**Reasonable & Necessary podcast**

**What does good NDIS support look like? Participants tell all and it’s not what you think!**

George: Hi I'm Dr George Taleporos and you're listening to Reasonable and Necessary.

The NDIS podcast series brought to you by the Summer Foundation. This episode is in partnership with the NDIS Quality and Safeguards Commission. On today's episode, we’re talking about what good support looks like and what NDIS participants want from support workers. And you know what? It might not be what you think. I speak with La Trobe University PhD research student, Megan Topping, and NDIS participant and the director of Sort Your Support, Carl Thompson.

Check it out.

George: Hi Guys, Welcome to the show.

Megan: Hi George, great to be here.

Carl: Hi George.

George: How about we start with a bit of an introduction to both of you. Carl, you’re on the NDIS and you also run your own support coordination business, right?

Carl: Yeah, so I've been on the NDIS since 2016 roughly so about 6 years now and I've been running my own support coordination business for about a year and a half now, it's going well. Obviously, I was doing things before then as well. But I think being an NDIS participant really helps in terms of understanding the ins and outs of the NDIS and I can give people some kind of advice from the ground around how to build their own support team and how to deal with the NDIS reviews and all that stuff. So it's going well, yeah.

George: Fantastic. I love it that more people with disability are getting into the service side of things, I think it's really really valuable. So, Megan how about yourself, tell us about you and what you do and your research because that’s what we are here to talk about today.

Megan: Yeah, thank you. I'm Megan, I'm a final year PhD student at La Trobe University and my research is supported by the Summer Foundation where I also work as a research assistant. My research is looking at the factors that influence the quality of paid support, so that's support from disability support workers, primarily for people with acquired neurological disabilities.

So, I'm talking to people who have had an acquired brain injury, a spinal cord injury or neurodegenerative diseases like multiple sclerosis. And I'm asking what they think influences the quality of support, and as part of my broader PhD I'm also talking to support workers about what they think and also close others, so, partners or family members of people with disability as well. But today I'll just be focusing on the people with disability’s perspective as that research has recently been published.

George: Yes, it’s probably the most important perspective, isn’t it?

Megan: I would say so, yes.

George: So, what led you to get interested in this topic of what people with disability want from their support workers?

Megan: Well, with the introduction of the NDIS we obviously really expected and hoped to see the needs of people with disability really centre to kind of service redesign and how we, what support looks like for people. But I feel, almost 10 years on and there's still limited evidence from people's perspective about what they want, which is meant to be the centre. So, I really wanted to go to people with disability and ask what is it you want from support and from your lived experience, what else can impact whether that quality support is happening in practice. I interviewed 12 adults with acquired neurological disability in Australia who had a range of complex communication, physical and cognitive impairments, and all required 1:1 disability support about their experience and what they want from support as well.

George: Alright, so how about we have a chat about them, and it would be great Carl to get your perspective as well, in terms of how you feel like these things relate to your experience.

So, the first theme and you know it seems quite obvious to me, but not always obvious according to the participants in your research. And that was to treat me as a person.

Megan: Yeah, so you would think that's quite obvious and it's quite sad that it's something that people feel they have to point out. But in the words of my participants, people felt they were treated by support workers as just a job or a number, a patient or at the kind of worst end of the scale, someone said they felt like they were just a body in a bed.

George: Wow.

Megan: And this is not the way anybody should be treated and participants felt they wanted support workers, what they meant by this, being treated as a person, was to be treated with respect, with dignity, with a sense of empathy, which was caveated with, not sympathy, empathy. And just in practice, this looks like talking directly to me, not being condescending, not talking for me when I can do for myself or doing for me when I can do for myself. So yeah, it was mainly about that kind of respect element and 1 of the participants, who I will call Ashley, when I talk about quotes today, I will be using pseudonyms, they're not the participants’ true names, to protect their identity. But Ashley felt he just captured it, as all support workers have to do is treat other people how they would like to be treated. It really just demonstrates that, just treat me as a person.

George: Ah, so true. Carl what are your thoughts?

