**Reasonable and Necessary Podcast with Linda Hughes, Brigette Kirkpatrick and Marnie Baulch - October 2020**

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 Taleporos, and on today's episode, we're joined by 3 support coordinators to talk about what it takes to get great outcomes for people who have complex needs.

This podcast is especially for support coordinators. So I'll hand you over to my colleague and lead of Summer Foundation's UpSkill Project, Linda Hughes. Linda has years of experience in support coordination and I'm thrilled to have her host today's episode.

**LH:**Hi, I'm Linda Hughes and I'm hosting Reasonable and Necessary today for Dr George Taleporos and I am here with 2 support coordinators, Brigette Kirkpatrick from Create a Sense of Place in Newcastle, and Marnie Baulch from Trio Support Services in Mildura. Welcome Brigette and Marnie and thank you very much for coming along.

**BK:** Hi Linda, thank you.

**MB:** Thanks for having us, Linda.

**LH:** You're more than welcome. And look, I know you're really, really busy people, so I really appreciate your time, having the time out of your day just now to have a chat to us about working with people with complex needs. So, I thought we'd just start by just hearing a little about the work that you do and yeah, just tell us a little bit about the work both of you do, please.

**BK:** Yep, so it's Brigette. So, I work for myself as an independent support coordinator. Went out on my own about 5 years ago here in Newcastle in New South Wales and never looked back. It's been great. My team's slowly started to grow in over 5 years and I think we have about 7 lovely support coordinators now. And yeah, it's just a really great job. We tend to get a lot of people I guess that we work with that have probably not really understood the support coordination role in the first place and possibly haven't got the best out of their plan. So, we usually work with a lot of people to help them understand I guess what support coordination - what we do and yeah, love my job.

**LH:** Awesome, thanks. And Marnie, tell us a little bit about your work and you're in regional Victoria, so that might be a little bit different as well?

**MB:** I'm in Mildura in Victoria, so it's right up in the northwest. I work for a provider named Trio Support Services, which was an existing disability service provider, working with people who had state funding at the time, so which is transitioning to what we now know as core supports in the NDIS. But when we were registering and we heard about support coordination and recognised that essentially it was quite similar to the work I was already doing for Trio, so we chose to register for that as well and I've been providing that service since we had our first local people roll on to the NDIS, which was a year or 2 before NDIS officially rolled out in Mildura. We were the last area in Victoria. Rollout wasn't until January 2019 here. But I had my first support coordination participant start with me in April 2017. So I've been a support coordinator for about 3 and a half years and it's great, I wouldn't go back to any other job.

**LH:** So that's really interesting because, Brigette, you're in Newcastle, where I am as well and we were the launch site of the NDIS, so we've had support coordination since 2013, haven't we?

**BK:** We have, and it has been an interesting ride. Yeah, that's actually what prompted me to go out on my own because I was working for a big organisation who transitioned over to the NDIS from their state funding and probably didn't understand what support coordination was meant to be, so were trying to get me to do some pretty unethical things. So hence going out by myself. So I think it was very unknown back then, well for some, what support coordination was meant to be, how it was meant to look and I think even the NDIA weren't exactly clear with their communication. I think we're still waiting on a framework, aren't we?

**MB:** I believe so, yes.

**BK:** Yep.

**LH:** Yeah, yeah. What happened to the framework? I was hearing about that years ago.

**BK:** I know, I know. Yeah. Seven years in the making, I'm not sure.

**MB:** I'm sure it will be great when it comes though.

**BK:** Yes, yes.

**LH:** So you're both support coordinators who work with people who've got complex needs and we hear that term a lot. So what does working with a person with complex needs mean to you?

**MB:** I'll jump in if you like, it's Marnie.

**LH:** Yep, yeah.

**MB:** So I guess, as I mentioned, I picked up the early entrants to the NDIS here in Mildura, which were the people who were waiting for state based funding or waiting for increases in their state based funding so they tended to be the people who had the more complex needs, to use that term, and they still are. So I still have my existing participants that I've had the whole time. So I guess a lot of them are people who are learning what it's like to access the level of support that they I guess should be entitled to, that previously they've never been able to, there's never been enough funding for that in the past. I'm not sure what the New South Wales funding system was like, but the Victorian one was quite limited.

