**PODCAST SERIES 5 – EPISODE 1**

Q: Hi, listeners and welcome to Reasonable and Necessary, Australia’s premier podcast series of everything you ever wanted to know about the National Disability Insurance Scheme.

I’m your host, Dr George Taleporos, and on today’s episode, we’re talking about ethnicity, culture and the NDIS.

Joining me today to help shed light on this important topic is Sophie Dutertre from the Centre for Culture, Ethnicity and Health.

Hi Sophie.

A: Hi, George.

Q: How are you today?

A: Good. Thank you.

Q: Thanks for joining us.

A: You’re welcome.

Q: So why is it important for support providers and support coordinators in particular to understand culture and ethnicity?

A: I think it’s important for everyone because the NDIS is for everyone who’s eligible, regardless of their ethnic backgrounds and we know that at the moment, people of culturally and linguistically diverse backgrounds are not really engaging with the NDIS. In Victoria, about 10% of participants are of culturally and linguistically diverse background and that versus 25% of the general population. So there’s definitely an under representation, so the NDIS needs to be more accessible for people and support providers and support coordinators have a great role to play in making sure the system meets people’s needs, even if their needs might be different for those of the general population.

Q: And you’re currently working on a project in this area, aren’t you?

A: Yeah, so we’ve been funded by the State government to help with the rollout of the NDIS in Victoria with a focus on culturally and linguistically diverse communities and we have been doing cultural competence training for the disability sector and a lot of the information that we have imparted in those workshops has been information I’ve gained from training interpreters. So I’ve trained more than a thousand interpreters in lots of different languages and we ask interpreters, in your communities, what are the cultural barriers to engaging with the NDIS? So that’s been a very rich conversation that we have then been able to share with the disability sector.

Q: It’s very important work.

A: Yeah, it’s been really interesting.

Q: Now, yesterday, I had the pleasure of speaking with Julie Delong whose family’s Chinese about her experience as an NDIS participant, let’s hear some of what she had to say.

A: Hi, George, thanks for having me, so I myself am from a Chinese background, my parents are Chinese, but I was born in Australia. It’s only recently I’ve reflected on how that’s sort of intersected with the Australian culture and disability amongst all of that. I think it’s just been a challenge balancing traditional views of Asian view of disability in terms of what people are able to do, the stigma behind all of that and in Australia where it’s a little bit more accepting. Things like the NDIS are obviously here to support people with a disability to be independent, make their own choices and often times, I feel that coming from a Chinese background, it’s a whole different world where parents and people who are older than you essentially have more of a say in what you can and can’t do in your life. So it’s been pretty hard to have some tough discussions with my own parents about where I want to go in my own life and what they see I’m able to do. They obviously love and care for me, but being independent is something that is hard for them to grasp.

Q: That’s really interesting, so are you saying that it was hard for your family to accept that you would like to be independent and that you want to access services that help you more to be independent?

A: Yeah.

Q: And how do you deal with that? What sort of strategies do you need to put in to place?

A: Yeah, well, it’s funny, I was having a think about how I even began to access supports in the first place and it was actually in the middle of 2016, I randomly received a call from the NDIS asking me a bunch of questions about my condition and I thought it was a really bizarre phone call and then all of a sudden, I get a letter from the NDIS saying, we’re going to come and do a plan meeting with you and I thought, what is going on? Luckily, I was in link with some of the disability support organisations and they really helped me prepare in thinking about what I would be needing because at the time, I was at university and before all of this, I never received any supports, so my parents did everything for me and my family and that was something that was just a given, especially in our culture and I suppose I was really just forced in to having all this and I literally had my plan, I had funding and it wasn’t until 6 months later that I hired my first support worker and that was quite challenging in terms of having that conversation with my parents that somebody is going to be coming in to the home, let’s start small. So I think having that respectful conversation about what they’re okay with or what they’re comfortable with and what I’m comfortable with as well and it was definitely starting small.

Q: That’s really important for people to understand that you need to start small, that it can be quite overwhelming for people to have support in the home, particularly when their culture is effectively quite different in a sense that the family has the responsibility to take care of the person with disability, is that right?

A: That’s it, that’s exactly it.

Q: Okay and how is it now? Have they accepted it? Have your family embraced your independence? Are there still some challenges?

