##### [00:00:07.050] - Bernard Namok

Hi and welcome to Yarning Disability, the FPDN podcast. I'm your host, Bernard Namok, Jr. I'm a proud St. Paul Badu and Erubian man from the 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 People's Disability Network. Join me now on Yarning Disability as we showcase First Nations people living with the disability, as well as their families and carers and other industry professionals.

##### [00:00:44.750] - 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 People's Disability Network and the producers of this podcast recognise 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. FPDN would like to acknowledge our founding elders and their lasting legacy. Uncle Lester Bostock and Auntie Gail Rankin and acknowledge all first peoples living with a disability. 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 People's Disability Network and the producers of this podcast recognise 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. FPDN would like to acknowledge our founding elders and their lasting legacy, uncle Lester Bostock and Auntie Gal Rankin and acknowledge all first peoples living with a disability.

##### [00:02:13.370] - Bernard Namok

In future episodes of Yarning Disability, we're going to be shining a spotlight on our advocates and the work they are doing around the country. In this episode of Yarning, Disability FPD and advocate Bernard Namok had a yarn with Proud Yidinji, a New South Wales advocacy manager for First People's Disability Network Deb Lee. Deb's advocacy journey started when she was a young child having a challenging upbringing where she was faced with a lot of racism and bullying. One important thing that I took away from our yarn is to understand anyone's journey, first you got to hear their story.

##### [00:02:53.290] - Deb Lee

All right, thanks, brother. So my name is Deb Lee. My real name is Deb King, and I'm a proud Yidinji Jalbu. So my connections go back to China, camp there at Borawara, and I'm also a proud Kamilaroi woman, so I live on country New South Wales.

##### [00:03:16.020] - Speaker 5

Tell me a little bit about you. I guess in the early days, what made you wanting to become?

##### [00:03:24.130] - Deb Lee

Well, isn't that a good question? I don't know how much time we all got, but yeah, look, my journey goes right back to when I was a young child. I always had a life that was very different from other kids, very isolated, found it very hard to fit in, found that I kind of thought differently to a lot of people, but I never really understood why that was. Anyway, growing up as a young girl, I had a very challenging upbringing. Yeah, lots of stuff there in the background. And anyway, was raised by aunties and uncles and stepparents, but never knew my biological family. As a young girl, that put me in a position where every day I had to go and visit the stepparent in mental health institutions. So gone back to Kenmore and on Nunawal country, that's where I was growing up. Every day I've spent there going to mental health facilities and wards and I learned as a young child that for as much as I was different, that's what made me, I guess, come to love living with a disability. At the time, I didn't understand that that journey was going to be about me as well.

##### [00:05:06.450] - Deb Lee

I just thought I didn't think nothing of it. I didn't know that I was any different. Even as a kid, I guess I always had an interest to talk to all the aunts and uncles and try and understand why life looked the way that it did for them. So I would ask them a lot of questions and they would give me a lot of answers. And what I learned, I guess, brother, as a young age, that's the most important thing to understand is that if you want to understand anyone's journey, first you got to hear their story. I think as young person growing up in a really disadvantaged childhood, yeah, it was always something that was around me. But then as an adult, I guess I went on to be a mum and realized that again, that I wanted to work in disability, I wanted to work with mob living with a disability and just see if it was something that each day you can make a difference just by sharing information that you learn. So, yeah, that was kind of me and how I got here. Look, I tried a lot of other jobs, but they weren't right.

##### [00:06:33.660] - Deb Lee

I faced a lot of racism, a lot of bullying, and particularly, I think, you know, as as pale skin mobs. Sometimes it made it even harder for me because there was an expectation that I wouldn't do my job properly. That was, I guess, what drove me to always want to work with people living with disability.

##### [00:07:01.130] - Speaker 5

And over times since you were introduced into mob with disability, have you seen changes from when you first kind of was introduced to, I guess, mob and their families with disability?

##### [00:07:16.970] - Deb Lee

No, brother, not enough. Far from enough. I haven't seen enough change. Look, what I see is I see a lot of good intention, particularly from our governments, I see a lot of assumption on what would work, but what I don't see is enough focus on the actual thing that might be able to make a difference and that's our culture and our healing. And if our spirit sorry, if it's not strong, if we're not connected to our culture, how do we then get the right supports. And what I see on many days, Brother, is I see a lot of our families often reach out, they ask, they ask, they ask for help, but there's always this continual dismissal of the stories that they're trying to share with those departments. And therefore that's the beginning of the problem. And as we know that that problem can continue for many years. But I'd have to say, although there are some really fantastic things that I have seen changing the industry, I also at times see our industry go stale and stay stagnant, whereby we go back to a time in the 1940s where if you had a disability, you had to be locked up, you can be seen in public.