**LH:** Ours is the same as well so -

**MB:**Yeah, it's been quite a journey for those people and still learning new things, new supports to access every day. An additional issue here is the thin market, as not nearly as many support providers of every kind that is funded by the NDIS as what we need. So I'm not sure how you guys go with that up there in Newcastle.

**BK:** We've got a saturation of providers, being the trial site and I think the issue is everyone's trying to be everything to everyone and doing every single type of support instead of doing what they're good at or my sort of thing is to be the best at what you do, not the biggest, and I think in Newcastle, and I don't know what you think, Linda, but everyone's just doing everything. Everyone's doing SIL, everyone's doing core supports, everyone's doing support coordination. And so it's very hard to wade through the sea of registered providers up here to actually find one that's doing a good job or what you need done or is the right fit for the person. So yeah, even though there's kind of a lot of choice, it's kind of not because everyone's just doing the same thing.

But I guess in regards to probably complex needs and I guess the - yeah, it is definitely a term that gets thrown around and I'm not sure how a lot of people define it, but I guess for me and how I see it is usually when there's - I mean, everyone has more than one thing going on, I guess, but it might be an array of different issues, challenges, dual diagnosis, triple, quadruple, like a whole range of different disabilities and then there might be - like the justice system might be involved or multiple hospital admissions and I guess that's the thing.

If I think of a gentleman that I've been supporting since I went out on my own and he lives with an intellectual disability from a traumatic birth. He then developed paranoid schizophrenia in his 20s and then due to that medication, he's now in his 40s, he's developed Parkinson's. I guess those sort of diagnosis in itself make him a bit more complex because of the different types of supports that he needs and sometimes it's been trying to work out, which you can never quite work out, is where he's at at that time. So he might freeze, his body might freeze because of Parkinson's but it actually also might be his mental health that he's freezing and then it might be the medications that are causing that and then obviously having an intellectual disability as making that hard for him to I guess understand what's going on with his body and then understanding why at times he could run around the block and then at times he can't sort of get out of bed.

And I think then what - we've got a really great team around him, a really good person-centred positive team from all different independent organisations. So he's residing in a SIL at the moment but then has external staff, has an OT, speech, behaviour, psychologist that are all from different places and then obviously support coordinator, myself, in a different place. And it's great, everyone works really well as a team but he has a lot of hospital admissions. We also work closely with a neurologist and a psychiatrist and I guess the language around people I guess trying to educate other I guess medical professions as well about how to work with someone like him and help him understand and speak to him I guess in a way that is really respectful and then have them be able to understand how he communicates, so then they can understand his needs.

So with the multiple hospital admissions, they might be due to falling or it might be due to his mental health, so it just can be very different. And I guess in the mental health wards, getting them to understand how he communicates and I think - I guess I don't see him as complex but other people do and I guess bring it back to how does he communicate and how can you help people understand what it is that he's trying to say or express his needs. So I think all that probably makes someone quite - have complex needs, if you want to define it that way, like yeah.

**LH:** Thanks, Brigette. Because I think sometimes it's the systems, like and there's almost demarcation lines between housing or health or criminal justice or education. So that's sort of almost where the complexity comes and it sounds like you're doing capacity building within other systems to support - so this man is supported well.

**BK:** Yep.

**LH:** Is that fair to say?

**BK:** Yeah, definitely. Definitely. And I do think you're right, it's the other things, external things that make someone complex or seen as complex, not necessarily the person themselves.

**LH:** Yeah. So what strategies, Marnie, would you have for navigating complex - for helping people navigate complex systems? Have you got some strategies or some learnings that you've got from, yeah, those tricky demarcation lines perhaps is what we could call them?

**MB:** I think first and foremost is having a great team in place, like Brigette mentioned for the gentleman she just described. So we are lucky in Mildura to have a number of well skilled allied health professionals who are working well in the NDIS space and I guess I have for a lot of my participants consistent teams made up of those people around them. Again, lucky, I guess, that most of my participants were early entrants and got in quickly. But yeah, definitely that has been the gamechanger in my experience of communicating with other stakeholders, hospitals, you know, justice system, child protection system, housing, all of those to get the best outcomes for the participants.

