:08

Yarraka Bayles

You know, all the kids, what's happening in Alice Springs, no one's taken into consideration. What's happening to the kids in that community and the intergenerational trauma. They just straight jumped to conclusions and very, you know, all the unconscious bias they want to follow that's just aligns with racism and ignorance. It really, really needs to be taken into consideration because it is impacting us more than more than we know.

00:23:01:16 - 00:23:25:02

Yarraka Bayles

It is debilitating. It's more than it's you know, you look at the studies of of a brain when you're sleep deprived, you know, a lot of my insomnia, I struggle to sleep with my mind. So there's always so much I need to do and prepare for. And, you know, I everything I just overanalyze everything and it's all a trauma response.

00:23:25:21 - 00:23:51:04

Yarraka Bayles

So there needs to be more research and more consideration, especially when dealing with mob that you know I in contact with the the I don't know you can't even call it the justice system with the injustice system. All of that locked up, whether it's in the youth detention centers or the adult prisons, they're all impacted by intergenerational trauma.

00:23:52:01 - 00:24:29:07

Yarraka Bayles

And it's you know, it's not the the statistics are self evident of that. So it really does need to be taken into consideration ASAP before more lives are lost or more innocent people are locked up when they should be traded for intergenerational trauma and culture is the only healer to be able to fill that void. Because when your spirits detached, when you might not have had that cultural knowledge and wisdom or practices, you know, embedded from birth, a lot of us, you know, I wasn't able to be raised on country with culture and language.

00:24:29:11 - 00:24:54:12

Yarraka Bayles

It was something that I've made a priority later in life, later in life, knowing that that's what's healed me and kept me clean and sober for the last 17 years. Otherwise I wouldn't be alive right now. You know, that

was my coping mechanism. That was what was filling my that emptiness and that void inside myself, like a lot of other people that doesn't discriminate, whether you're black, white, man, woman, gay, straight, it doesn't matter what religion or where you come from.

00:24:54:18 - 00:25:00:00

Yarraka Bayles

You know, these things can impact anyone at any given time. So people do need to start learning more about it.

00:25:00:12 - 00:25:18:05

Carly Wallace

Yeah. What do you think? It was time just to take it back around the house stuff. You talking about the system? What could the health system have done for you when Quaden was born and diagnosed with his disability, what could they have done better?

00:25:18:05 - 00:25:46:02

Yarraka Bayles

Everything. Be a bit more sensitive around the diagnosis, not just give me two pieces of paper. My son's got a cognitive biases later. Like, Come on, you know, if I wasn't a strong black woman that I am, that would have been enough to a to send me to the madhouse or kill myself. And that's putting it nicely. That was it was horrific to see the way that it was so insensitive.

00:25:46:02 - 00:26:08:16

Yarraka Bayles

No support like I would love to be able to say resources available at the hospital you know disabilities increasing on the daily you know there's so many different diagnosis and to think pre colonization that was none of this. So it's not something from our mob it's not something that we're aware of. So it's something, it's such a foreign concept.

00:26:09:00 - 00:26:28:10

Yarraka Bayles

Yet we're now seeing, you know, more than half of our population diagnosed with some sort of disability. There's got to be better research, there's going to be more resources available, more support systems. You know, don't just let people leave the hospital. It's a yeah, it's life or death. It really, really is.

00:26:28:21 - 00:27:05:07

Carly Wallace

You were saying, you know, it's it's because your family and your networks and our culture really that's kept you going and kept you guys alive and well even when you weren't. Well, you know, you that's the things that you leant on at that time. We had this culture of inclusion, hey, where we don't see the difference. Like, Yep Quaden is shorter than other people, quite different features and some differences, but white and still that kid that's running around on the field and still invited to this and that, like how important is culture when it comes to our kids with disabilities?

00:27:05:07 - 00:27:07:14

Carly Wallace

Or for our community members with disabilities.

00:27:07:24 - 00:27:31:11

Yarraka Bayles

That's the foundation, you know, that's what and once you've got those solid foundations which culture has embedded for us, it's and it reminds me of a quote. Aunty Lila says, When you know who you are and where you come from, the ground beneath you is rock solid. Nothing can break you, but a lot of mob don't have that, you know, that strong cultural identity sometimes that may not come to later in life.

