**Reasonable & Necessary podcast**

**Our Relationships with the NDIS – what makes them work or fall apart?**

**George:** Hi. I’m Doctor George Taleporos and you’re listening to Reasonable and Necessary, brought to you by the Summer Foundation. Joining me on today’s episode are Mark Brown and Kate D’Cruz. We’re going to explore the complex relationships that we have with the NDIS. What makes these relationships work and how do they sometimes fall apart? And when they do get difficult, how do we rebuild trust? Check it out.

Hi, Mark and Kate, welcome to the show.

**Mark:** Thank you so much.

**Kate:** Thanks for having us.

**George:** Yeah, it’s great to have you on. You’re going to talk to us about research. There’s a whole research team at the Summer Foundation. What do you guys do individually?

**Mark:** I’m a Research Fellow at the Summer Foundation and I have been since about 2018 and my job varies from project to project, from crunching numbers, using administrative data, to interviewing people and doing qualitative research, so a wide range.

**George:** And Kate, yourself?

**Kate:** Yes, I’m a Senior Research Fellow at the Summer Foundation. I have a background as an occupational therapist and found myself really interested in doing qualitative research. So, my particular interest is listening to people and being curious and finding out a little bit more about their experiences and really I guess 1 of the main focuses of our research is partnering with people with lived experience of disability and working together to understand their experiences and hopefully then communicate those in a way that has impact, and particularly at a policy or government level.

**George:** You’ve both been doing some really interesting research around the NDIS and you’ve done a study where you’ve done quite in-depth interviews, right? Why did you talk to people about the NDIS and how many people did you interview?

**Mark:** This project that we’re currently working on, we began late last year in the - it was still in the leadup to the election and there was a lot of discussion at that time about the future of the NDIS, the S-word was being thrown around a lot, sustainability of the NDIS, and so the project that we started is a qualitative project to look at the NDIS from the perspective of what it’s like to be a participant, what it’s like to be in the mind of the participant and live that experience. So, we’ve been interviewing people 1-on-1 or 2-on-1 with a friend or family member or someone involved in their lives and the interviews have been really interesting, in-depth conversations.

**George:** I like it, I like depth, it’s good. What have you found so far?

**Mark:** We’ve done 13 interviews and the key thing is this idea of the relationship participants have with the NDIS and with the NDIA. It’s a relationship that their life depends on because they require reasonable and necessary supports and so, for the participant, making the relationship work is non-optional.

**George:** Yeah. Like if you and I opted out, like “Oh, we’re done with this NDIS,” we are - I’d be dead in a few hours really or maybe 3 or 4 days if I’m lucky.

**Mark:** Which is a bit different to some other government schemes or government services where the idea is something is provided short-term and then the idea is that you won’t need that anymore and, “Goodbye, we hope not to see you again.”

**George:** And that’s what we advocated for right, we advocated for a lifetime scheme, something that will be there that we can rely on. These are all good things that the NDIS is there for us.

**Kate:** Yeah and can I add there, George, that’s something I think that’s really important from what we’ve learnt is that there is this really strong goodwill, this vested interest or commitment for the NDIS to be successful. So, for that very reason that this is an ongoing relationship, it’s really central to people’s lives, they can’t opt out of and I think that point in itself is really important that we pause and recognise that, because that really just - I think that shapes the rest of our understanding around people’s experiences of the NDIS currently.

**George:** Yeah, indeed. So, what’s it like, Mark, when you’ve got this relationship with a government bureaucracy which - I think that once you’ve got half a million people on the scheme, it’s hard not to be a bureaucracy.

**Mark:** The takeaway for me from doing these interviews and looking through the data is how complicated the relationship is and the mixed feelings that often came up. So, on the one hand, most people we talk to would bring up on their own, a range of really real benefits and important things where the NDIS has been vital for unlocking opportunities and making a range of things possible. So, most people on the one hand are really wanting to emphasise that to us, that the NDIS is working for them in some way and that it’s not a scheme that they would ever want to see go away. And then the other side is something that came up a lot, which was a sense of a loss of confidence or a loss of a sense of stability in the scheme and their relationship with the scheme.

