



Reimagine Today Podcast

NDIS Back To Basics

Episode 02 - Personal Stories, Misunderstandings & Contexts

(Transcript) [24 minutes 10 seconds]

Charles Manila, Intro

Welcome to the reimagine today podcast where we talk to people about their stories and experiences of the NDIS. This is Charles Manila, and I'm the host for the reimagine today podcast.

This is part two of a multi-episodic series called NDIS Back to Basics, where I have a discussion with Sophie Duterte from the Centre of Culture, Ethnicity and Health and Mohamed Umar, a Support Coordinator for Neami National and an NDIS participant.

If you haven't listened to part one, I strongly recommend you listen to that first - as we discuss Sophie and Mohamed's backgrounds, the concept of psychosocial disability and delve into some of the struggles and barriers CALD community members can face.

In this episode, we'll be delving into Mohamed's background as a support coordinator, the importance of goals and dreams and how CALD community members might feel when applying for the NDIS.

Charles Manila, Safety Message

Please note that this episode and the series as a whole involves discussions of sensitive topics that can be distressing or uncomfortable. We advise that you listen to this somewhere you feel safe and if you are affected by the content, pause the recording and take a break, and consider speaking to someone you trust, or calling a helpline for support. Thank you.

Now, we will dive straight through where we left off from part 01 and Mohamed will now take us through to his experiences as a Support Coordinator.

So, let's get to it!

Charles Manila, Acknowledgement of Country and Lived Experience

Before we begin, I acknowledge the Traditional Owners of the land on which we are meeting. I pay my respects to their Elders, past, present and emerging, and the Aboriginal Elders of other communities who may be here today.

I would also like to acknowledge all people who have personal experience of mental illness, whether as consumers, carers or workers. Your voices, insights and experiences are invaluable and important. Keep fighting to be heard!

Mohamed as a Support Coordinator

Mohamed Umar

I have had the opportunity to work for a variety of organisations and that's always been my issues in terms of understanding of what it is that I want to do, where do my values lie and where I can contribute the most. That allowed me to walk around and see something that felt meaningful to me and always get into that. I have heard all types of conversations with whether it's colleagues, whether it's community members or whether it's people within the welfare sector and the question that always comes is "there is huge underlying issues in terms of this individual that they are dealing with, but at the same time the issue is with engagement." I don't know how that's going to be addressed, but I think that can only be addressed by inclusion. When I say inclusion, I don't mean that people need to be put into spaces that they feel they need to be in there but I feel like we need to create an environment where people feel like they are part of that environment by putting them in the front line of delivering services rather than receiving services. And also creating that space where people are allowed to engage in that conversation and awareness, that's always been the key thing.

Distinctions Between Terminology and Concepts

Charles Manila

That's an interesting point. I think people sometimes don't realise that things such as rapport, relationship building and adapting to changes in your life is really difficult for people in general but especially for people in the CALD community. You're adjusting to a new environment. Things are or can be completely different and there's a lot of things you don't know because you haven't been exposed to it. When you consider the differences in culture and misunderstandings that can happen in language and what is and can seem unfamiliar, it's a massive shift. I mean, particularly if English isn't your first language, you're already off to a really challenging start. It's particularly difficult when Australia is very diverse with many different cultures. What do you think the solution is, trying to get everyone who needs these services to engage with the NDIS and mental health services to all come together with the same understandings and be on the same page?

Sophie Duterte

With the language of the NDIS, there's different things. There's the language that is the terminology, you know with words like "psychosocial" and "portal" and "capacity building" that are words that are likely not to be understood because they are complex. But there's also the language of empowerment. The NDIS is very much about individual empowerment, choice and control and independence and people making decisions for themselves. And that's a language that culturally might not be understood. So, it's not about understanding the words, it's about understanding and accepting the concepts and that's something Mo, you might to elaborate on. The idea that people with a disability can claim independence, can make their own choices, and

separately from what their families might want from them. It seems to me a very western idea. It doesn't mean that it's bad, but it means it will take people a long time to get their head around that and that's not just a linguistic issue. What do you think about that Mo?