00:27:31:11 - 00:28:00:00

Yarraka Bayles

So culture is the only thing that we have been able to rely on and draw strength from. With hundreds of thousands of years of track records, you know, of our healing practices. It's everything, you know, would wouldn't be I couldn't imagine being born into any other race, and I wouldn't want to be nowhere. It's it is the biggest blessing and privilege and honor, knowing that we're born into the oldest culture in world history.

00:28:00:17 - 00:28:30:21

Yarraka Bayles

So that, you know, I can't get any better than that. You know, we're the first doctors and medicine men and women and healers and teachers and storytellers and artists and authors, astrologers, astronomers like the first environmentalist and conservationists and humanitarians like that in itself is, you know, where we just draw so much strength from. But to be able to remind our kids, you know, that's who we are, that's where we come from, coming from that real strength based approach.

00:28:30:21 - 00:28:54:21

Yarraka Bayles

And to be able to constantly draw from our strengths and not from our weaknesses, I think that's where the magic lies there, and that's how I've tried to raise my kids while trying to raise myself at the same time. So it's been a huge learning journey. But around that inclusivity that you mentioned, sis you know, we know what it feels like to be excluded with the even just government policies that still impact us.

00:28:54:21 - 00:29:23:08

Yarraka Bayles

Now, you know, passed legislations being on the receiving end of racism and discrimination and the social exclusion and the fact that we weren't able to access, you know, health services and schools up until one generation ago. So we are, generally speaking, a very inclusive race of people. You know, we might notice a bit of differences here and there, but doesn't mean we treat people differently because they might look different to us.

00:29:23:14 - 00:29:42:09

Yarraka Bayles

Now. We got all types of people in our family, in our community, and to me, you know what? It makes me just want to allow them even more. And that's what I love, knowing that, you know, I would go out, especially our old mob, to be able to help guide and support us, knowing that their our cultural authority.

00:29:42:20 - 00:29:59:12

Yarraka Bayles

And one thing Aunty Lila said as soon as Quaden come home to meet the family, she said, he's been born into the best family. And every day I tell myself that and I remind him of that when he's doing it tough, or when he don't get his own way and he's running away. And I'll just say you'll be sorry, mate.

00:29:59:13 - 00:30:21:00

Yarraka Bayles

You don't realize how blessed you are to come from a family like ours. So you'll realize one day he is slowly, you know, really starting to understand, is very blessed and very fortunate, despite the adversity that he deals with on a regular basis. It's all character building and it's going to make him the strongest, deadliest black man.

00:30:21:00 - 00:30:43:17

Carly Wallace

Yeah, well, look, he's already I can say that he's already grown into that. And I've seen photos outside of him the other day and I just couldn't get over how grown up he looks. And I know he's, like, turning into his little man and being inclusive as a community that we are sometimes. The flipside of that is we're too inclusive and we don't always see the difference.

00:30:43:17 - 00:31:02:22

Carly Wallace

And sometimes our mob go without that support because of that life, you know, we don't see the disability and we just treat them like normal. But hey, that person may not just be a hotheaded kid, they might have a deal, they might have some, you know, extra needs that need to be met 100%. Do you think like our community need?

00:31:03:15 - 00:31:04:14

Carly Wallace

Yeah, a little bit more.

00:31:04:14 - 00:31:28:12

Yarraka Bayles

What we need, we do because it's not something that we've ever had to deal with up until, you know, recent times when the number of disabilities and there's still diagnoses that don't even have a name. All of that is really rare, you know, diagnoses that are coming about now. There's no knowledge on it. So how are we supposed to educate ourselves?

00:31:28:20 - 00:31:51:17

Yarraka Bayles

But I've got nieces and nephews that that do need to be diagnosed. But because we're so inclusive. Exactly what you said, no one's going to take him to the hospital or doctor to tell them something, you know, to to give him a diagnosis. So they just live their life and they do struggle because they know and feel that they look and feel different to everyone else.