##### [00:08:57.880] - Deb Lee

But then that also takes me back to the 1970s where our mums still weren't able to give birth in our hospitals. That's only the 70s, that's not so long ago. But what I also see, I guess, Brother, is that for disability to really change that space, we can't just invest on one day a year. Say, for example, when we're announcing who's Australian of the Year, we can't just acknowledge disability that day and we can't only acknowledge physical disability or disability that we can see. We need to acknowledge disabilities that we also can't see. But I think the key thing for me that I would really like to see change more, I guess, is the fact that every time a person with a disability goes to a department or to a system or they're in a situation where they want to ask for help, their disability gets considered first, not the person that's actually living with the disability. So I think for the industry, and it's a change thinking, but I really could say that some of the important stuff that I think still needs to be done is that we need to remember it doesn't matter what line of work.

##### [00:10:47.250] - Deb Lee

We actually do that every single time you see an aunt or an uncle or one of our mocks there and there before you, you need to remember their person. So their disability comes second to the person. And I think that's something, brother, that I'd still like to see change more of, because the person living with the disability continues to be the forgotten part of the very important conversation you're about to have.

##### [00:11:24.170] - Speaker 5

Yeah. And I think especially having mobile disability and being First Nations in higher places can kind of make that changes. Like recently, announcements for the first ever First Nations person from Darwin was elected onto the board for NDIA. What are your thoughts? Do you think there is some sort of hope that having our mob sitting in positions like that would give some sort of hope for mob in our remote communities?

##### [00:12:04.070] - Deb Lee

Yeah, look, I think, brother, absolutely we.

##### [00:12:11.520] - Speaker 6

Need to be involved in every part of the conversation and there needs to be a presence, I think, not only of just one mob, though, sitting at the table from one area. It's a case of having voices from many lands and there needs to be a representative Arnie's voice, voice for our women and a voice for our men as well. I think it is a time for growth and it is a time for opportunity. But in saying that, I think that it's something that we can do more of and we can do better at it.

##### [00:12:58.170] - Speaker 5

Some of the stories that I've kind of heard throughout my travels, it's to do with NDIS and the confusion with our mob being English, second language to some of our mob, and also accessibility and just things that you don't kind of think that could be a hinda for people living with a disability. Is it the same that you're seeing down, I guess, there in New South Wales?

##### [00:13:33.670] - Deb Lee

I think if I talk about what.

##### [00:13:36.870] - Speaker 6

I see when I talk about Mama, it is very different, brother, because a lot of hindrances do come around language as well. But I think that they always go back to our mob understanding their rights. So what we see here in New South Wales is that it's very challenging. A lot of mobs still aren't aware of what you can actually ask for within your NDIS plan. A lot of families are also.

##### [00:14:15.170] - Deb Lee

Not.

##### [00:14:15.570] - Speaker 6

Aware that they can ask for a cultural goal within their NDIS plan. So for example, I need support from the NDIS to maintain my cultural connection. Now, what that would do is that would allow our aunts or uncles or nieces, nephews and that to go out on country, do men's business, do women's business, and it might be some of that yudiki therapy or it might be just some weaving or it might be just sitting on country and taking that time to heal. I think that's one part of it. But I think another element that is very challenging for our families when trying to access the right NDIS support is that quite often the Lacs, they're not well versed enough to understand our culture and therefore promote a healthy conversation that actually starts the development of a good plan that will actually meet that person's needs without the need for a review or without the need for contending for why it is you need those supports.

##### [00:15:41.310] - Deb Lee

Probably.

##### [00:15:42.430] - Speaker 6

Although the issues are similar around rights not being acknowledged or not being understood, as I said, there's a little bit of a difference with the barriers around language. But in saying that, brother, also depends on how remote the communities are. So of course these issues get deeper the more remote our communities are, of course as well, because there's less of a presence, obviously, of information landing on the ground in those communities.

##### [00:16:21.930] - Speaker 5

And that's some of the things that we see in our travel and hearing too. Not much people know what services provide families and I think it's coming back to them not kind of making that community engagement with people in the community. So, yeah, I think little things like that could kind of be improved. But I guess is there a message that you would give for the families that may be going through struggles and also, if mom with a disability tuning in, is there any encouraging, I guess word for them?