A: It’s still a work in progress, I have a team of lovely support workers who do come in and out of the house and that was just, it was a conversation that I had with my family or my parents mainly as well, do you want to meet this person as well, making sure they’re comfortable because these are people coming in and out of my house, our house every day, so it’s really, right now, they’re accepting of that aspect, but of course, the NDIS has so much more potential in terms of housing and really being able to live independently. In my own home, I’m as independent as possible, when I do go to work, when I do go out with friends, I’m able to bring someone else and not have to be limited to what my parents are able to do for me at that time, but a whole new conversation and challenge will be getting them to let me go out in to the big wide world, living on my own or living with someone else, whatever it may be. For them, it’s still a family responsibility, so they’ve always envisioned that once they’re too old, my siblings will then look after me, but it really doesn’t have to be like that, especially in Australia and especially with the NDIS, so that’s a conversation that I need to tread carefully. But I think over time, they will see, especially seeing other people do it, has really eased them, yeah.

Q: Okay, so listening to Julie and introducing how culture had played a part in her experience of the NDIS, is this a common experience for people from culturally diverse backgrounds?

A: Absolutely, Julie was talking about her experience as a person of Chinese ancestry, every culture is different, but something that to different degrees is across all cultures is the shame around having someone with a disability in the family, the shame that the family experiences and the discrimination they might experience from their community, the other thing that’s very common is the sense that the person living with the disability is maybe a burden or at a minimum, someone who doesn’t have great prospects, so someone who has great limitations, so it’s not so much about expanding that person’s opportunities as it is about making sure they’re well, but not really about engaging them with the community and the NDIS is all about engaging with the community, so that’s an aspect of the NDIS that there’s a long way to go for people in different cultures to understand that, I think.

Q: It’s really interesting, particularly those contexts of shame and being a burden, these are all things that as people with disabilities in particular as a member of the disability alliance group that I would say how dare you think that way about me, but it can be quite deeply ingrained, can’t it?

A: It is a big thing and as in every culture, including a more western culture, there are degrees and some families will be much more open to taking their child to community events or to engaging their child in opportunities, some families will have the child at home. Some families, their friends won’t know that the child exists. I’ve come across instances of that.

Q: And you also mentioned that there is also a culture of low expectations of people with disability, I know this is quite interesting for me because I always wondered why my mother has this, I’m from a Greek background, and my mum has this habit of telling random friends that I’m a doctor and I’m like, Mum, you just met this person, there is a problem with that, but I think it does reflect that she felt as if the culture was, disabled people don’t really amount to much and she wanted to say, well he’s a doctor.

A: Yeah, and an interpreter the other day was telling me a story that really stayed with me, he was from an East African community and he was saying that they had a mum in the planning meeting and it had taken a lot of work for the mum to come with her daughter to accept that her daughter had a disability. The daughter was a child and in the meeting, she was saying but why are you spending that money on my daughter? Why are you offering me this money, because my daughter’s never going to get better. So she was actually saying, save your money, we’re very grateful that we have a life in Australia, but don’t waste your money on my daughter, so there was really no understanding that I think her daughter had autism and she’d always have autism, but she could really benefit from support and engaging with the community and learning, so that really stayed with me because I think that’s coming from a mum where as Julie said, it comes from a place of love and care, but no understanding that there are opportunities for people with disabilities.

Q: And that’s really very hard the daughter to hear that and how does that benefit the daughter and her view of herself and her ability to benefit from the NDIS? That’d be quite profound. Julie talked quite a lot quite a lot about the importance of family and how with the NDIS, the focus is on the individual and that can be challenging when your family effectively thinks it’s their job to take care of you, is that a common train of thought?

A: Absolutely, I think you’re talking about collective cultures where decisions are not made individually and the NDIS with its model on focusing on the individual, individual empowerment, choice and control, those are all concepts that culturally can be really difficult to accept. I think Julie spoke very eloquently about her experience and her family and she’s extremely articulate and still feels that she’s not at a point where she can talk to her parents about moving out, for instance, and we’ve certainly had feedback that some families can feel really criticised by the NDIS because they’ve been looking after someone 24/7, and suddenly there’s a discussion about this person making their own decisions and that’s something that they can really take as a criticism. We had actually, Chinese interpreters were saying that some adults living with a disability might be reluctant to embrace the opportunities of the NDIS for fear of upsetting their parents and offending their parents and being alienated from their community, so I think the role of family and the way the NDIS focus is on the person rather than the family’s wishes is something that planners, local area coordinators, support coordinators really need to take in to account in their approach and they really need to approach things slowly and with great sensitivity around that.