Mohamed Umar

I think you hit the nail on the head by looking at the meaning of those words rather than what it is actually saying. The underlying factor that is, you can actually have that word interpreted and they can understand it, but I don't think people would actually understand what the concept means for people from CALD backgrounds. In terms of empowerment for example, the idea that people are empowered is something that's not really experienced in my community or any CALD community at large to be honest because you are excluded, there is no empowerment there at all. You are isolated. Within the framework of their families, when you look at disability and the role of responsibility, it's important to realise that different communities have different takes on what it means to have a disability and also understand that families come first and foremost as the first support and usually last support needed for those people that have got the limitations whether it is psychosocial disability or whether it's a physical disability. And it's something that people naturally take it as a great pride in terms of there's a great sense of responsibility that "this is my family member, this is my responsibility and I would like to deal with it and I don't need anybody else to take any responsibility." But you can also see the side effects of that, which basically means there is no sense of individuality for these people because they feel like the other person is just responsible for every aspect of their lives. And you add that with the terminology of the NDIS and you're asking things like "what are your goals and what capacity building supports you would like to receive?" People have never had those supports. It's like asking someone something that they have no clue of and the idea that they should actually go there and ask for these things is almost impossible to imagine.

Because there's enough issues for me to actually understand where this person is coming from, then their understanding of these things must be the same as well, so the effort should be doubled rather than making it into something lesser by giving them for example less funding which is very common for people of cultural backgrounds when they are receiving supports. The sense that they will go into an interview or plan meeting and they would just have a conversation in regards to "what do you need?" and most of the time they would just say "I need nothing" because they never had that support before. The only thing that they have needed is the person that was supporting them.

The importance of goals and aspirations

Sophie Duterte

I think that, well just that it's very interesting. It's this idea that... it's really about cultural awareness of being aware of the person that's sitting with you at the planning meeting for instance will not come to that meeting with the same knowledge and expectations as you might have. And I like that you mentioned goals and I think that goals is a really, for me it's a term that really brings together what a goal is in terms of what it means but also culturally how tricky it can be for someone to define what a goal is for them. So, you know, the word goal can have

different meanings, it can be a soccer goal. But it can also be something you want for yourself. And when you are, maybe when you're newly arrived and the things you want are the very basic necessities that you've mentioned Mohamed, it's really hard to think outside that. And you know if you say to the NDIS "What I need really is right now is for my family, for my father to work, for all of us to have a house", that's not the sort of goal you can have in an NDIS plan for yourself so that's one thing. But also how hard it can be for someone to think of what they want for themselves when their whole life has been about either what their family wants, for their unit, the whole unit or what their family really wants for them. But it's never been that idea that they can actually think of their own dreams and aspirations. And once again, it's a matter of time and accepting that the person across from you in the meeting, that might where they are coming from and therefore the concept of goal will need to be explained and they will need to be given time to unpack it and unpack what it could mean for themselves within the concept of the family that also will need to unpack it and accept it. That you know, if your goal is independence, it might take you for you to realise that is your goal but it also might take your parents a long time to accept it that this might be your goal. It is so multi-layered. Yes, some if it is about terminology, some of it is about concepts.

Mohamed's personal story and experience

Mohamed Umar

I think I personally kind of had an interesting experience when it came to the NDIS. That was around early 2019, it could have been late 2018. It's also the same thing that encouraged me to come back and start working within the NDIS framework simply because my experience was something I never really had expected. I had a disability probably most of my life, as much as I can remember. I had an acquired physical disability at the age of 8 and you kind of just learn to grow with that. Young people, children especially have the capacity to adapt. And in terms of getting support of all the times of that I have been, initially for my disability whether it was the limitations of my physical disability, as well as also the traumatic impact of how that injury happened and the issues that came with it. Especially coming from a war-torn country. That's something that I have lived with most of my life while I was in Australia and I never really particularly received any kind of support. So when the NDIS came, I was very excited about it simply because I thought "Okay, now you're in a place where you actually understand most of these terminologies, I've been lucky enough to have been working within welfare for quite some time. With the promise of the NDIS I thought, "Well finally, I might be able to be in a position to address some of the health issues that were very present in my life. To the extent where I never really could exceed working for more than one year, at any work because my health issues would deteriorate to the point where I'd collapse. But in the previous healthcare system, if I tried to access any service, it was more in regards to my physical disability. I was just being told by organisations in that were this sector all we could do is we can offer you to be part of whatever groups that these organisations had and there's no tailored, targeted supports that was actually there.

Mohamed's application process

Mohamed Umar (continued)

My application process for NDIS started for myself and so I made the contacts and I had some wonderful experiences. And that made me actually think of a lot of things that I hadn't previously thought that existed as barriers. These things included things like no proper medical history for CALD communities members. There is no specific mental health or no specific medical history of you that's been around or that's been recorded. That's one issue. And the fact that you don't particularly have a specified doctor that you go and see, because if people go anywhere, they go to their local GP and most likely you see a different person each time that you go there.