So, even when people talked about, “Being able to use my funding to do this and this and that’s been a great improvement for me and my quality of life compared to before the NDIS,” for a lot of people, there is this underlying fear in some cases or apprehension that what if the rug is pulled out from underneath them and that’s a really key thing that we plan to investigate more and talk about more in our upcoming report which will go into things in more detail. But I suspect that this is a key issue that we need to have a conversation about in the disability community.

**Kate:** And Mark, I guess 1 thing, we got a sense from the people that we’ve spoken to so far that what’s fuelling this loss of trust or confidence is experiences of really long wait times for funding, people feeling kind of vulnerable, at risk in those wait times. People in particular who don’t have other external family and supports. People are also describing this lack of feedback around the process of their funding or trying to make contact with the NDIA and not having people that either understand their particular situation or not having the skill or knowledge in that moment to understand and talk with them because particularly, people with cognitive and communication difficulties were sharing a lot of frustration with that feedback and the nature of - so, the lack of feedback and the nature of the feedback.

So, there were some really specific examples that participants have given us around these experiences that continue to happen that seem to be eroding this confidence and trust in the stability of the scheme to support their needs.

**George:** And you had a really nice quote around that, didn’t you, around someone who had that experience?

**Kate:** That’s right, yeah. One of our participants said, “We rely on the NDIS and I think that for the NDIS to recognise how much we rely on that funding and especially for people like myself where they’ve got no internal support like family and partners, we rely on that external support because we don’t have a family to rely on, we don’t have a partner.”

**George:** Yeah and that’s the reality for a lot of people and that’s really I think where - if the NDIS isn’t working and you don’t have the informal supports that it’s even more critical to get that relationship working for you.

**Kate:** Absolutely and people also talked about examples of where there’s that gap in funding and actually then agencies continuing to provide support without funding in that time because of the vulnerability of that person in that moment. And that’s a really big ask for someone and what was happening is people are saying they felt guilty or uncomfortable having to be a burden on an organisation that’s not being funded in that moment for providing support. But they didn’t have any other option and the agencies have recognised that, and those who do have external support were really reflective and concerned about others who may not. So, they could recognise those risks for others.

**Mark:** That was a really interesting thing that came up a lot in the interviews, Kate, when people would say things like, “I’ve worked really hard and I’ve advocated for myself, I’ve fought to be treated fairly and to get the reasonable and necessary supports I need but I’m lucky that I had the ability to do that and if I wasn’t in a position to do that, what would happen to me?”

**George:** Yes, the self-advocacy that you need to do every day is really intense sometimes and it is concerning that not everyone necessarily has that ability or that support or those skills to advocate for themselves.

**Mark:** It brings up that self-advocacy and advocacy skills are always great to have but if the relationship with the NDIA was a partnership where you both had the same goals, then would you have to advocate to NDIA to support you with reasonable and necessary funding or would it be a process of, “Let’s work out the funding plan together because we both have the same goals.”?

**George:** Yeah. I think their goals are tricky, aren’t they? Because the NDIA’s goal is to obviously provide the supports in accordance with the Act and that’s all open to interpretation and often, the planner that you are lucky or unlucky enough to end up with. Is that something that came out?

**Mark:** Yeah, particularly that idea of, “Look, it depends who you happen to be put in contact with on the day.” One planner might tell you 1 thing but another planner might have a different interpretation of what the rules are, what the guidelines are and what you’re entitled to.

**George:** I reckon there’s a lot of fantastic planners out there that are doing great work and we need to acknowledge that. It’s just that not everyone is lucky enough to land that planner and then there’s when the funding is of a particular type like it might be SDA, then there’s all the bureaucracy of getting that looked at. So, it does get more complicated, doesn’t it?