Carl: Yeah, I think that's, it sounds obvious but it's harder to find than you might expect. And I think some of that can be due to the training some support workers might have received. I think often the training is a little bit based on people's diagnosis, or what support needs people have so rather than coming from the view that everyone is different and everyone is unique, some of the training focuses on if someone has autism do this, or if someone has cerebral palsy do this and that kind of clouds people's views around actually treating someone as a person first and then working out what supports they need after that point. And so, I think that's yeah, that's true in my experience as well.

George: And you know that body in a bed. You know that really resonated for me because I had a friend and she and I used to talk a lot about workplace health and safety and the agency would say to her, “Oh this is how we lift things”. You know you're not a thing, I’m a person and when you move me this is how I need to be moved. And ask me, and they’re like, “Ah that isn’t how we were told to move things”. It’s like, yeah right that’s the problem.

Carl: Yeah, it's that you know realising that people are unique and even if they might have the same disability as someone else that they're working with, it doesn't mean that all the supports provided have to be done in the same way or the expectation that everything should be the same.

George: And the other thing that I can agree with 100% is the 1 around people being seen as the experts in their own care, can you tell us more about that Megan?

Megan: Yeah, and I was going to say that flows on really well from the treat me as a person because as you were talking about there Carl, about the disability type and that was something people said, people make assumptions based on my disability type, as you're talking about, rather than seeing me as the expert in how I would like to be moved or how I would like to be supported, or all of anything I need support with. I know best about what I want from that.

So, this kind of emerged as almost 2 themes - 1 from thinking about what the support worker needs to do, which is see the person as the expert. And then the other is that the person with disability needs the opportunity to lead their own support, so they go hand in hand. And as we've said, people with disability are all different and will need things done differently, will need, will want things done differently. So, what this looks like is support workers listening to the person with disability, being willing to learn from the person with disability that they're supporting, not coming with those preconceived ideas, not with those assumptions, not ‘oh when I worked with this person they wanted it this way’, that doesn't matter. It's what I want.

And some people with disability talked about how sometimes they felt like they were perceived as demanding or too opinionated for asking for what they wanted when actually that's what the role is.

So, I have a couple of quotes here which I feel will say it a lot better than me.

George: Yeah yeah,I love quotes so bring on the quotes.

Megan: Great. Yeah, so I have one from Alex who said, “even if the rules seem ridiculous and over exacting, if I say something's important just trust me that it's important, respect my perspective”. So, you know, don't do things because you think that's the way to do them when that's the way I've asked

and similarly, Charlie said, “you're here to help me. It's not what you like it's what I like. If I don't like my shirts ironed, don't iron my shirt because you like them ironed”. Again, it just captures It.

George: Carl I know that this is something that we've talked about before, but you know often we would say that people who, when we're recruiting people, we often feel a bit nervous about people who say they have lots of experience right? Or lots of qualifications.

Carl: Yeah, it sounds a bit counterproductive, but I really like hiring people who are enthusiastic and willing to learn but might not have very much experience or qualifications and then me training them in the way that I like things done rather than perhaps getting people who have lots of experience or lots of qualifications who might be a little bit more set in their ways and maybe falling into some of these traps that Megan's been talking about in the research. So yeah, it is tricky. Like I don't want to discount people's experience but for me personally I like starting with someone who has the right attitude and the right willingness to learn rather than someone who might be a bit more set in their ways and want to do things in exactly their way.

George: Yeah, and I think that’s something that I hear a lot and I feel like we're not saying that experience is a bad thing, or qualifications are necessarily a bad thing, but it’s like each time you meet a new person with a disability, you need to come in knowing that they’re not going to be the same as the person you might’ve worked with 10 hours earlier and that you need to listen to them and not impose what you think they might want, yeah?

Carl: Yeah, exactly.

Megan: Absolutely yeah.

George: Another key thing was the importance of compatibility, right? And that having shared interests was kind of more important than other things.

Megan: Yeah, absolutely. Participants really acknowledged the kind of complexity of the support worker/person with disability relationship can be because, you know, it can often be a lot of time spent together, a lot of time that's very personal and it's that weird hybrid of the kind of personal and professional coming together in your home and so participants felt it really helped to be the right fit. So find someone that you either… for some participants this compatibility looked like, as you said, shared interests - being a similar age or the same gender. Whereas others talked about it more implicitly as a sense of gelling or connecting with their support workers so you just get a feel for it when you meet them that they're going to be someone you're going to be able to work well with.