**LH:** Yeah, it's kind of like a bit of a maze sometimes sort of navigating through that but just kind of - just sort of I think sometimes it's just like knocking on doors, do you think, or have you got some strategies, Brigette, as well? Like, the sort of finding your way through those other systems or -

**BK:** You know, sometimes it's kind of luck of the draw who you get, for example, in the hospital ward. Sometimes you can have amazing people that really understand and have the patience to really take the time to get to know someone, as much as they can in that sort of I guess space, but listen to how someone communicates and take note of that. But I guess sometimes in those environments it's so fast paced and people are in and out, they don't necessarily have that time to do that.

So it's just - yeah, I find it really tricky with police as well, I guess with the justice system and stuff. I think it's not very I guess set up and whether there's much training around people with the disability, especially people with I guess an intellectual disability and how things might present, what might be seen as aggression, for example, or a challenging behaviour really might not be. So I think there's just - yeah, there's lots of barriers there.

Strategies, it's just really trying to educate, I think. Really just trying to help them understand from the person's view the best you can. But it's really hard because I find one of the biggest challenges is as soon as people know that you've got something to do with the NDIS and you're a support coordinator, everyone seems to think you work for the NDIS and you have all this access to all these things and you can make decisions about all these things and funding and all this sort of stuff and it gets really difficult to try and get people to even just understand your own role and then top of all this other stuff, so - that's true.

**LH:** Yeah, yeah. I think I've experienced that as well. It's like "You're the one with the money" … no.

**BK:** Yep, yep.

**LH:** So what skills do you reckon you've developed along the way or what have you learnt along the way, working with people with complex needs?

**BK:** I think the main thing is - and probably a lot of us go into this role of support coordinator anyway with certain values and skills and I'd say one of them is listening. I think that's probably the biggest skill to have and if you don't have it you'll - and if you stick as a support coordinator, you will go far if you do listen because it's all - it doesn't matter how complex someone is or how little support someone might need, you just need to listen to what it is that they need and listen to what it is that - they might need change in their life or help change in their life or what isn't going right, things that are going really right, what is it that they actually want to do, what their dreams are. So it's just I think the biggest one's listening really and then understanding the NDIS, the processes, the funding to try and then help that align with what it is that they need.

**MB:** Yeah, I agree. Listening is definitely the first thing we need to do and I guess try and put ourselves in the participant or the family's shoes so that we can try and I'm going to say advocate even though the NDIS will tell you that support coordinators can't be advocates.

We're not advocates, are we? No, but -

**LH:** ….little "a" or maybe -

**MB:** But certainly - yeah, to assist the participant and their family to negotiate for what they need, to meet their needs and try and empower them, capacity build them, just start learning some of those skills and take some of those responsibilities on themselves where possible.

**BK:** Yeah. And I think another really important skill on the other side is I guess about compassion fatigue and as a support coordinator, again you're probably in the field because you want to help people or you want to try and make a difference or whatever it may be and you can get really - some people that you work with are extremely vulnerable and going through some pretty hard times. So as a person, sometimes you can take that in.

So it's really important I think to obviously build up your resilience but realise that you can't be everything to everyone and try and make your expectations of what you can and cannot do really clear. But also for your own self, to get supervision and self-care, take care of yourself so you don't burn out, so you can continue to support people. And I think that's really important in support coordination because sometimes you can do the best job in the world and you can move heaven and earth and it's still not going to be what someone wanted or you can't do what it is that they wanted and that in itself can be really challenging as well.

So I think it's just really important to, yeah, make sure that you look after yourself, you have a team around you that supports you and realise that - yeah, I think that you don't need to know everything because it's ever changing system and you can always go and find answers and stuff like that. So I find I think some support coordinators give people answers because they think they need to give an answer but they're not necessarily the correct answer because they haven't felt like it's okay to say, "Hey, I don't know that but let me find out." So I think, yeah, just that whole just looking after yourself, staying within your role, trying to stay professional and yeah, looking after yourself, which in turn you then better support the people that you are working with.

