

Podcast Series 3 ep 3

GT: 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 talking planning and complexity and one family's journey to get great outcomes from the NDIS.

You may have seen him give out some good advice on the popular Facebook page, NDIS Grassroots or maybe you've heard him speak at a conference or workshop.

He is someone who knows a lot about the NDIS, both personally and professionally.

I'm pleased to be joined today by Les Cope.

Q: Welcome, Les and thanks for joining us.

A: Thank you, George, it's nice to be part of the conversation.

Q: So can you tell us a bit about your journey with the NDIS and particularly what was life like before compared to how life is like now for your family?

A: Well, certainly right now, we're getting far many more supports and our son is being fully supported in pretty well everything that he's doing. Prior to the NDIS, obviously, we had to put in quite a lot of worker hours ourselves to support him and to get things moving. The journey before the NDIS is one that has sort of captured a lot of what the NDIS is actually now. Because we've always been involved in individual planning and ensuring that he had a good plan and structures put together so that he can achieve goals and have good outcomes in his life.

Q: Can you just give a practical example of what are some outcomes for your son?

A: Well, right now, we're (my wife and I) are now ageing, we're over the 70 bracket, so we are ageing parents. We're actually now able to just be his parents, so we can go down and visit him in his house, we can spend time with him. We can go out to activities, we can do things - go to shows and so on. We have choices, he can come and visit us when he needs to for family events, for example, Christmas and New Year's Eve and birthday parties, and special family events. He can come along with his workers and just generally be part of the group and be part of the family.

Q: That's fantastic, so along the way, what problems have you encountered and how did you work through these problems?

A: Well, initially, when we came, I'll have to talk about initially because that'll sort of expand the problems a little bit further, I guess. Initially, he transferred early across to the NDIS because his needs were exceptionally high. He was living in an area that hadn't gone across to the NDIS as yet. So, we initiated contact with the NDIS, they sent a planner out to his house and we had a great planning session with her and with him, and she worked everything out with him. And she gave me everything that he needed to ensure that he had a good life. The problem that occurred, though was when his plan came up for review, the region had come across under the NDIS and the planner who came out absolutely did not

know what she was doing. She came in to his house and she set up, and she started as if she was setting up a whole new plan. She went through a whole testing mode of trying to test his capacity in a whole range of things, which was not appropriate. And it went back to the region who then rang us several weeks later to say that his plan was complex, and she started talking about moving out of his home in to a group home. Which was clearly not an option for him... which was horrible. So, we eventually, we talked about the legislation, she asked why we hadn't actually put those bits in when we, in the original planning meeting, and our response was "we don't put bits of the legislation in when we have a planning meeting because that is confrontational". We said that he pitched within the legislation and she said, well, we should've actually recorded that. So we actually saw her three or four days later, we took down a hundred page document with the legislation in a whole range of things that explained why that was reasonable and necessary for him to be where he was. And she was then most unprofessional, in such a way that she said that he would be fine, she tried to tell us that he would be fine, and a group home is just not on.

Q: Yeah, and let's talk more specifically about that legislation then. Because obviously you're not the only person who's had this issue with the NDIS. We have a lot of people who've had to basically get, become lawyers or become very legalistic, and inform or educate the NDIS about the law, but what kind of things did you bring to their attention?

A: All right, let me, I'm just picking that up now, sorry, I have got some things in here, we picked up, there are actually three parts of the legislation that we picked them up on. The first one is the NDIS act, which is section four which talks about the principles. Now in the principles, there are guiding principles that define what has to happen under the act. In numbers, there are probably more than half a dozen little points that they make. And we went through and we picked up on all those points and we gave answers to why it was necessary for him in that case. Or as to where the act said he had this right to do these things and be intent to the legislation and we actually came across and we worked out aspects to illustrate why in fact he was fitting those principles. And for them to do otherwise would be going against the act, so they were under principles. The second part of the act was, where are we? I'm just scrolling down. The second part was to do principles relating to plans and that talks about... I'll just pick up on the first one, for example, the participant's plan, so the preamble to that is that the preparation, the review and the replacement of the participant's plan and management of the plan for supports under a participant's plan, as far as reasonable and practical and individualised should, and then we had a response to that which said it should be individualised. So, we said he has a holistic plan that we shared with the planner at the face-to-face meeting and we had some appendices to back that up. And we had another point that said if the individual wishes, need to be heard, and adhered to and without continued pressure to change your mind it can really justify your choices.

Q: And obviously, that had an impact.

