**Disabled Parent, Disabled Child & NDIS**

**Host: Pauline Vetuna**

**Guest: Cubbie Mako**

**Transcript by Leilani Fuimaono**

CUBBIE: As a migrant and a non-binary person of colour, I acknowledge other than those stolen and unseated lands of the Woiwurrung and the Boonwurrung people of the Kulin nation. I pay my respects to their elders, past, present and emerging. Always was, always will be Aboriginal land.

*[“Where Is My Mind”by The Pixies plays]*

CUBBIE: Hi, my name is Cubbie and I ride with a pen name a CB Mako. I'm a disabled carer to a disabled child who has down syndrome, cancer, hard-of-hearing. We are both hard of hearing and I have mental health issues that were previously undiagnosed prior to migration to Australia in 2003.

I've been actually taking two kinds of education just to get through the day. I'd like to share my experience with you guys, how a disabled carer with a disabled child gets through the NDIS and what were the blocks and difficulties, and what are the tips we can give you to go through the bureaucracy and finding your way as a parent of colour.

Among the CALD communities, CALD is culturally and linguistically diverse communities, there seems to be a lack of empathy when it comes to either having an invisible disability, or even disability that they can see. They're treated among the religious communities as either you're punished by God, you've had bad karma, you did something wrong, you didn't follow your parents, and because of that you're already alienated and from your own community and that's what happened to us when I had my child.

At the same time, when we tell them we have depression and we are taking medication, again, that is a taboo discussion. Even at this very day. Even on social media sometimes when I speak to friends from overseas, from the Philippines or from the United States, they would troll me and call me out that I'm such a bad person because I've got mental health issues.

They do not understand that Australia has universal healthcare programs, which includes mental health. That we get free psychological assessments, concession medication and free visits to the psychologists and counselors. And we've done that throughout our journey as a parent of colour because we do not get the support inside our CALD community.

I had to actually go out of my way to find the support, either from the breastfeeding mothers group back in the day when my child was still a baby. I even went all the way to this organization called PANDA for postnatal depression. They could not help me because they said, "Your child is disabled. We don't cater to that kind of help," and that threw me out.

So I decided to leave the breastfeeding group ‘cause I couldn't handle that. I had to find other ways to seek help for both of us, for myself and for my child. And eventually we found through Royal Children's Hospital, an amazing support when she had cancer. We were connected to different charities. And then there was also the [inaudible] branch of the Down Syndrome Association. They linked us up with other parents as well.

We live here in the West of Melbourne, so we're from Sunshine. There is this school for the deaf. As early as three, we were already signing with our daughter. She and I can sign Auslan, and she's in mainstream school right now here in Sunshine as well, where their language other than English subject is Auslan. So the entire campus, all the students and the teachers are able to speak with her through sign language, which is amazing. And I even took up classes myself apart from just learning from her teacher. And NDIS was able to include that in her NDIS plan.

So now that I mentioned about NDIS, what were the hurdles that we faced? First of all, because we were already in the system, what bothered me, or really confused me, we were enrolling from scratch. I had to gather all her documentation from birth to confirm that she has down syndrome, she has cancer, she has hearing impairment, and everything should come with a document, even though we were in a system called Better Start prior to NDIS. That's a program, when you have a child with a disability from ages zero to just before seven years old, you can enroll on that funding. That's before NDIS rolled into the West of Melbourne.

So by October, 2018 that was the rollout for the inner West, and we had to prepare for that rollout. Because English is my second language, what bothered me with NDIS is that it seemed, even though everything was written in English, it was like learning a new language.

So I had to attend a workshop first, how to go about it. I had to read these three sets of booklets to understand what the system is. It's quite complicated. The way I presented my daughter's, my child's schools or whatever documentation I had, was like preparing for an academic thesis.

You have to substantiate, is that how it's called? Have everything in paper, evidence based. Everything has to be in documentation that okay, if she does have down syndrome, show me a document. Come on, this is in the system already. Why am I doing this? Back to level zero. So that was quite frustrating.