00:31:52:02 - 00:32:21:10

Yarraka Bayles

But it's like, yeah, no one acknowledges it. So they just continue to yeah, navigate through our world, which is all inclusive. So it's all good. But yeah, the, the discrimination and the bullying and the racism in the Western world like we're much more comfortable in our own and nothing grows in your comfort zone. So yeah, I think that's a really good point that you made because it often does just yeah, let things slide a bit because we are so inclusive.

00:32:21:24 - 00:32:51:00

Carly Wallace

I think to why we let it slide is because of the things like you talked about with that the entrenched racism that you felt through the health system, through injustice systems like these, like you talked about education systems that you and Quaden have dealt with. So why would I as a as a Aboriginal or Torres Strait Islander mother or father with a child with a disability or may have a disability undiagnosed, go through that system and want to put myself through that.

00:32:51:00 - 00:33:07:17

Carly Wallace

When I've got double discrimination going on as a man or as someone with a disability, with differences, with maybe poverty going on with all the things we're dealing with. Right. So like exactly we go through that. That's that's I guess a big barrier in itself.

00:33:07:17 - 00:33:45:12

Yarraka Bayles

Exactly. And you know why it is so confronting? Like he doesn't want to be reminded that he's different. He doesn't want to be reminded that he's got dwarfism. He just wants to be known as Quaden, he's a kid. You know, his name's Quaden, he just wants to be treated like everyone else. So to constantly have it thriving, if he doesn't want to be around anyone else with dwarfism, he doesn't, you know, and now that he's old enough to tell me that, because for the first five years, I was raising all his awareness, you know, doing the merchandise, making it my life's mission to change the world and make it, you

00:33:45:12 - 00:34:22:16

Yarraka Bayles

know, a kinder world for people with disabilities. And now I realized I was oversharing. And it wasn't until, you know, the video went viral where I realized it can be really dangerous not having the awareness or the education and the resources and the support to help guide and navigate anyone you know with a disability. There's an amazing woman that

I've been able to connect with, Carly Finley, who is, you know, a woman of color with a disability.

00:34:23:01 - 00:34:47:16

Yarraka Bayles

And she's probably been the best go to just a sounding board to run things by because I wasn't aware of it. I didn't know how to raise a son with a disability. I thought I was in for a life of hell. And that's what it felt like a lot of the times until I started, you know, I just reaching out and connecting up with amazing people like that that I was aligning with.

00:34:49:06 - 00:35:20:20

Yarraka Bayles

But yeah, it's, it's very confronting, but even more so for a child that's to try and to understand and come to terms with their differences. So it's something that I'm more mindful of now that he's old enough to tell me and I look back on everything I was trying to do. Bless and oh, look, I just thank God that I've learned and hope that I can help got other people to learn from my mistakes because it was detrimental to both of them and it impacted my other children and family.

00:35:20:22 - 00:35:42:10

Yarraka Bayles

It impacted my relationship, you know, so and it was because I had no idea. I didn't know what to do. I didn't know how to deal with it. I pretended I was alright, you know, got up every day, and made out every day, yep we're all good. But I wasn't. I just didn't want anyone to know that I was really struggling.

00:35:42:10 - 00:36:07:19

Yarraka Bayles

I was at the lowest point in my entire life where I was contemplating, you know, I was self harming, like it was just too much. But we get up and paint a bright face on face the world and pretend everything's alright. And that's our coping mechanism. Yeah, but yeah, like we couldn't suffer in silence anymore. And I thank God that we have the courage to stand up and speak out, because otherwise who knows whether we'd still be here if that video didn't go viral.

00:36:07:19 - 00:36:27:17

Yarraka Bayles

So it was a blessing in disguise. There's always a positive to be drawn out of the negative. And I we're very grateful. It was such a humbling experience and it's brought us all so much closer together. The relationship that he now has with his dad and his siblings, you know, all of his mob it's just. Yeah, it's been the biggest blessing.

00:36:28:08 - 00:36:39:24

Carly Wallace

Yeah. It was incredibly hard for you guys. I know. And, you know, I reached out. I think nearly everyone in the black community reached out to all of you. And I hope you felt that love from everyone, one.