A: It did have an impact, so I'll just quickly go through to the last one, which is probably the most important one. And I know you're going to talk about this at some other point, but the last one of course, was the reasonable and necessary supports. The reasonable and necessary supports, there's a number of points in regard to that, but the one that they tend to pick up on is, it's under reasonable and necessary supports, section 34.C and that is the supports represent value for money. In that the constant supports are reasonable, relative to both the

benefits achieved and at the cost of alternative support. So, I won't go through all the responses, but thirdly, we went through the process of saying that the offer we had for him were totally reasonable and any other alternative support that might be cheaper would not have allowed him to achieve his goals. In fact, it would've been detrimental to his health and his wellbeing and it could well impact his whole life and impact... He would be very much at risk in any other situation. So that's his story of what we did in that area, but that last point is the biggie and it was very, very clear when we spoke to the second lot of planners when the region moved across, was that that planner was not relating to his plans as to what was required in the plan. Her whole focus was on that reasonable and necessary support in terms of money, she was just simply focused on the money, on the financial part of it. And not on the individual planning and that seems to be a general status that comes across to a number of planners where their focus is on money. She possibly, and I believe that she would've come across from the old system from DHS, where and that would've been part of where she sort of been a protector of government money, as opposed to actual planning. So just rolling on from that story, we then took, we made a whole lot of strategies and changes and we actually sent them all this information, do you want me to keep going on this point, George? Is that-?

Q: Yeah, that's very useful.

A: That's cool, so what actually happened then was that she, we said, no, this is not good. So, we went through a whole range of stages and processes, we went through the local member who was a Federal member of Parliament and we identified within that they had actually not followed process. Because that's the main way in which you can actually have an outcome with government. Politicians can't tell the NDIS what to do because the legislation is there and they have a job to do, but if the process is not being followed, then that's where they come on board and can be very, very useful. So, it was because the process hasn't been followed that we actually then had people from the NDIS ringing us over the next week or so to rectify this. It took about nine months and even then, it wasn't... it's still not rectified, we're still waiting. We'll have an outcome in a week or so, but they were still sorting it out. Now all of that time I would believe they had that legislation sitting, probably with the legal team, trying to work out what to do with it.

Q: Very interesting, very interesting, Les.

A: See, we're hopeful of a good outcome because eventually, we got on to the top person in the NDIS who actually met with us and with the planner who was focused on getting what our son required. And we had an acknowledgment that this should now be a two-year plan as opposed to a three-month plan. Mind you, from his first plan, he had three-month plans, which is a ridiculous way of working when you're trying to keep your life on track and you're trying to support your son and you're running through all these little plans that don't give you any consistency at all with staff. We had intended with, after the first plan, we said when the second plan comes along and we know that it's secure, we were then going to offer our staff permanency, which we weren't able to do ever. We still haven't been able to do that and, that in fact, has impacted on actually keeping some of the staff who we would've wanted to keep, as some of them have moved on because they actually want permanency in their job and in what they do. So, it's big picture stuff, but certainly that, picking up on those three points in the legislation was pretty important.

Q: And it's good that you're an advocate for your son and I worry about people who don't have that level of knowledge and involvement, but people really need to speak up for themselves.

A: Absolutely and it's not easy to do that, I worry about them, too. I'm supporting a number of other people who are in similar situations and it's just horrible when you see where people are ending up and so on. And there's a whole story there about advocacy and how that can sort of work. But even advocates don't necessarily have all of the knowledge as well, and it tends to sort of appear to who you can actually pick up on with the NDIS, so whoever you might know will be able to go through to get someone to come up with an outcome.

Q: But it sounds like critical to the outcome was your ability to put forward a case of reasonable and necessary.

A: Absolutely.

Q: Les, are you able to tell us a bit about how people can do that in terms of the term being quite an esoteric term, really in that some people might not understand what that means, how do you prove to the NDIS that funded supports are reasonable and necessary or that it's reasonable and necessary to live independently as opposed to in a group home?