##### [00:17:12.250] - Deb Lee

Yeah. Look, brother, I would always say, and this is one thing that I've learned from many aunts and uncles that I have much respect for. I see our aunts and uncles, we're all so humble. We never take more than what we need and we always walk to the table and we all know that, as I said, we don't take more than what we need. But what I would say to everyone out there, and especially for our beautiful aunties and uncles, what I would say is it's okay to ask for what you need. Don't be afraid that by asking for what you need that that means aunt down the road is going to miss out. Because that's not the way that the NDIS system works. How it works is there is enough money there for all of our families to actually have what we need. Because if we don't get it right the first time, what happens is going to come back and it's going to cost them fellas more money anyway, right? That's the first thing I say to families out there. Don't ever be afraid to ask for what you need. The first meeting with the NDIS is only for really it's a yarn.

##### [00:18:29.450] - Deb Lee

It's a yarn to discover what it is baby needs. How does baby need and how is he going to achieve that? That's the first thing to understand is always keep it very simple, right? Decide what you need. Do you want baby to you want him to go and see Uncle NAN every fortnight? Because, you know, he's disconnected maybe from his family a little bit too much. All right. And it's okay to ask for any goal in the world, right? Your goals are your own. Don't let anybody tell you that you can't ask for them. It doesn't always mean that we'll get told, yes, but it's okay to ask for them. That's the first thing I would reassure everyone. The second thing I would say that is around the NDIS, it is so important that you understand that with the NDIS, you are able to ask for a cultural goal. So as I said, ask for that cultural goal because that can mean many, many things. And what it most importantly can mean is that you don't just get clinical Western services, but you get a combination of services that are right way business, and if you want to be healed on country or whatever it is that you need, you can choose to do that.

##### [00:19:57.600] - Deb Lee

So I would say that that's the second most important thing to know that those two things sorry. Before you walk into that NDIS meeting, be very clear that you're entitled to ask for any cultural goal. And that's a very broad goal. And yeah, don't be afraid to ask for what it is that you need.

##### [00:20:21.030] - Speaker 5

And I think that's the thing that our mob, I guess that's during the travels, again, like mob, they don't ask questions, they only give what they take from them. But there is options around to suit their needs. And I think that's what families especially are not get the message that you can really ask for more information.

##### [00:20:52.130] - Speaker 6

And I think that comes down to.

##### [00:20:54.660] - Deb Lee

Brother.

##### [00:20:57.650] - Speaker 6

In the NDIS and the Lac.

##### [00:21:00.330] - Deb Lee

Program, I've been the project manager for.

##### [00:21:03.440] - Speaker 6

One of the big contract providers and I think it comes down to two parts. Some of it comes down to the way that a lot of it comes down to, to be honest, the way that the Lacs are trained and the.

##### [00:21:19.130] - Deb Lee

Way that the Lacs engage with our families.

##### [00:21:22.530] - Speaker 6

If it was more of a yarn.

##### [00:21:24.160] - Deb Lee

And a conversation, hey, morning Aunt, how are you? Tell me about your boy there. If we just kept things simple, brother, I think that the process would be a lot easier for our families. But what concern is a concern is that when this doesn't work well for our families, because people don't take the time to explain their rights and explain this whole new system properly, those agencies need to understand if you don't have a relationship with our mob, we're not going to feel safe enough there, to tell you the truth. And we're not going to open up and trust you when that could lead to somebody else like DCJ turning up on our doorstep a couple of weeks later as well. So it's very important for services to understand what is needed here is just have a really good conversation with mob. Be honest with them, ask them what they want and let them know it's okay, that they're not going to lose in any way their centerlink pension or it's not going to affect their life in different areas. And I think if we could make that very clear in the first conversation, families feel more comfortable to start telling their stories and deb.

##### [00:22:55.000] - Speaker 5

Is there anything else that I guess you wanted to add? Like this yarn is just about getting to know our advocates that are represented around the country working for FPDN. Is there anything else you wanted to.

##### [00:23:11.310] - Deb Lee

Yeah, look, I think look, for a lot of our work, brother, it's about taking on the issues what doesn't work for our mom. But I think too, what is important also is that when the NDIS does work well for our mob, brother, we have seen cases where it has challenged the government, it has challenged the precedents, it has challenged the way that our families can use that NDIS funding. What I would say is never give up asking the question as I said, like the person sitting on the other side of the table, they might come back and they might tell you no. But again, I would always ask. And when they give you the explanation, don't be afraid to ask why. If you need that bit more information, go ahead and ask for it, because that's what helps us to make our next decision.

##### [00:24:33.350] - Speaker 3

That was proud. Yindinji and advocacy for new South Wales advocacy manager for First People's Disability Network, Deb Lee. To connect with advocates in your area, you can check out First People's Disability Network's website on www.fpdn.org au.

##### [00:25:06.530] - Bernard Namok

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. I'm your host Bernard Namok Jr. Follow FPDN on our social media accounts to stay up to date with future episodes and information. You can also visit our website@www.fpdn.org au.