And then beyond that, there's the kind of mutual respect and communication that having that compatibility really makes you comfortable and means you can kind of have that trusting relationship with someone. So yeah, people really did see it as often more important than most other elements. There was 1 participant, Sarah, who said, when she was talking about recruiting new support workers, she said, “never once have I asked to see resumes or qualifications, I really don't care what she's got, I care about how we gelled”. So it's exactly what you were just saying, it's that actually those things don't matter. It's… what matters is whether we can work together, you know, it's people working with people.

George: Absolutely, Carl?

Carl: Yeah, I was going to say, yeah sometimes, because I work with lots of nursing students and sometimes the nursing students say, “oh you know this is very different from what I do during my nursing placement”. And I say yeah, it is very different because you know you're in my home. You're not in a hospital. The aim is some of those softer skills and having a place where I can relax. And the aim isn't always treatment or therapy, or things like that, it can also just be a bit of leisure and a bit of chilling out having a coffee. So, it's that thing where some people think that disability support work is the same as nursing, or that kind of acute care. Whereas in my mind, there's some similarities but there are also lots and lots of differences and 1 of them really is around the importance of compatibility rather than just qualifications and skills.

George: That’s really interesting Carl because I feel the same way and I do find that people with a nursing background can kind of make you feel like you’re sick and you need treatment and it’s actually you know this is different. It’s support work, it can be a little bit more relaxed and not necessarily as engineered as how a nurse might work in a hospital and we want to not make our homes feel like hospitals do we?

Carl: Yeah, exactly. Yeah, it's very different context.

George: Yeah, I think that’s an important thing for people to keep in mind. So, Carl I’m Interested in hearing from you in terms of your experiences. Have you had any experiences similar to what we’ve heard in terms of working with support workers?

Carl: Yeah, so I suppose before I was a bit more actively involved in the recruitment and training of support workers I did run into more of the issues that Megan uncovered through the research. So, thankfully, that hasn't really happened with me as much anymore because I have a lot more kind of control over it. But I definitely have experienced it in the past and that was traditionally through some of the more conservative, or the more traditional, disability support worker agencies.

My favourite example was when I went to university and I had some support workers come in from agencies. They always were 50 to 60 and I was, you know 19 or 20. They always wore these bright blue polo shirts, and that made me feel really kind of uncool, and you know, didn't want to be near them and didn’t want to be associated with them. And so, it didn't really fit in with what I wanted in that situation, but because I was young and new to everything it wasn't something that I felt like I had much control over. And that's where some of those issues that Megan has found through research came up. But now luckily it happens less because I've got more control over people that I work with.

George: I’m so glad you said that Carl because I know when you and I, we had a bit of a history where we worked together at the Youth Disability Advocacy Service and I do remember working with young people, and they did talk about that a lot, that they want people in their own peer group, people who aren’t going to feel like they’re from an agency, yeah?

Carl: Yeah, and I think yeah, I don't want to digress too much, but it is that balance because even though you know I'm very friendly with support workers and some of them I would say that they're my friends but there is still that professional relationship, so you don't want to go down the trap of making … of having paid friends. You still want them to do a job and to be professional and all of that but you also want them to be compatible with your own interests and kind of fit into your life in a good way. So, it can be a bit tricky at times. I think it is fair to say that you do want someone that can fit in well with your life and your own circumstance and someone who doesn't stick out like a sore thumb.

George: Megan I know that you explored that in your research, you talk about boundaries and making sure that people were, had an understanding of the nature of the support worker relationship. Do you want to talk a bit about that?

Megan: Yeah, I was going to say everything you were just saying Carl was really resonating with what the participants in my research said, and it was that it's really hard because, as you said, it's someone in your home and it's someone you want to be compatible with but it's still someone doing a job. And when those boundaries get blurred, it can then be difficult, especially if you're managing your own support team. It can be difficult because you'll then have this weird dynamic if you do want, if you have a problem with the way they're working or something, it can make that kind of element more difficult. So it's having that balance, as you say, of the kind of friendliness and it's comfortable for us and I enjoy your company, but also it's led by my boundaries, like I don't want you to be involved in Xyz. So I have some participants who really want that closer relationship and then other participants who are like no, but when I'm with my friends I'm with my friends and you're here to support me and whatever I need. But you're not kind of 1 of the group, which sounds… I don't know if that doesn't sound … but that's how it is and it's that kind of again, it's led by the person with disability and what their preferences are. But it can be quite a challenge to get that balance right in such a … kind of personal space, like when it's in your home.