But once you do get into the system, you think you've got relief, "Oh yes, I'm inside NDIS already we've got a number, a reference number, and I'm happy. But no, that's not how it goes. So to the parents who are listening, some people think, "Oh okay, I'm going to fill up this NDIS form, bring it to the GB, have it signed and that's it."

No. Because I had several discussions with other parents, they thought that was it because some parents with kids already, they didn't get to have that opportunity to collate all the documentation all these years. My daughter's very young so we got all the documents fairly easy. But then just to gather them is time consuming.

The tip is always photocopy whatever documents you have. Have a second set, have it scanned, save it in a digital format as well. If you do call NDIS for a query, ask for a reference number of that call. Make a logbook of your calls with NDIS. Remember who you speak with on the phone each time you call in the NDIS. Even though the system will assign you a LAC, unfortunately because of the high turnover of people inside NDIS, I've had three different LACs assigned to us with a very, very short period of time.

Imagine yourself, you're inside a huge supermarket. You want services for your child. At the same time you're having your own stress and mental health issues. And it's quite overwhelming, even at this point where we are. So you're in a supermarket and you're seeing all these services and you don't know where to start. And they're just going to give you a huge database. You're going to sift through that and say, "Okay, you need this and you need that for your child," but you don't know where or how to get through that.

Sometimes your budget will allow you to give you some support, but apparently everyone else is too busy or overstaffed, sorry overworked or understaffed by other organizations who are NDIS providers, so you really have to do this mostly on your own.

The problem is not all of the documents are translated in other languages, which is quite difficult. There are organisations, however, who provide training first for the carer, how to go about NDIS. There's an organization called Carers Victoria. They have free NDIS workshops. I attended one separately for a month. Even though I went through that workshop for four weeks long, once were in the system, it was still very daunting and confusing. So I've got a journal separate just for navigating through inside the system.

Writing skills there. You have to be able to explain your child's disability in a way that it's quite confounding in a way that, how do you word it, that you need services for your child. And they will always, always raise a set of words called necessary and reasonable, or reasonable and necessary. You have to defend the needs of your child for a service using those terminologies in their language. Using their language that, "Hey, my child needs speech therapy because this is reasonable and necessary," and yeah, you continue to defend.

I'm going to be frank here. It's quite ableist inside the system. I don't know if they understand why people with disability go through. There's so much to show as evidence for my daughter's disability, and have to explain it to them as well so they could understand it. For example, right now they just had a change with the rules on, they call it assistive technology. So this is a 14 page form within the system of a already budgeted plan of my child, which is kind of going around in circles a bit, which I couldn't understand at this point. Why do you need another 14 page form for assistive technology approval when her plan is already approved?

So the speech therapist filled out the form and all of the questions were in essay length. It was just shocking, and have to read through them, and just to substantiate to prove that she needs this equipment for her speech therapy. We lodged it on July, mid July, and it's what now? End of September and there's still nothing. We're still waiting. And the wait is just... It's just too much because I did tell them that my kid's goals is aligned with her individual school goals. They call it ILP, individual learning plan, with her year level. So it's already term three, end of term three, school holidays now while we're recording this, and then we still don't have her equipment for speech therapy.

And I unfortunately have to add this, another tip for everyone whose, who is in need of speech therapist, there is not enough speech therapists out there right now. So I've been speaking with clinic owners themselves, having difficulty looking for speech therapists for the West, so they can't even, yeah, fill up their requirements. So when I started calling a lot of clinics around the West, they're all either fully booked, they can't go to school to visit the child. You have to go to the clinic. So it didn't subscribe to what we needed for my kid. So whoever's out there listening, if you want to go through speech therapy as a degree, go for it because there's so much demand and not enough numbers, speech therapists to fulfill the requirement. But now we do have a speech therapist. Took us like half a year to find one and they're not from the West, they're from the North side. They had to drive all the way to the West to my kid's school once a week to provide speech therapy.

We are now in this stage of our NDIS plan where we're supposed to do a review. And to do that, again, I have to go through a whole lot of documentation to prepare for this review coming October and in December.