**LH:** Yeah. So I'm like - I know, as a support coordinator myself as well, I've come across these barriers which just could be impenetrable. There really are wicked problems around housing and there's sort of problems that are just not easily solved or are really hard to solve, so it's sort of working through those as well, I suppose. So have you got any thoughts about that at all? Once again, I think, Brigette, you're really right, like that sort of self-care is really important. So and understanding I suppose that we're working in a very imperfect system.

**MB:** We've been trying to set up a community of care, a community of practice, I can never get the term right, here in Mildura for the support coordinators working locally so that we've - we're all familiar to each other and feel like there's a big group that we can reach out to to talk about issues and get advice from. So we've really been promoting working together, we're all trying to achieve one common goal, which is to provide the best outcomes or assist participants to get the best outcomes.

So we've been - pre-COVID we were meeting once a month in a local disability provider's building. Since we've been working from home, we've been attempting some Zoom sessions, which have been less successful than the face-to-face sessions. But we do have an email list and hopefully we all understand that we can reach out and ask each other questions or get support at any time.

**LH:** That's a really good idea. And you do know about the community of practice, the UpSkill community of practice with Summer Foundation, don't you? You should join.

**MB:** I have heard that. Yes, I should join.

**LH:** No, it's an opportunity for people to ask questions and get together and share our information around support coordination and it's an online thing, it's on Slack, it's an online platform. So you can just sort of do it at any time that suits you. So just thought I'd mention that when you're talking about community of practice -

**MB:** Yeah.

**LH:** So when we are talking about people with complex needs and just sort of thinking about the role of family and informal supports for people with complex needs, how important is it for you to work with the family and the person to get the best outcome? How do you sort of work that out?

**MB:** Well, for my participants it's just I worked out that they each have a family member or a guardian of some kind who is the primary contact. So I don't really have any people I work with where the participant lives independently or would be the primary contact for coordinating their supports. So Brigette might have some better information for you on that. But certainly for my people, working with the family and/or guardians has been very important.

**LH:** Yeah, yes. I'm sorry, I probably read the question wrong but it's just the role of family and working with them I suppose is more the question. You know, how do you sort of integrate the role of family and the person. Brigette, how do you -

**BK:** Look, it can be - family dynamics can be really interesting to work with and I work with a bunch of different people. Some have no informal support, who live independently, some people only have paid supports and then there's other people that have great supportive families. And then there's some people that have what might be perceived as a great supportive family but the person may be having their decisions taken out of their hands.

So they can be, depending on the situation, can be when you get a really supportive family, it's just such a great space to work in because everyone's on the same page. Because when you have a really supportive informal supports around and family members, they can then help educate the support workers and the therapists and all that about how to best support their loved one, which is really, really great. They play such a vital role.

And I guess then you've got those situations when perhaps the person can be more independent but the family member may, without realising or realising, may be kind of stopping there because they're so protective of them and so it's being able to then I guess have those conversations just about how do we build independent decision making for someone who definitely has the capability of being able to make decisions about their daily life. Not sure if that's where you were sort of going but they definitely play a very, very important role.

**LH:** Yeah, yeah. No, I think family - like when there's informal supports around, you absolutely work with them because when there's family around because it's sort of - the more people around a person who are there for freely given relationships, it's usually the better for the person.

**BK:** Yep.

**LH:** Would you say so as well, Marnie, or -

**MB:** Yes, definitely. I've had some great outcomes with some of my participants because of the level involvement and it has happened with the family from the therapy team and from myself and from everyone involved, schools and those sort of things. I don't think, yeah, it just wouldn't be possible to get the same sort of outcomes if you weren't able to all work together, yeah.

**LH:** Yeah, yeah. So what - I'm just going to ask you if you want to share a challenging experience, without identifying a person, but I'm just - could you share a challenging experience that you've had and what did you learn?