Q: And that’s very important, but it’s easier said than done, isn’t it? It’s easier said than done, because you’re funded to provide a service to a person and suddenly, you have 5 other people who you need to think about and manage. How do you do that in a way where you don’t end up A, being overwhelmed, and B, taking over because you don’t want to do that either.

A: No, and I think Julie talked about going slowly and let’s start small and it certainly, it’s the right approach really, because it’s challenging to have someone in your house who seems to be making decisions and decisions that lead to your child being taken away from you, or that feeling they are being taken away from you or suddenly having control over finances because something that might happen in families is they’ve always controlled the money that was for the person with a disability in ways that in a western framework, you go, that is financial abuse, but that might be a totally accepted practice in a family, so you’ve got to be very sensitive of that and how to not be overwhelmed, well, I don’t know that there’s a way to not be overwhelmed, I think this might be very overwhelming.

Q: I have an idea, come to the training session and learn some skills.

A: Come to the training session that we run with the Summer Foundation as part of your UpSkill project, yeah, absolutely. But I think support coordinators who themselves are from the same cultural backgrounds, I think that’s a really great step because they would have an awareness and the family might be more open to receiving their advice as well because they’ll assume a cultural understanding.

Q: How about gender? Does gender play a role, so whether someone’s male or female?

A: I think it really depends, it depends on the family, it depends on the skills of the person, I think it really, it’s very much a case-by-case basis.

Q: On that topic of case by case, I think that one of the dangers is that we stereotype people. We say, oh, they’re Chinese and when you work with Chinese they’re this or that, and you know that culture is really quite dynamic, but how do you avoid stereotyping and also become fully aware?

A: And we all are guilty of this, I’m definitely guilty of this and I think stereotypes exist for a purpose. I think sometimes you can make a general assumption that is likely to be correct as long as you are open to the fact that it might not be. You might assume that because a family is Muslim, it’s their daughter who has a disability, a female carer will be more welcome, that’s I think a very valid assumption. Be open to the fact that that might not be the case for that particular family. I’ve worked with quite a lot of Syrian people in the past couple of years and you’ll have people who are extremely educated, extremely worldly, speak another 2 or 3 languages, have studied in Paris, and then you’ll have people who come from a village, have lived on a farm all their life and have very little education. Now the difference between let’s say those 2 families in terms of understandings around disability and perceptions and openness to services is as if they came from 2 different sides of the planet, it’s not the culture in that instance that is the strongest, it’s the class and the education, so I agree, we really shouldn’t assume that someone who walks through the door who is Chinese or Somali or Russian will be exactly like the same Chinese or Somali or Russian person we worked with.

Q: There would be some common issues that would arise at the same time, I think and ask, if you’re unsure, ask.

A: Yeah, look, it’s the key to everything, when we train in cultural competence, we always say we are not going to tell you how to work with this specific community.

Q: But that’s all people want Sophie, people want easy answers, they don’t like complexity, but this is complex.

A: It’s very complex and I don’t know every culture in the world, and I don’t know every person from every culture in the world, so I can’t tell you how to work with them, but it’s about being open minded, being open to the fact we make mistakes and really, if you apologise, people are generally very forgiving and being open to our own ignorance and just asking questions, to not come there with our knowledge and our jargon and the idea that the NDIS is going to be great, do it slowly and be open to the fact you might have to explain things and have things explained to you as well.

Q: What about barriers, what kind of other barriers do you find people from diverse backgrounds can experience with the NDIS?

A: So with the NDIS, one that’s often mentioned to me is the fact that it’s called NDIS. If you talk about Medicare, the name says what it does. The NDIS, the name doesn’t say what it does, so that’s something that’s been mentioned to me a lot, that people don’t quite know what it is because it’s an acronym, then when you unfold the acronym, it’s got the word insurance in it so people think you’re going to have to pay a premium or they think it’s a marketing person who’s calling them trying to sell them insurance, so there’s that issue at the beginning. Culturally, it’s more about if you experience shame about having a child with a disability, you’re not going to want visibility and if you access services, you’re going to be visible, so it’s easier to hide the person at home than to actually take the risk to be seen by the community and you know we are here, sitting in Box Hill, very Chinese community, if you go to a service, there will be other people, other Chinese people who might see you. So there’s a risk associated with that that stops people from accessing services. Another reason I can think of is that many people, particularly if they come from refugee producing countries, so if they come from, I don’t know, Syria, Iraq, countries in East Africa, might come from countries where there is no such thing that services people with a disability, and there is no such thing as a benevolent government that looks after your welfare. So it’s not just about learning about the NDIS, it’s about learning about a service system that is there to support you, that you won’t have to pay for and that is wanting to provide help and support, not punishment, so it’s a whole concept about what government does and what services do that can also be something to learn.