00:36:39:24 - 00:36:40:15

Yarraka Bayles
Hundred per cent.

00:36:40:23 - 00:37:00:03

Carly Wallace

Every corner of the world. And you know, I think you look you just said, you know, you look back on, oh, I shouldn't have done this. And, you know sis, I think that's the world. A lot of people, a lot of parents, especially with kids with disability, they're just trying to navigate how to do the best that they can with what they got.

00:37:00:05 - 00:37:19:16

Carly Wallace

And I think you you know, although, yeah, everyone makes mistakes along the way. You've you've raised this little fellow that's been through so much but is so resilient. And it is thriving now. And yeah, it's been hard, but you should be so proud of how far you mob come because we all are so proud of you.

00:37:19:16 - 00:37:32:09

Yarraka Bayles

Glass No, thank you. Yeah, we definitely felt that. And that's what got us to this point. That's what helps get us through the hard times and all that. Love and strength from sending us all the good vibes definitely makes a difference.

00:37:32:09 - 00:37:54:21

Carly Wallace

I think to like having conversations around disability and normalizing it. So and so. Kids not quiet and don't like don't try and detach from it or trying to. Oh well I don't want to be that because it'll be different. But hey difference fine as well. And it's okay to have a disability and have these discussions because otherwise people will feel very isolated and feel a lot and hide.

00:37:55:15 - 00:38:19:06

Yarraka Bayles

Exactly. And that's what, you know, I mean, his father talk about one day, we hope that he will be he will be able to come to terms with his diagnosis. And sometimes it's okay. He'll ask questions. But other times it's taken front and he doesn't want to be reminded that, you know, he won't be able to play football and he won't grow tall like everyone else in his family.

00:38:19:12 - 00:38:42:01

Yarraka Bayles

And, you know, I being even seeing other people with dwarfism in the community or at the shopping center or any random spot, we see someone with disability, with dwarfism, he runs the other way and basically don't talk to them. I'm like, and I'm learning to respect his approach. Like he's old enough now to, to be able to tell me and express himself.

00:38:42:01 - 00:39:10:13

Yarraka Bayles

And he's very good at that. So I have to respect that and let other people know, look, I'm really sorry. I don't mean to be rude. You know, sometimes I want to maybe even sometimes he's okay with it, but it's it gets very draining. It's overwhelming when it's too often. I just he's happy and just trying to fly under the radar and just try and blend being and sometimes, like, just say, sorry, bub you were born to stand out, you know, like, he's just going to have to get used to it.

00:39:10:13 - 00:39:31:23

Yarraka Bayles

I don't know what else to say. I'm not going to lie and sugarcoat it, but I'm just going to say it's it's actually going to get worse in a good way, though. People know who you are now and people recognize you for all the right reasons. So, yeah, I'm going to have to get used to it, especially if you want to be this deadly big actor because he's got all of his natural talent, natural ability on set.

00:39:31:23 - 00:39:51:02

Yarraka Bayles

He just goes into character and the photographic memory. So I know he's destined for greatness. He's got a big, bright future ahead of him. So we're just going to try and prepare him for that. And yeah, let him know like it's going to get worse in a good way. So that'll be ready and be prepared is all just practice now, so make the most of it.

00:39:51:14 - 00:40:11:00

Carly Wallace

Look I know it's been such a journey and you are an inspiration, you know, for our community. But for all families with disability, I'm up with that disability. So and if there's anything that I guess you could say to other families out there, you know, who may be struggling, like what would you what would you say to them?

00:40:11:07 - 00:40:38:07

Yarraka Bayles

Just especially for mob you know, just draw on the strength of our people, their guidance. And now everything that our culture has to offer us, that's the strongest foundations to be able to build from. And if it's not available, seek it out like there's so many mobs that are ready and waiting and, you know, willing to share and teach, whether it's language or culture, all that, different practices.

00:40:38:17 - 00:41:04:11

Yarraka Bayles

And I think, you know, that's our amour That's what really strengthens us from the inside out. We can, you know, be physically fit and strong, but mentally and spiritually to be able to take time out for ourselves and know that it's okay to learn as we go, it's okay to make mistakes. It's all trial and error. There's no instructions that come along with being a parent, let alone navigating.