I've lived around Melbourne for 15 years now. I've lived in almost every suburb. Point Cook, Werribee, St. Albans, Ascot Vale, Broadmeadows. And that is not due to something that I actually wanted personally. That's just due to because you never really in a place where you're actually home and you know what social housing is like in Australia.

I tried to access the NDIS, I couldn't get any medical history or any particular doctor that knew me well enough to actually help me fill out the first form

I could not get anybody because every person that I went to said "I don't really know much about you. Or some of them didn't really know, I live in the West now, some of them didn't really know about the NDIS. It opened my eyes. It made really think about the people are going through issues that they don't even know they are going through issues, they don't where to go for issues and they can't advocate for themselves. And here I was trying to just get somebody to support me to fill out a form when I knew where to go, what to say and what I needed.

The worst experience was one doctor, once I gave him the form I said "I would like to be assisted in filling this form which was the national disability insurance scheme... I'm not making this up, I actually had a friend with me in that meeting because I wanted to show him what it is like after I have told him I actually can't get someone to help me with this. For him to see because he was working for a service provider. As soon as the doctor heard the insurance scheme, he actually threw the form back at me, he was like nah he doesn't want to touch anything that said insurance in it with you because I don't know you. Mind you, that was a doctor. Eventually, I had to improvise and actually get myself admitted at a hospital, at emergency so I could get I get a letter from the hospital with my health analysis and a letter recommending any GP to address my issues. And I had to do that just to get that. There's a lot of issues and there's almost zero support and the people that are supposed to be the front line of these services aren't really... I think it comes down to education, I think it's just their knowledge and understanding that's just limited to the needs of these communities. It's something that's multifaceted and it's not something easily fixable by the NDIS. But I've also seen opportunities for a lot of improvement but I've also opportunities where more people have actually been interested in getting services now because for the first time they can physically see that people of their community are getting support from the NDIS and the conversation

about the NDIS is far more heard around the communities around Australia probably, far more common now than ever before. It's got potential for things for things to improve. Yes Sophie?

Charles Manila, Post Commentary

Reflecting on this story, it highlights that there is still a significant lack of understanding about the NDIS. More education is needed, including for health professionals such as GPs. And, as the NDIS is still a relatively new scheme, this understanding will unfortunately also take time.

Sophie Duterte

I think also, Mohamed, your experience which was obviously so terrible... Everybody was learning at the same time and as you say, I think people are more aware of the NDIS now. But also, there are agencies like ADEC which is Action for Disabilities and Ethnic Communities who can help someone in the process. It's one on one. It's free. They don't have a waiting list as far as I know. They can really go through that process with someone at whatever point in the process they are. It doesn't guarantee they'll be accepted in the NDIS but it certainly means they get support. At the time when you were trying, people were on their own and there was just no funded service to help before they got into the NDIS. Once people were in, there were services. To be able to apply, which is not always an easy process, there were really no supports which was your experience. I think that has improved; I think there's more of an understanding now that people need help pre-NDIS in the application process. I'm hoping also that GPs have got a better understanding of what the access form is and what their role can be. It's certainly as you say a working progress, but less than it used to be. And I'm really pleased to hear that you're saying people are more aware of it in CALD communities and that there's also good examples that people can see how it works for other people and that's so important. That's when people are going to want to apply, when they see it has positive outcomes. So, I'm really pleased to hear that.

Charles Manila, Outro

This was part two of a multi-part episodic series for the Reimagine today podcasts called NDIS Back to Basics, where I sat down and had a conversation with Sophie Duterte from the Centre of Culture, Ethnicity and Health, and Mohamed Umar, a support coordinator from Neami National and an NDIS participant. Join us next time, when we discuss what improvements Mohamed and Sophie feel the NDIS could take and the role of interpreters.

I'm Charles Manila, the host for the Reimagine today podcast, signing off and remember, your voice matters, so keep the conversation going.

Safety Message

This episode contained discussions of psychological distress and trauma. If, after listening to this episode, you need support, please reach out and talk to someone you trust. You can also

reach out to the following services: call Beyond Blue on 1300 224 636 for brief counselling and referrals. Or call Lifeline at 13 11 14. If you need an interpreter, you can ask these services for one. If it is an emergency, call 000. Take care and stay safe.

Acknowledgements

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