George: Ah, look I think that what you just, what you have pointed out is that it's complicated and this is where communication is really important. And to be able to say, hey these are some of the things that I feel like aren't working, or these are the things that are working and what can we do to address some of those things. And you don't really have those conversations easily, they can take a bit of practice. What do you think Carl?

Carl: Yeah, it is something that can take practice and I think this is where it is tricky because there is a shortage of support workers at the moment in Australia. And so, it means that courses are quite short, they're quite easy to get into and all of that. And that that's great in terms of increasing the amount of people working in the sector, but it also kind of reduces the utility of some of the training courses when it is actually a bit more complicated than some of the training makes it seem and so there is that real tension between increasing the workforce supply, but also making sure that those working in the workforce are either suited to it in the first place, want to be there, want to be working in there, or appropriate for the individual person they're working with. It can be really tricky, and it's something that we could talk about for hours, I'm sure.

George: Yeah, I also think Carl, that it is tricky. We need to also build a capacity of participants to have the knowledge and skills and the confidence to have those difficult chats.

Carl: Yeah, and if I can just add to that George. And 1 thing that I do through my work as a support coordinator is helping upskill participants around what their rights are. And often they would say to me “my support worker does this”, or they say that they can't do that or they say that they're not allowed to do this or that, and I say it's not true. You know, if you have a preference for something you're able to articulate that. And so 1 thing that I do is kind of help build their capacity to actually say what they need in that support. Because lots of people I think are a lot more shy, or less confident than maybe you or I George, or some of the people Megan that you were studying, working with in your research. So yeah, it is something that we need to build the capacity of people seeking support as well as the support workers themselves.

George: It's not something that you will develop overnight, it does take practice and it's great that you’re providing that support Carl for your service. Megan, there are also some interesting findings around the context of within which the support was provided and you talked a bit about how it can be different when you live in a group home or when you share supports. Can you tell us a bit more about that?

Megan: Yeah, so some of my participants were living in shared supported accommodation or had previously lived in a group home setting and it really showed that where people live and how their support is arranged can really impact how much choice they have around those arrangements. So, for example, people living in shared supported accommodation felt they had less choice around who supported them. They had to kind of take who was there and that was that, they also felt kind of less empowered to say if there was a problem with a support worker that they were working with because there was that fear, almost the kind of culture of the environment where they were like “oh I don't want to be the difficult resident” or “I don't want to be talked about in the staff room” and those kind of things, so they then didn't complain if there was a problem meaning that you're putting up with substandard support which, that's not choice around what you're … you know, around your supports.

And also, some participants talked about that being, we know high turnover is a problem, kind of sector wide. But it felt like it was more so in those environments where you just again, you saw whoever was there rather than had your own team of workers. So yeah, just showing how that kind of really impacted whether they had those choices around who supported them but also around their own day. So some participants, they kind of have to fit into the timetable which we're supposed to be moving away from that institutionalised setup. But yes, some people still felt that. I actually have a quote here from Kelly one of the participants who felt…They were living in shared supported accommodation and felt it was very much about getting through the numbers and the work as quickly as possible. They won't necessarily spend time on individual pursuits. So again with that kind of schedule, you just felt like you were another number to get ticked off and then …So it's again how that environment can reduce your autonomy.

George: Yeah, that's a really institutional experience that I think can be really really harmful for a person to have to be seen as a number, or for someone to work through every day.

I think that the psychological impact of that can be really really concerning and it's why I advocate, you know a lot of us do, for people to have the right to live in their own homes and not in group homes and to be in control of their support. That right Carl?

Carl: And yeah, definitely and it also goes back to what you're saying before Megan, about those with the least capacity to speak up about this type of behaviour are the ones that unfortunately will endure it the most because they're less likely to have the confidence to say “no, that's not right’ or advocate for other options. So some of that responsibility is on our shoulders as advocates or researchers or support coordinators, to try and make things better for other people as well. Yeah.