**BK:** I'm just trying to think of -

**MB:** I've had a few challenging experiences - well, my participants have had a few challenging experiences during our lockdown period. So quite a few people seem to display I guess what we'd call behaviours of concern or challenging behaviours, I guess as a result of not understanding what was going on in the world, not being able to access their programs and different activities that they used to be able to and not knowing how to process that or to communicate their feelings with others.

There has been a lot of work needed with behaviour support specialists during this time and that is an area that we have a very thin market for here in Mildura. So that can be quite challenging and also it's obviously a very separate category in an NDIS plan. So getting a review of a plan to obtain that support for a person who didn't already have it in their plan is, well, for one person in particular I'm still trying to get that in there for them so they can get the support they need.

**BK:** Oh no.

**LH:** Yeah, I was going to ask how COVID has affected your work as well, so yeah, so - oh gosh, I mean I can just - I don't think any of us could've thought at this time last year that we're going to be in lockdown or as you are in Mildura or you're not in complete lockdown now but we've experienced really, really drop in - a real change in our social lives because of COVID. Everyone has but particularly in Victoria more recently. So it's sort of like we couldn't have predicted this. So it's obviously affected - I think most of us, affected our work profoundly as well. So yeah, Brigette, have you had much effect from COVID or -

**BK:** Yeah, look, I think -

**LH:** Your people you're working with -

**BK:** Definitely what you were saying too, Marnie, with behaviour support and with COVID and people not understanding what's happening and I've found, and I find this a lot anyway, but with a lot of SIL providers and people living in your traditional group homes and stuff, that there isn't I guess communication tools and visuals or whatever it might be that supports a person, the individual person, and then the group home as a whole about how to - even in a normal environment, how to - what's happening with your day.

And I'm finding with COVID kind of the same thing, it's like there's no routine at all and but there's no sort of helping people understand what's sort of going on. So people that are suddenly in lockdown or in houses and stuff like that and like you say, Marnie, having these challenging behaviours which really it's just someone saying, "I'm not happy because why am I in a house that I can't leave?" So I'm finding that is a really difficult space, even pre-COVID, and just about I guess people working with other providers and support workers about that, like about the importance of all of that if you're going to have a group of people together in a home. You know, it's just really important to get that stuff in there right.

And I think like the other - if we stick on housing, like the other biggest thing is like there's all this talk about innovative housing models and like there's nothing out there really. So you can try and try and try but if you can only get so far because if you can't find anything or no one's willing to think outside the box or do something different, it's very, very hard. So I think that's sort of - yeah, one of the biggest struggles here and I've heard that housing's sort of a pretty big struggle around the country, yeah.

**MB:** Yes, that is another area that's limited, like SIL and SDA housing here in Mildura. We do have one or 2 providers or one predominant provider in that area and I did look into actually - Penny from the Summer Foundation put me on to a couple of builders who might be interested in coming up this way but we didn't quite get to that stage that the lady that I was looking for that for was in that group who was experiencing difficult time during COVID and she's now living in one of the existing properties because it was an emergency at the time. But it would be interesting to explore some more innovative design and more custom-built type options down the track.

**LH:** Yeah, yeah. I think that's a really interesting area because I mean certainly - Brigette, you'd know as well, where we are, like there's been a lot of building of 5 resident group homes, which most people, it's not their choice, they've not got the choice of the other 4 housemates and -

**BK:** That's right.

**LH:** All those things and invariably it's never best outcomes for people. Sometimes I think - the other thing I was just thinking, Marnie, we're sort of working in sometimes in really crisis situations where someone needs emergency housing or there's - you need a quick fix for something as well. So that's often some challenges that we experience, this juggling everything very quickly to sort of find an okay solution for the purpose.

**MB:** Yeah. I should say this provider has been amazing, they really stepped up and saved the day, no doubt. And it just would've been good to have - so we'd actually submitted - I don't know if you want this much detail but we'd actually submitted -

**LH:** Yeah, it's good, it's good.

**MB:** - an SDA application for this lady back in February and we're still awaiting NDIA approval of that. So she's actually living now, has been for 2 months now, living in an SDA home that the provider should be eligible for SDA funding for her but is not receiving it because we're still waiting for that application to be approved.

