

Cathy Bucolo

- DG Hi, listeners, and welcome to Reasonable and Necessary, Australia's premier podcast series on everything you ever wanted to know about the National Disability Insurance Scheme. I'm your host, Dr George Taleporous. On today's episode, we're talking about health and the NDIS. The NDIS was never intended to replace health services. However, the implementation of health and disability is complex, and it's not always clear what is a health need and what is a disability need. So to help us work through the tricky interface, we are joined by Cathy Bucolo, a clinical practice lead at the Summer Foundation. Hi Cath.
- CB Hi, George.
- DG Welcome to the show.
- CB Thank you very much.
- DG So Cath, let's start with this really key question, and that is how do we distinguish between a disability need and a health need, according to the NDIS?
- CB Yeah, and I was thinking about this, that it's probably easier to talk about the conflict in the middle, at least sometimes with this topic because it is so complicated, so I think the first thing is that the NDIS talks about it, that it's a health need versus a disability support. So they even change the language there, that they always talk about a support when it's related to them rather than a need, and I think that the obvious answer is a health need is related to a health condition, or someone's basic health, whereas a disability support need is related to their disability.
- DG Okay, so part of that is to say that you can have a disability and have a range of health needs, and at the same time, have a disability and not have very many health needs at all, so when it comes to understanding the difference, is it really about saying that my disability is identified as in as a particular thing, diagnosis, yeah, and that all that stuff will be supported by the NDIS, or is it more complicated than that?
- CB Yeah, it is more complicated than that, that's right, so as you know, to get on to the NDIS, you need to have a disability, but then if we just think about the supports, it's thinking about what is the support and then what can you attribute that support to? Is it because, do you need that support because of a health condition or do you need it because of your disability? And sometimes a good way to do that is to think about what's the purpose of the support, so if you think of a wheelchair, so someone may break their leg, and then they need a wheelchair, and you start to think, well, they need that wheelchair because they've got limited functional capacity, but it's time limited, it's not permanent, it's because of a fracture which is a health condition, and it's recovery orientated when you break your leg, you've got six to eight weeks and then you won't need that wheelchair again, so the NDIA wouldn't fund that support because they see that as a health condition, whereas if you had say a paralysis down one side of your body, and you needed a wheelchair, then the other way you could

think about it is, well, that paralysis is permanent. It limits your capacity to get around in your day-to-day life, and you need that wheelchair to live in the community and live at home and that's going to help you do your daily living tasks, then the NDIS would fund that because it's related to that permanent functional disability.

DG Okay, so what I'm hearing is that it's, that a lot of it is related to whether or not it's ongoing.

CB Yeah, absolutely.

DG Okay, well, let me make it a bit more complicated...

CB Go for it.

DG What if I had diabetes?

CB Yeah, I knew you were going to say that.

DG Yeah, and that diabetes is now something which I've had quite long, obviously, there are dietary factors, but essentially, my diabetes does limit my ability to do certain things.

CB Yeah.

DG Talk me through how as, let's say you're a very, how shall I say this, health NDIS bureaucrat and I've come to you and said, I have diabetes, it's lifelong, it impacts on my ability to function, how would you respond?

CB So what's your support need? What do you need? You might need insulin, so you're talking about the support need there, so...

DG But I also need help with being able to organise my diet because of my diabetes, it's quite difficult to necessarily have the energy always to cook and to look after my health.

CB So there's, do you think you're already a participant? Have you been, are we talking about eligibility in the first place, so it's complicated, isn't it, and I get confused about this so that's why I think it's helpful to try and separate it out of are you talking about eligibility or you're already eligible and are you talking about how you want support?

DG Can we start with eligibility first or that I'm not eligible, that I haven't been, I haven't tested my eligibility, so I'm here to test it.

CB Okay, we will try. So the first thing I think about is, so you're presenting with a health condition, diabetes, and then if you move through, we've got a fabulous new resource that I'll just plug here on the Summer Foundation website that goes through looking at the language that we use and that health staff might use, so the health condition would be diabetes, and if you think about then the impairment, what is it that in really medical terms, the loss of function, so you're saying it's hard for you to do...