Megan: Absolutely and just on that, you've just reminded me of a participant in the research who talked about feeling like this other resident in a group home situation was the favourite because they were non-verbal and not able to say “no”, and “I don't want that” so they were less difficult. And they spoke about “oh, she was the favourite because she couldn't complain, whereas I was really difficult because I could say what I wanted”, which, as you say, is that abuse of people who can't speak up and putting up with substandard support or worse when then the other people feel like they shouldn't be, so yes, definitely that's where the advocacy is really important, that we're not letting that happen.

George: Yeah, and I think it's really important that people know that they can complain, that there are, that they have rights under the NDIS Code of Conduct. And that all support workers, whether they are registered or unregistered, have to comply with that code of conduct.

Megan: Yeah, absolutely and support workers need to be aware, making participants aware that that's possible as well. If people aren't, or people need to be supported, make complaints if that's necessary.

George: Yeah, and I also know that the commission can support people through complaints, so if you’re having an issue with a support worker they can get the 2 of you together and help you work through what’s going on.

George: Carl, your thoughts?

Carl: Yeah, I like that there is the Code of Conduct. I think not as many people know about it as they should, and I think again, the Code of Conduct and lots of the points in there are you know common sense. But unfortunately, there are often breaches of the Code of Conduct. But I think what I would like to see to make it a bit more powerful is some examples of there actually being providers held accountable to it publicly because I can't really think of anything where there’s been a breach of the Code of Conduct and there's been any action against the provider. So, I think for me, to make it more effective there could be a bit more publicly … promoting it actually being implemented and used.

George: Yeah, absolutely communicating that because I think there’s a lot of privacy around it and I can understand the reason for that. But obviously it's important that we see people get the support that they need to address issues where they’re subjected to either abuse or violence or neglect. It's really important that people do speak with the Commission, and they are there to help. That’s what they’re there to do. So, before we go there's 2 things I want to do, I want to make sure Megan that I haven't missed anything in terms of your key findings, is there anything else that stood out?

Megan: I think we've covered most things. I was going to talk about the importance of the support worker really wanting to be a support worker, but Carl did touch on that earlier. But that really came through in the research as well, that they knew when support workers were there to just fill in a job or just for money or whatever other reason whereas those who really come understanding what the role is and wanting to do it are those who commit and who are reliable. It makes sense. But unfortunately, it's not always the case.

And I also just wanted to highlight because I don't want this to come off that there are many fantastic support workers that people also talked about, and they did have those people that really did see them as the expert and ask what they want and ask for feedback and all of those elements. So, this isn't to say that isn't happening it's just saying that it's not happening all sector wide and there's lots of room for improvement. But the main messaging is just to say that disability support, needing disability support shouldn't rob people of their selfhood or their choice or their control, and we need to make sure that that isn't happening.

George: Yeah, can I take it a step further and say that needing their support should enhance your life, it's there to make it better. If you’re a support worker you need to keep that front and centre of your work, that you’re there to provide a service that enhances a person's life.

Megan: Absolutely.

George: But let's talk about the implications, Carl and Megan, what do you think are some of the implications of some of this research? Start with you Carl.

Carl: Yeah, well 1 of the big ones I can see is that that there needs to be more input of people with disability in the actual training that is provided to support workers, and that's training, you know, on the job training but also, in terms of the written materials and the teaching of materials. It would be great seeing people who need support work teaching, you know people certificate 3, certificate 4 in Tafe. You know it'll also get people with disability in more jobs, which is another different topic. But I think, you can't talk about what people with disability need as a separate… you know thing that just affects other people. If it's coming from the person who it affects the most, it’s more authentic and probably higher quality as well. I always like equivalising disability with other marginalised groups. You know you wouldn't have a course on LGBTQI rights written and delivered by a white straight man, nor should you. But this type of thing happens in disability all the time and I think if we really want to improve outcomes, we need to make sure that people with disability are heavily involved at conception all the way through to delivery for training.

George: Absolutely, I also think that we need to do more to value and support on the job training. You know I often think that NDIS packages should have more funding for shadow shifts and for that learning that you need to be doing face-to-face with the person in the context of their life. Yeah?

Carl: Yeah, I think the at the moment you know the NDIS’ position on shadow shifts is it should just be something that is a cost that's worn by the provider. But as you can probably appreciate most providers are trying to save as much money as possible so they probably forgo lots of that on the job training, which is very important. So, prioritising that could be a really good way of getting people real experience.

