

SAM PAIOR (1)

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, and on today's episode, we're talking about how to implement your NDIS plan with the help of what the NDIS call support coordination. Joining us today is Sam Paior from the support coordination service, the Growing Space. Hi, Sam, and welcome to the show.

SP Thanks, George, great to be here.

DG Now can you start by telling us all about your service and tell us how did it, how did it get started?

SP Yeah, the Growing Space started probably in conception many years ago. I started with a group of other parents of children with disability at the time, many of them are adults now, and we started going to schools and talking to families about supports and services in general because we found it was a really big gap that we ourselves would find out five years later about supports that we'd never heard about. So in some ways, it was a bit like support coordination, but it was very peer led back then, and when the NDIS came along, we found there was such a huge gap, there was just no one actually talking to parents or to people with disability, and really giving them the ground view of what was going on. So from there, the Growing Space kind of evolved and from there, we found that the support coordination was the niche that the agency set up as a line and we've actually become a somewhat viable business.

DG That's fantastic, and I understand that you've got some personal interest, you said as a parent, so that would've helped, I'm sure.

SP Yep, it does. I have two lads who are both on the NDIS, one of whom has been on for about three or four years now, and everybody who works with us at the Growing Space is either a person with disability or has a loved one with disability.

DG Fantastic, now this term support coordination, what on earth does it mean for people who might have no idea what we're talking about?

SP Yeah, look, some people might think of it as case management, but it's really not case management, it's quite different from case management because it's more about, well, it's all about capacity building. So rather than us coming in and managing and doing everything for someone, our role is actually to make ourselves redundant, so our job is actually to do ourselves out of a job, so the best support coordinators will not have to continue doing support coordination which is great. So we help families and people with disability set up their NDIS once they get their plans, implement their plan, find their providers, supports and services. We do run case conferences and get groups of people together to help talk about situations and get everyone on the same page. We definitely help people through crises where they may not be able, they may not know who to access or how to get the support that they need. I think that's pretty much the

crux of what a support coordinator does. We also, well, at the Growing Space, we take great pride and work very hard to help people look at the big picture, and to think about the least dangerous assumption which is always thinking bigger than we've ever thought before and widening the world.

DG You said there the least dangerous assumption, what do you mean by that?

SP So, for people with intellectual disability, they've probably grown up nearly all of their lives with people making very dangerous assumptions, so if I were to use my son, for example, and I assumed that he was not able to catch a bus in to his Saturday morning job in the city, I probably have just guaranteed that he would not catch a bus in to the city. But by making a less dangerous assumption and assuming that he can, and giving it a go, I'm going to be broadening his world, and if he wasn't able to do it, which he wasn't a couple of years ago, it just means that we try again and I make the least dangerous assumption again a couple of years later, and he now can successfully catch the bus in and out of town on his own.

DG That's great, now tell me about who should receive funding for support coordination, as from my own experience, I did not ask for support coordination, mainly because I didn't want to have another professional in my life, I wanted to be able to just go ahead and do it, but not everyone's like me. Who should receive funding for support coordination in their NDIS plan?

SP Is your question who should or who does?

DG Who should and who does?

SP Okay, all right, so I'll start with who does. So who does get support coordination are people in areas where there are no local area coordinators, so they will often get support coordination from a first plan to help them understand their plan and know how to use it and that sort of stuff. It's quite variant, depending on the circumstances of the actual individual, so if you're in a bit of a crisis point, if there's a whole lot going on for you, because of the disability probably, but in general, there are lots of different system interfaces, so you might be involved with the justice system, there might be a whole lot of interfaces with the health system and you're not particularly good at managing that or just don't know how to get the help that you need. It could also be if you're at a big life stage change, so if you're moving out of home or if you're leaving school, they're changes in life, they're big changes in your life that might require some more support around those. If you live in a group home or supported accommodation and you've got no family, often you'll get support, most people living in a group home would get support, would get some support coordination. I think basically where there are a lot of complexities going on or extra vulnerabilities, you might have, you might not have English as a first language and need support from that direction as well.

- DG Okay, that's really interesting, now I understand that there are different types or levels of support coordination. Just to make it even more complicated, what are the different types of support coordination that you can receive in the plan?
- SP Yep, there are three different funding levels for support coordination, and then there are different levels of money or packages within those three levels. So the first or the lowest level would be support connection, that's funded at about \$57 per hour and that's really essentially for people in areas that don't have a local area coordinator, so you'll find that if you're in an area with local area coordination, you're not likely to get support connection at all because your local area coordinator should be doing that job. That's falling over a little bit in this stage of the scheme because the local area coordinators are overrun with doing plans and not prioritising plan implementation and helping people, so it's a bit of a problem. But that's generally how it should work and will work as the scheme rolls out better. So the next level is support coordination, that's the standard level and that's what most people who get support coordination will get. So that's funded at about, I think it's \$94 an hour, and that's where someone, you might only be funded for an hour a month or two hours a month of support coordination, and they can help you on an ongoing basis. They'll also probably help you with getting ready for your plan review at the end of your year, get ready for your annual review, helping get the reports together and evidence and talking about your new goals and those sorts of things. And then the third level, the highest level is specialist support coordination and that's funded at the therapeutic rate, so you really need to be either a psychologist or a developmental educator, an OT, somebody like that and they're funded at that quite high level of \$179 an hour. And that's really for people in a full-on crisis, homeless, lots of stuff happening in your life, maybe you've just come out of jail, those sorts of things, they're times when you're more likely to get specialist support coordination.
- DG Okay, so we're basically looking at what kind of situation they're in and what would be the most appropriate level of coordination to ask for. Okay, yep, now...
- SP I should just, can I interrupt for one second there?
- DG Yep.
- SP Whether you ask for coordination or not is probably not all that relevant. The planner will actually make a decision, whether you want it or not, so I'm going to actually hypothesise, George, that you probably should've accepted support coordination so it was there if you wanted it which meant you don't have to use it, you don't have to engage your support coordinator, but the money is there if you need it.
- DG Okay, now that's a very handy tip and now even I'm still learning about this, as we all are.
- SP Yeah, absolutely.