As early as October, I'm supposed to gather all the documents, the reviews from each therapist that my kid had, plus probably documenting all of what I've done from the very start of her plan to the point where I'm already data gathering. Showing them that you've been using these amounts, or who has not been doing their work. Yeah, showing that we've been using the plan actually. And it's their side why we can't even touch a big amount because we're waiting for approvals when it's already an approved budget.

We even have an approval for a tricycle for her and what is happening right now because of that, they still consider it as an assistive technology even though it's a trust for disabled kids. They say they will cover it, but then to cover it, they want to extend the length of my kids NDIS plan. And I couldn't get that idea because why would you extend the plan when it's already budgeted inside the plan?

So this is going along with what everyone's saying in the news, that "Oh, the NDIS budget has not being used and it's surplus." This is the effect of that, "Oh, we're surplus," because we can't even touch the plan. The amount of money's there. It's sitting.

We want to use it, but we can't, we can't move because of the additional requirement of the forms they want from us. And we're waiting. Yeah, we've just waited for their approvals and it's dragging. It's months. We're waiting for months here. So that's quite frustrating. And it's a redundant, like how many layers of approvals do we have to go through even though the plan is already approved? So I don't get it.

So it's some people call it, it's like the Centrelink for the disabled. The people inside the system, they're using complicated language which is not everyday English, unfortunately. They call it capacity building. They use words like assistive technology. Those are not everyday English words. So you have to learn their jargon. In the very beginning. It took me a month to find a head space just to understand NDIS language. It's like speaking another language and writing another way of writing. Apart from say, being an artist already, and a writer, it's a different kind of writing altogether.

If you know people who are doing their NDIS, tell them to attend as many meetings. There are Facebook groups I reckon, but then each plan is a different plan. Don't compare your plan to other parents, or other kids or other disabled individuals, for their plans because each plan is different.

They say no two plans are alike because it's individualised. It's needs based. So right now, there's still so much money sitting in her plan. We can't touch it because we're just waiting for approvals for the assistive technology.

Do your homework in advance. If you know your child, for example, is needing of occupational therapists in the future, do your research now. Find some in your area. Make those calls as early as you can because I didn't know that in the beginning. I thought people would just hand me a list of occupational therapists, “This is the ones nearest to you”.

And no, apparently there's many, many wait lists involved, and it depends on your plan as well. If you’re plan-managed or NDA-managed or self-managed, three different kinds, so we're plan-managed. So it all depends again from the provider, what type of plan their willing to accept in terms of service. So it's all a bit more jarring and confusing. I wish I could only probably forewarn you at this stage, but do your homework.

I know it's overwhelming. If you need to be medicated, do your self care because this is quite big really. It's not a grade at the end of the day. It's not like going to school. "Oh, at the end of the day you get a pass or a fail." No, this is someone's life. Okay? This is your life. This is your kid's life. It's a different matter. And it's quite draining as well, so pace yourself. It's going to be frustrating at times.

We need a better system. But we do have that budget already, but please allow us to use that budget. It's just sitting there. If you can't find it in your CALD community, unfortunately it's difficult. But if you could find a translator as well. There are people out there, you just have to find them. My first LAC was a person of colour, which is good. The therapist we found was also a person of colour, which is good as well for us. So they are out there, you really have to find them.

PAULINE: When are you going to find out the outcome of your review in October?

CUBBIE: The review will be in December, but the data gathering starts in October so that when I meet the LAC in December, I've got all this documentation ready. And the LAC who is assigned to us will start writing the review. She would compose all these. Collate everything, compose everything and make that review for us.

Unfortunately, it's not us who write the review. It's someone else, but make sure the LAC composes the review, before she hits send, make sure you see. Ask that you can see the review. I did that in the beginning, like when they submitted, "This is what we're going to propose to NDIS for your kid's plan."

I made sure with the LAC, "I want to see what you're sending to NDIA." You have the rights to ask for that. They'll say, "No, we won't show." "No, you have to show me what you're going to send before you hit send. I would like to see that please."

So make sure you know what they're submitting to NDIA. If we need to add a sentence or two, or you need to add more to the review that they will compose for you. So make sure you're ready for that.

*[“Where is my Mind” by the Pixies plays again]*

CUBBIE: I'm so immersed into it, like I breathe NDIS in my system.