- DG Well, to find the energy because of my diabetes, to do a lot of the housework, I'm often unwell and I also need help to go to my doctor's appointments.
- CB Yeah, so the NDIS would say, first of all, those things are permanent and is the diabetes permanent? That goes without saying, but is the impairment, so will you, will that fatigue always be there? Will whatever's stopping you from being able to do your shopping, if it's the fatigue, is that a permanent thing? So they start there and then look at what does that fatigue related to your diabetes stop you from doing in your everyday life? So you're saying shopping is hard, and then the NDIA would say, is that limit, so your ability, your difficulty with shopping, is it extreme, or is it moderate? Probably, moderate to severe in again medical terms, so if, and we're kind of just working through this, but what I would guess is if it's a mild difficulty, if health are going to say this is a mild difficulty, then the NDIA wouldn't look at funding that, but if it's really impacting on your life, then they're more likely to.
- DG Yeah, and this goes back to the NDIA, so this would be the test, wouldn't it?
- CB That's right and that's why, you can't, as it's really simple you kind of could say, well, diabetes is a health condition, so anything related to that is not the responsibility of the NDIS, it's all health, but the NDIS is about, it shouldn't be about diagnosis or labels, it's about what they say, how you participate in life at that level, so your daily activities, your community ability to, the social and economic participation, it's at that end of the spectrum, not at the health impairment end, so it shouldn't really matter what your condition or disability is.
- DG Okay, so there's not a magical list of impairments or conditions, there's no list that says this is a disability or this is a health condition.
- CB No, there's a list, so again, this is where we've got to be clear. So we're talking about eligibility, there's a list of conditions that mean they've said, if your, the condition that you've got is on this list, we think your participation is affected enough that you're eligible for the NDIS, so some examples are cerebral palsy, intellectual disability, spinal cord injury, but all at moderate to severe levels is the way they term it. But there isn't a list of support, actually, that's not true, so there is a list of supports then if you talk about so you're already eligible, there are the COAG Principles so people can Google that, COAG Principles NDIS where they go through saying, these are the types of supports that the NDIS is responsible for funding, and these are the types of supports that health's responsible for funding.
- DG And is that, the interface, does it basically be recognised at, sometimes it's not that clear, that as a person with disability, there may be a range of things that I need and that some are the responsibility of the health system, some of them are the responsibility for the NDIS, and then some of them might be a bit of one and a bit of the other.

- CB Yeah, they're grey, absolutely and that's the trick with the principles and that some things are really clear, so it says health is responsible for diagnosing, treatment, rehab, time limited, early intervention, so all those sorts of words and the NDIS is responsible for maintenance, small incremental gains, things that are related to your day-to-day activities, but it's all the stuff in the middle, isn't it, that sort of, when you're talking oxygen, pulse meters or whatever they're called and some of the stuff and some of the decisions that have gone through to the AAT, the administrative appeals tribunal, about this interface are really interesting to look at.
- DG Yeah, that close proximity case was interesting as it came back as saying that person, yes, may have needed that because of their disability, but it was the responsibility of the health system to respond, so I think that does help, but it also reminds us that it's not necessarily always what falls in what area.
- CB Yeah.
- DG I know that the NDIS tend to use terms like maintenance supports as being within their domain and that for health, it seems like diagnosis and treatment, is that another way to help to understand the difference?
- CB Yeah, I think definitely and even that's tricky and it gets confusing for all of us. The one thing that I found really helpful from say that decision is that you ask yourself, is what I need, what my support is, if I don't have it, will I end up back in hospital, and if the answer's yes, then it's probably a health related, health need rather than a disability need, and another question...
- DG Can I challenge that one?
- CB Yeah.
- DG So if I don't have perfect care, I'm not dead, I will end up with a pressure sore and will end up in the hospital, but pressure care is the responsibility of the NDIS, so maybe that doesn't apply in that case.
- CB Yeah, and that's, it's the same, there's that list, isn't there, the PEG feeding, so in the COAG Principles, it lists actually specific oral suctioning, so actually, that's probably a good example, so it ended up in the AAT that health should pay for the oral suctioning equipment, but it's, if you look at the COAG Principle, then the NDIS might pay for somebody to actually perform that function because the person's disability is limiting them being able to do that themselves.
- DG It reminds me of how complex it is, so it can't say that suctioning which is around managing someone's secretions is only the responsibility of the NDIS because it's a piece of medical equipment and in that sense, it's the responsibility of the health system and to add to that, people with disabilities are living in the community so they need the NDIS funding to pay for that because it's a known thing. If we end up in

hospitals, heaven forbid, then it might be the health system's responsibility and this is where the confusion is.