**LH:** Wow, wow. We could do a whole other podcast on that. Come back soon and we'll talk a bit more.

**MB:** So definitely shout out to that provider. They're amazing, yep.

**BK:** And that's it, Linda, I think what you were saying is about - I think the whole housing thing is so backwards because it becomes a placement as opposed to a place to call home and someone's home. And then within that home, obviously you don't choose your flatmate but you also don't choose your staff and then your staff leave and then you get a turnover of staff and you get a new house manager and you get this - and everything's so reliant on this one organisation. And then if that organisation falls or gets taken over or decides they don't want to do SIL anymore, then that person effectively becomes homeless or they're just given to another organisation that takes them over without it being looked upon about, okay, well, is this the environment for this person? But then sometimes you're stuck because you don't have anywhere else for that person to go.

**LH:** Yeah, exactly. So and I think what you sort of - our housing solutions often aren't the - are not person centred. We found the solution before we even found the person quite often.

**BK:** Yeah.

**LH:** Or we're trying to put the person into sort of a situation that's not quite right to fit them. So can I just finish off, can you tell me about one of your wins, one of the things where you've gone "Yes"?

**BK:** One of my wins, it probably goes back to the gentleman I spoke about earlier, for years the NDIA just would not accept that he needed more support than they were providing. They just wouldn't listen, it took years. It took numerous hospital admissions, it took numerous different housing options for him to show what doesn't work. It took an extreme running out of support coordination funding every single year because they just couldn't understand that this person needed more support than what they were getting, apart from the fact that there's probably 13 specialists involved and then you've got all your NDIS providers. So the biggest win of recent was the recent plan review. Even though he's now had light touch reviews and about to have another one, but the recent plan actually reflects what it is that he needs.

**LH:** And that's a "Yes", that's a good.

**BK:** They've listened, they've finally - it took a lot, it took formal complaints, it took review of reviewable decisions, it took change of circumstances, it took almost going to the AAT, it took - everything, it took - and unfortunately a really bad situation to happen which has had a positive outcome because he's now receiving the support that he needs. And it's sort of like - I don't know how you both feel, but sometimes you can get a planner that clearly has no experience, doesn't know how to read a report and therefore makes really stupid decisions. And we finally got someone that read the reports and understood them and knew how to apply that to funding and actually took note of hospital admissions and reports and case notes and all that sort of stuff. So that was a win.

**MB:** Well done.

**LH:** That's awesome. Well done. Marnie, how about you? Can you tell us about one of your recent wins?

**MB:** I've got I guess probably more of a long-term win. So one of my participants, a young man in his early 20s, received his NDIS plan nearly 3 years ago now. I didn't know him prior to that but he was already linked in with a day program and some other supports through the state-based funding but there wasn't a lot of meeting or working together and he didn't have access to therapists because that wasn't really part of the state based funding system.

But when he transitioned to NDIS, over time we were able to get a good team in place with speech and OT to work together with his day program and his other social support providers. He has a therapy assistant who works really well with him and he's made a lot of progress, he's doing really well with his day programs. He does ADE as well. He does 2 or 3 days a week of work and his goal, from when I first saw his first NDIS plan, was to run his own gardening business and he is now with his ADE he is I guess you could say running - he's teaching other new people - so he was involved in setting up that program and he's teaching other new people as they join that program what to do, what the policies and procedures are and how to do the job. So one day realistically he might be able to run his own gardening.

**LH:** Awesome. That's awesome. That is another win and that's a long-term win, isn't it, that's just sort of his life is turning around and being what it needs to be for him. So that's an awesome win. I'm just going to wrap it up now. Thank you very, very much to both of you for the time today and just sharing those experiences. We've just got a really great podcast here, I think, so I really appreciate both of your time and sharing and yeah, just thinking about how we do our work, particularly when we're working with people with complex needs.

**Dr George Taleporos:**That's all we have time for on today's episode of Reasonable and Necessary, brought to you by the Summer Foundation. Check out our Facebook page for previous podcasts and transcripts. We love hearing from you, so please leave your comments and suggestions for future episodes. And until next time, stay well and reasonable.