**Kate:** Yeah and I think if you go back to this concept of being in relationship with, something that we heard from the participants was this need for consistency or someone who understands you and your needs and can travel alongside with you, so they talked about this idea of having a - people really relied on it, an ally or someone who they could trust and who could provide that support and sometimes that would be a support coordinator or planner but other times, it might be close others or other allied health professionals. So, that became really - I guess that was a really central theme, wasn’t it, Mark, that people talked about, was this idea of having an ally?

**Mark:** Yeah, having an ally seemed to be something that for the people that felt like they had that, that it was something protective or something that helped them cope with the relationship that they don’t have with the NDIA. So, for some people, having a support coordinator that they have a really good relationship with or a friend or family member that helps them work through their NDIS journey meant that the fear and uncertainty about dealing with the NDIA was a shared problem and seemed to make it an easier process for a lot of people.

**George:** Yeah. You reminded me of the quality and safeguards framework that talks about developmental safeguards and it talks about all of those relationships that we either have or don’t have in our lives that are actually the basis of whether or not you have - you’re at risk of abuse or whether or not you’re able to be resilient in certain areas. I think that a lot of people with disability, because of the social exclusion, because of the discrimination, because of community attitudes, a lot of us don’t have all those really important foundational relationships.

**Mark:**  I was just thinking about the - just the level of self-knowledge and thinking about life goals, it’s kind of an odd thing. I think most people would think it’s an odd thing to be on the phone or having a meeting with a government agency and talking about, “What are your life goals for the next 5, 10 years?” It’s more like a job interview question but it’s - I’m an NDIS participant myself and that’s always a tricky part for me to answer and think about. What are my life goals and what makes for a good life goal and how does what I say about my goals affect what supports will be deemed reasonable and necessary? I personally find I definitely need other people to help me think through what it is I actually want.

**Kate:** George, I’ve got a nice quote from another participant. Can I share that now?

**George:** Yeah, love it.

**Kate:** So, one of our participants, in reflecting on a really similar point said, “You need to get a good support coordinator but it’s very important that you get along with your support coordinator and she or he understands your needs and what you need for your plan because there’s no point getting a support coordinator that doesn’t know who you are because it’s all about supporting you as a person,” and I think that really nails what we’re talking about here, doesn’t it?

**George:** Yeah, I think it does. Can I add on another layer of complexity to that? Support coordinators come and go, don’t they? So, there is that issue around when we’re dependent on someone paid in our life, what happens when that person leaves or what happens if we can’t find the right support coordinator for our needs? It’s complicated.

**Kate:** Yeah, absolutely and that contributes to that lack of stability, that fear around, “I might be okay for now but I don’t know in 6 months or 12 months,” and that was really evident across a number of the participants.

**George:** My little life lesson is, never rely on 1 person for anything. So, you talked about trust and how that’s important. What are some of the things that you’d think need to happen to strengthen and build trust in that relationship between people with disabilities and the NDIA?

**Mark:** If we are right, and this feeling that we’ve heard in who we’ve talked to is more widely shared, then rebuilding trust is going to be pretty important and if you think about it as a relationship between participants and the NDIS or the NDIA, then as in any relationship where trust has been lost, it’s going to take time to get that back. So, even if tomorrow, every policy changed to whatever you happened to think was the best thing, it can still be a lingering feeling of, “Okay, things are going better today but I felt that way in the past and then I felt let down later on.”

So, a consistency over a period of time of things improving is probably going to be important and the other thing I suspect is the dialogue that happens between participants and the NDIS and NDIA and government going forward. In relationship counselling, if you’re going to relationship counselling, a good place to start would be both sides having an open and honest dialogue where the mistakes can be admitted to and everyone feels safe to talk through their feelings about it. Maybe something similar needs to happen between participants and the NDIS.

**George:** Well, considering a lot of people are in court at the ATT with the NDIA, I think there’d be a bit of relationship rebuilding there that might need to occur there but that’s really tough. Once the trust has been broken, like you said, you’ve got to do some work to get it back. So, ideally, Mark, when you - what sense did you get from participants about what they want this relationship to be like? What’s a healthy relationship with the NDIA?