DG All right, so what do you think makes a good support coordinator? What are some of the skills and knowledge and characteristics of a good support coordinator?

SP It's a really good question and I think in some ways, it's an evolving question and I find it when I'm doing hiring as well, to try and figure out, well, what qualities am I looking for. What do I really want in a support coordinator? But I have come up with a few key things, and a few things that are variant according to the individual who you want to be serving as well. So I guess generally speaking, I think a lived experience is really valuable, so having a person with disability doing support coordination is exceptional, if you can find that, if you can train someone to be a support coordinator, that is, that's the gold standard in my book. Then someone who's a carer, so someone who has that lived experience of actually growing up and being with someone with disability, whether they're a spouse or a sibling or a parent, that's pretty valuable too. I think anyone who does support coordination needs a really strong understanding and grounding in human rights and a knowledge of the convention of the rights of people with disability. I think that's an absolutely essential piece for anyone doing this work. From a practical sort of nuts and bolts perspective, you've really got to have a deep understanding of the NDIS processes, how they're working. You've also got to have a whole lot of flexibility, so when I train support coordinators, the first thing I do at the beginning of the session is I give them a slinky, and I say, you have to be this flexible if you are going to work in this space because the policies are changing on a day-to-day basis, and the needs of the people you serve will change on a day-to-day basis, so that's really, really important. Going back to that human rights thing, George, I think a deep belief in the value of all people and that everyone has something to offer is utterly essential because if you don't value the people you're serving, you should absolutely not be in this game.

DG Absolutely, and I think that I would also add to that that you need to really understand what's possible for people, because often people will look at an NDIS plan and just think of the traditional day services or the traditional support services. A good support coordinator should be able to look at the person and think, what is it about that person in the community or that world out there can bring to them, and vice versa, so that we start with disability silence that we live in and start living in the world.

SP Yeah, dead right, George. And in fact, that's one of the things I've got written on my list here, too. What you said first, though, goes back to that least dangerous assumption again, but also, to really have a deep belief and inclusion, and being part of the world and the community and not segregation, not instantly thinking that day options program and disability employers, that these are the first line, and for me, they should be so far down the rung, it's unbelievable, they really, you really don't want them on your radar if it all possible to avoid them.

DG Absolutely.

- SP Yeah, I think a strong willingness to be redundant, a strong willingness to do yourself out of a job and that's hard for some people, I think, it's easy to become quite co-dependent on the people you serve. When you work with people, you get to know them quite intimately, and I guess at some level, you end up with a love and a mutual joy in each other, and it's hard to sort of let that go, so you've got to be careful not to be a co-dependent support coordinator.
- DG And I guess by that, it's being able to build up their skills and talents of the person who you're working for, so you're not just doing everything for them, but they're building up their own capacity to do things for themselves, I think that's critical.
- SP Yeah, a hundred percent right. And part of that also is teaching people self advocacy, so teaching them how not just to do the work, but how to actually speak up for themselves when things aren't going right. There are so many people, particularly people with intellectual disability, but I think probably across the board, who don't want to ever make a complaint about their service providers, and we need to support and encourage people to be able to do that.
- DG Okay, so what if you're unhappy with your support coordinator? What do you do then?
- SP Well, I'm going to go back a step from that, George, because if you're unhappy with your support coordinator, you should be able to make a complaint to that support coordinator. Sorry, going back from that, the first thing is to make sure that when you choose a support coordinator, that they are not from the same company that provides any of your other supports and services because that's what we call a conflict of interest. So if you have your support coordinator who also is from the same company that provides all your support workers, it becomes a little bit more difficult to complain about your support workers to your support coordinator.
- DG Yes, that's a very good idea, and also, it was never intended in the NDIS that you would have your provider and your personal supports to be the same as your support coordinator, and somehow, in the rush to get the NDIS up, I think that a lot of providers and supports also got away with providing support coordination which is not ideal, so I agree with you.
- SP Yeah, but there just weren't enough providers, there just weren't enough people doing the work, I think that's what happened. But I guess the first step is to try and sort it out with your support coordinator. Make sure they know if they're not doing a good job, don't suffer in silence, send an email and say, hey, you haven't called me for six weeks, I need some help, get your act together. If that doesn't work, then you want to go and find a new support coordinator and you can switch support coordinators, there is nothing stopping you. There may be a two-week gap in between service while a service booking is cancelled, and the new one is created, but generally speaking, read your service agreement with your support coordinator, read that before they become your support coordinator, and if they've done something really heinous like if they've

done something fraudulent or harmful or they really are genuinely incompetent, then you want to make sure there are some official complaints made. So those complaints should be made certainly in the coming months to the quality and safeguards commission, the new quality and safeguards commission through the NDIS, and then of course, just even through your local consumer business bureau.