00:41:04:11 - 00:41:33:04

Yarraka Bayles

You know, you got our world. The Western world. And then there's this whole new world, the world of, you know, people that identify with a disability or LGBTQ class or the migrant community. We're constantly code shifting and navigating all of these worlds all at once, and it's really, really difficult. So we need to learn how to look after ourselves because as carers and caregivers, you know, it's bloody hard when you've got to try and make time for yourself and it's something I'm not very good at.

00:41:33:20 - 00:41:56:04

Yarraka Bayles

I love helping everyone else and being a service to my mother and my community. But the most important thing is now realizing if I don't start looking after myself, I'm not going to be good for anyone. I won't be here for my kids or my grandkids and my nieces and nephews and future generations. So it is the hardest thing to do to learn to love and respect and appreciate yourself and treat yourself with loving kindness.

00:41:56:15 - 00:42:23:13

Yarraka Bayles

But it is the best thing to do for yourself and your family. So that's probably one thing that I'm learning and I'd love to be able to. Yeah, just supporting others on that journey because it's not easy, but you know, it's so much better when you know you're not alone. There's so many other love out there might not be with the exact same scenarios, but we can relate and we can help support each other through it.

00:42:23:13 - 00:42:38:01

Yarraka Bayles

So just reach out, you know, it's worth it. It really is just taking that first step, swallow your pride and just asking for help or seeking out some support services. It's so worth it. So reach out. That's all I could say and encourage people to really do that.

00:42:38:11 - 00:42:43:05

Carly Wallace

Nice. And one last thing, what are your hopes for Quaden.

00:42:43:14 - 00:43:06:05

Yarraka Bayles

Look every parent just wants their kid to be happy and healthy ultimately regardless of you know what career he chooses as long as he's happy and healthy within himself, you know that that's all that matters to me. And he knows that will support him with whatever he wants to do. He wants to do, you know, learn more about music.

00:43:06:05 - 00:43:24:14

Yarraka Bayles

And that's a great way to express himself. So I was like, okay, I have to go get some music lessons and do some freestyling and get all of that out. Stop writing down your feelings. That's really good. But he's also very good with, you know, he wants to be an engineer and he's really good at fixing things and helping his dad and his brother around the house.

00:43:24:14 - 00:43:45:07

Yarraka Bayles

So I know that. And I tell him, you know, I just have to be one thing. Like I've done so many different things and we we wear many, many hats, as you know, family members and community members with so many different job titles. And we've got that lived experience. So I know that, you know, he'll be an actor and he'll be in the music scene.

00:43:46:01 - 00:44:09:14

Yarraka Bayles

He'll be having a little side hustle. He I know that he'll get into fashion and and design because there's hardly anything cool available in his size, you know. So I said, well, wherever you see the gaps, fill those gaps. You know, if you see a job that needs to be done, do it. So I know that he will do many, many things and we'll support him with anything and everything he wants to do as long as it's in alignment.

00:44:09:14 - 00:44:30:00

Yarraka Bayles

And, you know, I will support him as long as he's going down that path of Yeah. Wanting to do his best and be his best and if he needs extra support, if we see him there and also as we all do, peer pressure and might be, you know, struggling to cope, then we know that we need to support him even more.

00:44:30:04 - 00:44:53:10

Yarraka Bayles

But it's his journey and we're just here to help guide him. So, yeah, that's all I can hope for all of my kids and for anyone, you know, just to be happy and healthy because it's something that we take for granted and it's something that we may not even realize how to do. So, yeah, if he's if he's happy within himself and he can grow into the man that he was destined to be, then my presence and.

00:44:54:03 - 00:44:58:16

Carly Wallace

All of that says, thank you so much for having a yarn with us today on yarn and disability.

00:44:59:06 - 00:45:01:10

Yarraka Bayles

You're welcome. Thank you. Appreciate it.

00:45:04:19 - 00:45:37:17

Carly Wallace

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. 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.

00:45:38:08 - 00:45:51:06

Carly Wallace

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