CB Yeah, and I think it's where all the historical stuff comes in to it that we were speaking before about where people don't think of themselves, carving themselves up, it's a different, so the systems need to make boundaries and this is what the NDIS is going to pay for them and this is what health is going to pay for. But people don't think of themselves that way and then historically, there probably has been some flexibility, so in the old days, if you had your ISP, individual support plan funding, maybe that would pay for the equipment and the person to do it, whereas now we're starting the new world and that because of the NDIS and the principles and what's been agreed to, they're starting to split it back up again, so you've got equipment versus who uses the equipment suddenly is really important, whereas it used to just be all together.

DG Yeah, that's right, so it's becoming even more important to empower yourself to understand the difference.

CB Yeah.

DG Now I know that you have a lot of expertise around the acquired brain injury area for your work, and I know this is a special point for people with acquired brain injury because they end up in hospital and then to get out of hospital, often their support needs are around rehabilitation, so where does rehabilitation fit? Is that NDIS or is it health?

CB Yeah, so again, that COAG principle says it's health and makes that very clear, so I've seen a plan come back and it says, the physio has said in their report that the person is still making gains, would benefit from rehabilitation and they need this, this and this in terms of a few pieces of equipment, and the NDIS has come back and said, that's fantastic, we're not paying for that because you used the word rehab, in my words, yeah, so it's very clear that anything to do with rehabilitation is health and anything, as you said before that we went off on another tangent, in anything to do with maintenance is more the NDIS's field.

DG Well, this gets very complicated, doesn't it?

CB It keeps going.

DG Yeah, because I understand that for someone who has, acquires a disability, that rehabilitation can be a lifelong process and add to that the fact that they might need their NDIS funding to support things like therapy, we know that here in Victoria, there was the very successful slow to recover program that was then disability funded, and we've seen those programs no longer available to people. Is health coming to the party? Is it filling the void?

- CB No, and it never did, and I suppose if we talk about Victoria, why the slow to recover program started here was because there was that huge gap of community based, functionally based, how we all in the sector know that rehab should be done is in the person's context, their real life, that's the best way to do it, and there was a real gap there, so then the slow to recover program worked beautifully to fill that gap so people could leave hospital, go home, but keep having rehab, and you're right, that we would, so to me, this split between the NDIS and health in terms of rehab is really sad in lots of ways because it's going back towards that medical model that we all fought for so many years to get rid of. So the medical model said, you had your injury, you had your ABI, and then if you imagine a graph that goes up really steeply as you quickly recover, and that's where all your therapy is, and then you get to the two-year mark and suddenly, it all plateaus on the graph and the thinking was, well, whatever you're at, at two years, that's as good as you're going to get. So a whole bunch of us here and around the world, really, said, we just don't think that that's true and rehab doesn't stop at two years, that's an old medical model, so now when I look at the principles, and I get that there has to be some kind of way to manage the funding as there has to be some kind of barriers or, but it does really not sit very well with all of us thinking that rehab goes for years and years and years, but I would say definitely don't write that when you're trying to get NDIS to fund in their words, the capacity building, the allied health disability support workers to keep supporting someone to keep developing their skills, you wouldn't use the rehab word there.
- DG Okay, so I remember you said that we need to be smart in how we present our situation. What I'm hearing is that you say there is a bit of an art that needs to be developed in terms of allied health developing that kind of language, that we all explain a person's needs in disability language.
- CB Yeah.
- DG How do you do that?
- CB Well, you would go on to our website, George, and find a beautiful new resource called Getting the Language Right, written for health practitioners, and you can look at that.
- DG Okay, Getting the Language Right and that's on the Summer Foundation website?
- CB Yes, yeah, and it's, it is an art, so the first thing I'd say is that lots of people, again, Victoria and New South Wales, lots of health people will have worked in the TAC, will have worked with lifetime care, will have worked with Work Cover, so the NDIS is an insurance model and lots of it is based on those similar programs that in that way, it's not that different. So we've all had to adapt how we've written reports or written information to meet the needs of the funding body, so I think when you start to feel, it's so easy to quickly feel overwhelmed with the NDIS that try and remind people, we've all done this before and it will take a long time to get used to it, but once you've written that first report, then you've kind of in the groove of it and you