DG Yeah, absolutely, you need to get the word out there if someone's not doing what they should be doing.

SP Yep, that's exactly right.

DG I'm interested in any myths or misconceptions that you think exist about support coordinators and we've talked about already the fact that the role of a support coordinator is to develop a person's individual capacity to effectively make the job of a coordinator redundant and I think that's important that people remember. But what are some other sorts of misunderstandings or useful bits of information that you might want to tell people?

SP Yeah, sure, and as much as, going back to that redundancy thing, look, there are going to be people who will always need extra support, they will always need support coordination, but most people won't and certainly, for most people, it can be reduced at some level. But about the misconceptions, I think the first one is some people think the support coordinators do everything for you. We're not allowed to do rostering, we're not allowed to manage those sorts of things, we're also actually not allowed to do advocacy which is quite fascinating to me because I think, I see a big part of my role as being an advocate and to teach or support other people to be self advocates. So if that means that I draft an email for them, that they then tweak and send to the agency, then I guess you could call that advocacy, but technically, we're not supposed to do that. We're actually not allowed to judge the quality of a plan either, so if someone brings me an NDIS plan and says, what do you think, is this a good plan or not, the NDIS have requested that we do not make a judgment on that. Now, I'll be pretty frank, when somebody asks me that, I just, I make a little gesture as if I'm taking off a hat, and I say, you're not paying me right now, I am no longer your support coordinator, your plan is great, shit, rubbish, awesome, whatever it happens to be. And then I put my hat back on and they're paying me again. And I think you'll find most support coordinators would do that, too, because we do see some pretty wide discrepancies in the plans that come out. Some people think that we work for the NDIS, we do not, we do not work for them. We need to report to them, but we do not work for them, we work for you, the person with disability, and our own employers, our bosses, and we don't pay bills, we don't run new rosters. I think they're the key things that we don't do that people seem to think that we do.

DG Okay, so effectively, in terms of the coordination role, my understanding from what you're saying is it's not about advocacy or rostering, but it's about bringing together

the different parts of the plan that will effectively allow the person to fully implement their plan to a point where they achieve the goals of the plan, is that right?

SP Absolutely, we are all about the outcomes. So we really want people to think big and really think outside the box and a lot of people have never heard of a micro enterprise or of a circle of support, there are a whole lot of things out there that can really help people live bigger, fuller, more awesome lives. And I think our role is to open those doors, it's not even necessarily to walk through those doors for everyone, but at least to open that door. Sometimes we'll walk through those doors with people, but we really need to know how to open them.

DG That's a very, very important thing that people remember, that the support coordinator is there to help you get to your destination or your desired goal. And if that's not happening, you might want to look at having a serious talk with your support coordinator or looking elsewhere, and that's what I think is very empowering about the NDIS. We're no longer trapped with one provider, we can shop around. Okay, are there any final thoughts or I guess advice that you'd like to impart to our listeners about support coordination if they may have just received their plan and their plan says this much funding for support coordination and they think, okay, great, but what do I do now? Any thoughts or ideas for that?

SP I think when you're looking for a support coordinator, I think you want to ask them, have they read the NDIS Act, because I don't believe you should be a support coordinator without an understanding of the legislation because that underpins everything. So I think that's a really good question to ask people, and set some expectations early, find out from your coordinator, look, how often are you going to contact me? What is the best way to contact me? How do we work together? Read that service agreement really thoroughly, really understand what you're getting in to.

DG And how can people find the support coordinator in their area? How do they do that?

SP Yeah, you need to go on to the NDIS website and look at the provider, the provider listings, you can, the most up to date is actually on the page that has a whole lot of PDF or Doc files for each state. And if you go on there for provider listings, that'll give you the most up to date listing and I think it's under lifelong learning, I can't remember the actual category, it's pretty messy, though of course, the traditional and probably the best way is just to Google your area, be it Geelong or Catherine or wherever it is that you live, and support coordination and NDIS, and up will come providers in your area. Of course, the very best way to find a support coordinator is to speak to other people with disability and find out who they're using and who they're happy with.

DG That's fantastic advice. Well, thank you, Sam for joining us today and I'm thrilled to say that you'll be joining us again on next week's episode to talk about self management, but for now, thanks for your time.

SP You're welcome, George, it's been an absolute pleasure, thank you.

DG Thank you. 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 to check our Facebook page, Building Better Lives, for all previous podcasts and transcripts. We also love hearing from you, so please leave your comments and suggestions for future episodes. Until next time, stay well and reasonable.

END OF TRANSCRIPT