Q: So people can be afraid of the NDIS, can’t they? They can be think well, what’s the catch?

A: Yeah, they can think there is a catch, they can find it very hard to understand, they can find it threatening because of the emphasis on the person rather than the family and also for people who have small children who might have had experiences in their community with child protection, they might be very nervous about their child being taken away from them and being judged as bad parents, so it’s what you said before, it’s really complex, there are so many layers to everything.

Q: Thank God for the training. So are there particular things that people need to understand? For example, are there some tips or hints that you can give people on how to deal with this complexity?

A: Yeah, I think, as Julie said, start small, go slowly, take the time as a support coordinator and I know there are constraints around how many hours they have and I’m aware of all that, but a big thing because it’s a big thing for me because I’m a plain language person is, don’t use jargon. You can use jargon with your manager in the office, but when you’re working with a family, don’t say psychosocial, use another word, don’t say portal, don’t call My Place a portal, it’s an online account, don’t use the jargon because even if you have an interpreter, if the interpreter doesn’t understand the jargon, they won’t be able to interpret it, so the responsibility is actually on you to speak in plain English to be understood by the family and by the interpreter, so that would be a really big thing and that is something I do a lot with interpreters when I train them about using simple words instead of the complex terminology. Also make sure that people understand their plan because I think a lot of the time and I’m sure that’s not just in culturally and linguistically diverse communities, people might not understand their plan, and make sure they understand their plan and they understand the services. People come from countries where there’s no such thing as an educational therapist or speech therapist, they might have the best services in their plan and have no idea where they are, so really taking the time to go through it with them.

Q: It’s part of the education process, that you need to support people to learn a whole new language to some extent because I sometimes think the NDIS is developing its own language, really, but the only thing that people know what all these words mean.

A: Absolutely, I’ve done a glossary at work and it’s core support, capacity building support, capital support and it’s just self management and plan management and it’s taken me ages to understand all those things, so my English is okay, but there’s very much a whole new vocabulary around it and I think, what I’m being told is the first year is the hardest with a plan, but it’s worth putting in the effort because then after that, people become more accustomed to the language and to the services and you really reap the benefits of it and I want the NDIS to work for everyone and to really give people choices they haven’t had before and if that means a bit more investment at the beginning, that’s worth it.

Q: Just to end, do you have any examples of people who you work with who have had some great outcomes that you’ve seen, they started off with a lot of barriers and problems and with the right support coordinator they’ve been able to turn it around?

A: Absolutely, and an example that’s very close to me because they are friends of mine and it’s a family who is Arabic speaking, they don’t speak English, and they have a daughter who’s an adult daughter living with a range of disabilities and in their first year, they had a plan that was in English that hadn’t been translated and they didn’t have a support coordinator even though they should have had one, so they completely underspent their plan, massively underspent their plan. So I went to the review meeting with them, explained what had been happening and their plan was renewed in its integrality so every service and all the funding and they’ve now got a support coordinator who they found themselves who is fantastic, knows more than I do about the NDIS, speaks their language, completely understands the plan, is always telling me to go slowly because I just want everything to happen now and it’s not going to work, so they’re really going to be able to get the services and I can see the daughter is just blossoming because of the opportunities she has to do things on her own, so I think by the end of year 2, it will make a massive difference to their life, but really, it’s thanks to their support coordinator that they have now.

Q: That’s a great story, and for the family as well.

A: Yeah, it’s fantastic and they’re friends of mine, so I’m very happy to see how well it’s working for them.

Q: Wonderful. Thanks for joining us on the show Sophie.

A: You’re welcome.

Q: That’s all we have time for on today’s episode of Reasonable and Necessary, brought to you by the Summer Foundation.

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We really do love hearing from you, so please leave your comments and we love to hear your suggestions for future episodes.

Until next time, stay well and reasonable.

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