can keep using that for all different people and adapting it to the individual person. So the common language art, you're right, is about we need health to keep being really great at describing the health condition because that's what we're good at, and really great at describing the impairment, but you need to pop in the word permanent because that's to meet the legislation to be eligible and then we all have to get much better, I think, at talking about how that impairment effects somebody's day-to-day life and even more importantly, how does that permanent impairment, say, a memory problem, affect how that person is as a dad with their family, with their friends, getting a job, in their real life because that's what's most important.

DG Yeah, and listening to you reminds me of the social model and medical model divide in that for a long time, the medical model was really at the forefront in people with disability's lives in saying, what's wrong with you? What is it that's wrong with your body and very focused on the body. The social model is far more interested in the environment or the way you face barriers in terms of interacting with the environment, so it seems maybe some allied health advocates could benefit from being more under the social model and consider environmental and social factors.

CB Yeah, I think that's exactly right, and I'd say it's, we've got it all because you can't also, so your diabetes, the example you were saying before is a great example, so if you just put in, I have trouble, I feel really tired and I've got lots of fatigue and that means I have difficulty going shopping, you couldn't just write that, could you? You have to write, which is because of a permanent impairment that I've got which severely limits my capacity because of how the legislation's written for the NDIS, so you can't just, the broken leg is another example, you can't, the broken leg is very difficult and it does mean you've got difficulty day-to-day, if you need to use a wheelchair or crutches, but it's not a permanent thing, so that's what the NDIS is all about.

DG I'm thinking in terms of the allied health people who are listening, they're obviously going to go to the Summer Foundation website, by the way, and download these and we have some amazing resources, not just around the language of health, but there are other ones as well, and what are the other ones that people can look at?

CB I happen to have them here, George. So the one that's really relevant is getting ready for NDIS planning, and you mentioned planning earlier, so this is a great new resource part of our DHHS project, and why it's really relevant is that it's a booklet where you look at what are my health needs? What's okay at the moment about, in relation to those needs? What could be better and then you go through all your different support needs, so self care, health and wellbeing, just having a little look, house and home, all the different areas of your life, you think about what do I need? What's good at the moment? What could be better and it helps you say, well, that's probably sounding like a support need that the NDIS might be able to fund, or that's sounding more like a health need that health need to fund, so you can take this booklet in to your planning meeting, having thought about all those things.

DG Absolutely, well, thank you, Cath.

CB No worries.

DG Are there any final words of wisdom or bits of advice for our listeners, apart from going to the website summerfoundation.org.au and checking our resources? Is there anything else you'd recommend?

CB I think it's just thinking about the support that you need, and asking yourself a bunch of questions which might be things like what does having the support mean you can do in your everyday life? How can it help you live in the community and at home? How will that support help you to be with family, friends, go out, do anything that you want to do? Will the support mean that you can work or study or volunteer or do a hobby? So if you can answer those kinds of questions around the support that you're asking for, then it's more likely that the NDIS will fund that, and if you're thinking, this support helps me, yet actually keeps me alive, helps me manage my health, if I don't have this, I'll end up back in hospital, then that's sounding more like a clinical health need.

DG Absolutely, and people should also remember that the NDIS was never intended to solve all of our problems, so we need to recognise that there are things that we need to actually advocate for. It's our health that matters and we should definitely advocate for ourselves around those needs, and not expect that the NDIS will solve all of our problems.

CB Yeah, yep, exactly.

DG Thanks for your time, Cath.

CB No worries, thank you, too. Thanks.

DG That's all we have time for on today's episode of Reasonable and Necessary, brought to you by the Summer Foundation. Don't forget you can follow us on our Facebook page, Building Better Lives, where you'll find all previous podcasts and transcripts. Well, sadly, listeners, that's it for this second season of Reasonable and Necessary. Please keep your ears open for season three. I'm Dr George, and until next time, stay well and reasonable.

END OF TRANSCRIPT