**Mark:** I think it probably looks different for different people but some common elements are this sharing of goals or sharing of the ultimate purpose of the scheme, that my goals of pursuing my personal goals and the NDIA’s goals aren’t in opposition to each other is one thing.

**Kate:** On that line, people talked a lot about this idea of being understood, so actually working with people in an organisation that really gets them and their needs, so it’s about together, problem solving solutions and working really positively together and perhaps less of trying to fight for this understanding of, “I need this funding,” or, “My particular situation is this.” So, understand - and I know that’s a nuanced concept - but that did come up a lot from participants, and this idea of - I think Mark, you talked about - making mistakes and learning together, so recognising that we haven’t got it quite right now.

Going back to the relationship though, also I think it’s good to remember this idea that there was a lot of goodwill because again, people can’t opt out of the relationship. So, rebuilding trust is difficult but it’s really central. People want and need this to work, so whether it’s hard, I think recognition of the importance and centrality of this relationship and the desire to get it right and there’s a lot more I think we can do in this space to work out together, some good solutions.

**George:** So, less fighting and more working collaboratively, yeah?

**Kate:** Yeah, it’d be great.

**Mark:** And more open, honest dialogue and actually, the Summer Foundation has another research endeavour which is trying to further that along a little bit.

**George:** Tell us about that.

**Kate:** So, we’ve got a survey out currently and it’s designed - some very simple questions but really focused on people having a say in the future of the NDIS. So, really keen to understand what’s working well from people’s perspective and what you would change if you could, like if you had a magic wand, 3 things you would change to make the NDIS better. So, really honing in on that understanding to them propel some generation of solutions. This survey is - you can find it on our Summer Foundation website, you just scroll down a little bit and you’ll see, “Have your say,” and it’s also on our Summer Foundation social media sites, so you’ll find that on Facebook and Twitter and LinkedIn and also, they’ve got a question there around if people are interested in sharing their story.

So, we would really love to hear from more people around their experiences to try and get together and to generate some solutions. In our study, Mark and I are also looking at going back to some participants who we’ve spoken to already and then also going back to some new participants to get a little bit more understanding around solutions and ideas that can contribute to a change and hoping to run some workshops as well which is very much designed around NDIS participants coming up with some solutions that we can then take back at a policy level and government level to try and inform some new developments.

**George:** Sounds great. So, when does the survey close? How long will it be open?

**Kate:** I think mid-July, it’ll be closing.

**George:** Mid-July 2022.

**Kate:** That’s right. Thanks, George. I’m really encouraging people to grab that opportunity because it is a really - it’s designed as a simple survey and it’s open to anybody in Australia who’s an NDIS participant.

**George:** And you know what I love about what we do at the Summer Foundation, is that we don’t just ask questions because we’re interested, we actually use that information. So, we have a new government and it’s a new day, a new opportunity to influence and why not get involved, do the survey and we’ll use that to tell the government what people want.

**Kate:** Absolutely.

**Mark:** Absolutely.

**George:** Any final comments?

**Mark:** Just thank you so much George, for having this conversation with us. It’s been great to talk about the research. We’re really passionate about it and it’s great to hear your thoughts and hopefully other people find it interesting.

**Kate:** Yes, thanks George and shout-out to our participants as well. They know who they are. We’re learning so much from spending time with talking with people about their experiences and really looking forward to sharing the learnings a bit more widely and hopefully getting some really positive change.

**George:** Yeah and thanks to both of you for coming on the show and hopefully we’ll do another one and we’ll talk about what the findings were.

**Kate:** That’d be brilliant. Thanks, George.

**George:** All right, have a good afternoon.

**Mark:** Thanks so much.

**George:** Bye, everyone.

**Mark:** Bye.

**George:** That’s all we have time for on today’s episode of Reasonable and Necessary. To be notified of future episodes, don’t forget to hit the subscribe button and the notification bell. Thanks for listening and until next time, stay well and reasonable.