George:

I also think that shadow shifts are a chance to get to know the worker and make sure that the job is the right fit for them or that you are the right fit for them, and that they're the right fit for you. We said how important compatibility is.

Carl: Yeah, and it not even shadow shifts in terms of jobs but also for placement for people who are studying. I think there's not much focus on placement and lots of it just through online quizzes or exams and things where that's not really the one way of going about it, it needs to be on the job training too.

George: Megan?

Megan: Yeah, I absolutely echo everything you've both just been saying, and I completely agree we can't go any further with this without working with people with disability to develop those kind of next steps. And I really do think this research really platforms people with disability as the experts and demonstrates, as we've been saying, it's people with disability who know best and know what quality support looks like and those next steps, I completely agree, need to be people with disability delivering the training. And, also, the flip side, being supported to train support workers and that's not only for people, as we've talked about earlier, people who maybe don't have the capacity in the moment to train their support workers or leave their supports in the way that they may not be able to say what they need, but it's finding mechanisms to support those people to do so. So I think there's a lot of work to be done. But I think this is kind of building that evidence base, and then what I will say is, from here we want to work, continue to work with disability to kind of build those next steps and continually evaluate everything as we go on so we've got that continual feedback loop because if it doesn't work for people with disability then there's no point in doing it. So yeah, I think it just really platforms that people with disability are the people we need to ask, and also I think it shows again that it's the individualised support is what's key. And I don't think 1 size fits all kind of training is the answer to individualised support. It almost seems a contradiction in terms and the participants in my research, really that wasn't what they platformed. They platformed the attitude of the person, that willingness to learn and the compatibility as we've talked about, so I think that’s where we really need to focus.

George: Yeah, absolutely. I think that 1 size fits all qualifications sends a wrong message and we need to make sure that people can have a range of training options available to them and you know also hire people who might not have qualifications because it sounds like from our experiences and from the participants that you spoke to, that certificates are not really the key when it comes to quality.

Megan: And what 1 person might need in terms of those technical competencies is different to the next person. So, it's kind of building that personalised training plan for that person. It's like “well, I need someone who's able to do xyz”, so then there needs to be the training opportunity for that person to go and learn that skill rather than learn all the other skills they don't need for that person… it's just again that individualised approach.

George: So, what’s next for the research?

Megan

So, as I mentioned at the start, this is part of my PhD research and I'm also exploring the perspective of support workers on the same question, and also close others of people with disability. So, those papers are written and hopefully will be published soon. And then I plan to bring the 3 perspectives together to build a kind of holistic model of what quality support looks like. And then with that basis I'd like to do a co-design study working with people with disability to kind of develop those next steps that we've been talking about. And kind of evaluate as we go so that we can hopefully use this evidence base to develop those solutions and help improve the quality of support. That is the goal.

George: I love it so much. It sounds very very useful. You know like we need useful research in the sector and I can’t even think of any other piece of research that would be as useful as what you’re doing. So, thank you for doing what you’re doing. Carl, any last thoughts?

Carl: I think what's also important is whenever anyone is doing a job, if the person you're doing a job for enjoys what you're doing and they get satisfaction from the work that you're providing, it gives you satisfaction as well. So if a support worker is providing good quality support and the client or the participant really loves that and appreciates that, then it makes the support worker feel good as well and makes them want to stay in the role for longer and want to tell other people about their day and encourage other people to join the sector and all of that. It's really… quality is not just for people with disability. Obviously, it's most important for them, for us. But it's also important because it raises the standard and encourages support workers to stay in the sector and to not leave and not get pulled over to aged care or to nursing, and that's important because there are those big workforce supply issues that are a real problem and so we need to also work out how to keep support workers in the support worker role as well.

George: Yeah, so well said. Thanks Carl. Thank you to both of you. Thanks Megan, thank you Carl and I really appreciate your time today and I reckon we can talk forever about this. I think we’ll do another episode looking at the support worker perspective, what do you think Megan?

Megan: I'd love to, that sounds great. We could keep going. Thank you.

George: Excellent, thanks guys. Bye.

George: That’s all we have time for on today's episode of Reasonable and Necessary. Thank you to our podcast partner for this episode the NDIS Quality and Safeguards Commission. 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.