A: Well, look, I'll give you an example, let me move away from the group home for a minute. I've got a nice little example of that. I was supporting a lady who was going through a planning session and in the planning session, this lady has some, she's quite able to iron her clothes, for example, but she has some difficulty in that if she drops it or if she moves in the wrong direction, she's likely to burn herself very badly. So, when we had the planning session, we talked to the planner about this and the planner's initial response was, "no, look, we can't put an iron on the list of things because that's not reasonable and necessary". And we said, well, why is it not reasonable and necessary for this lady to have this particular iron which will enable her to have safe practice? And she said, well, everyone has an iron, so it's not reasonable and necessary for the NDIS to buy one for her. Now, she was coming from the wrong direction. She was coming from a direction of looking at what everyone has in the house as opposed to looking at that person's disability. What we had requested for this lady was a more expensive iron, I think it was around about 180 dollars and it was an iron that if in fact, you had it sitting down on the table, it was actually cold. As soon as you picked it up, it got hot and you could then actually sort of move it and you could actually put it over the clothes and you could iron it for about maybe, I don't know, ten, fifteen seconds and it would cool down again and say give it a rest for a short while and then you'd start over again. So, this meant that this lady could use this iron, she could iron her clothes, she could have some respect and some capacity to look after herself. But the planner was focusing on what other people got and had a different view of what reasonable and necessary, was as opposed to the act which talks about, there are some bits in there which talks about the guy who I mentioned whereas-

Q: Well, it really has to come back down to the person's functional impairment and making sure that you're clear that if it wasn't for the functional impairment, you wouldn't need that support, yeah?

A: I'm sorry, you're right and that's an example, that's exactly the same thing in terms of communication devices and iPads. There's a whole lot of literature on that, in fact, for some

people, an iPad is actually a very cheap option for voice output for someone who has no speech. Because it's actually a cheap option, it's only about six hundred dollars plus the app, maybe eight hundred dollars whereas a very expensive application for speech generated devices can often be up to seven, eight, ten thousand dollars, so they really haven't got their head around.

Q: So it's value for money as well.

A: The individual, so in terms of cost, an iPad is actually quite a reasonable cost to provide for someone and they shouldn't be looking at it and saying, well, we won't do that because everyone has iPads, because they're missing the whole point of what the devices and so on are for. Sure, they're not iPads for playing games on and so on, they're very, they are specifically voice generated devices for people to use different apps and so on to enable that they have their voice and to interact with other people in society.

Q: I might go back to your arrangement with your son, I understand that you have a very individualised arrangement that enables your son to live independently in his own home and you actually went to the extent of setting up your own organisation, is that right?

A: That's correct.

Q: And how does that work?

A: We set up this organisation well before the NDIS started, it was based on his journey and bits and pieces that happened to him over his life. We found that most providers couldn't provide him with the support that he needed and he didn't have any understanding or capacity to do that. So the organisation, it's a non-profit organisation, well, putting it simply, it was just a matter of registering as a non-profit organisation in the same way that you might register a football club or a cricket club or any interest group, so it was on those grounds that we registered that in Victoria, we called the organisation Ability Dignity Access Management. We initially started off with the committee, who were literally, my son was on the committee, myself, my wife, my son's sister and a community friend, so we had five people who were running this organisation initially. And we were the committee and we were able to function and through that, we were able to employ our own staff to support him. We were able to cover insurances and so on through the money that was coming back in and we had the financial and the legal status to be answerable to all those things. So that was back in 19, in 2005, so when the NDIS actually came in, we were well placed. We'd already picked up a couple of extra people who'd come along just out of interest. We are now currently supporting about 8 people in their homes.

Q: That's fantastic, that sounds like you are, you're achieving some good things for lots of people then.

A: But in supporting those people, we're not looking at going out there and saving the world, we have no intent of being a Yooralla or any other large organisation. It just gets big and goes beyond their capacity to do what they really can do. Our focus is not on providing money for CEOs and so on and big office spaces, and signs and signboards. We only want to support up to a maximum of 10 people, so if we support ten people, we actually know all of those people individually by name. We know their capacity, we know that to chat to them on a whole

range of things and we can focus on their needs specifically. If we get beyond that number, they will become just numbers and not people.

Q: So my understanding is that you're providing supports and that means that you don't provide SDA and that's important because you don't want the conflict there. What are your thoughts on the SDA policy that's been rolled out, and I'm conscious of the fact that you're speaking at our upcoming conference on SDA, what are your thoughts on the SDA policy? Does it work? What do you like most or least about the policy and what would you like to see changed?

B: Well, when the SDA policy first started, I was aware of at least one lady who I knew of who was able to sort of get her own place and get SDA supports and make sure that that house was accessible in a whole range of ways for her. And she was living by herself on her own and that policy at that point was fine. It seems to have now taken a shift where there is a general push for SDAs to be places where you'll have more than one person living under the one roof or in the one place. And that's something that I really can't, for my person, for my son, and as someone in the community is something that I really believe is not reasonable and not something that people should be pushed in to. It's absolutely fine if someone chooses to have someone living with them and they choose to have someone with or without disability living with someone in their house, that is absolutely fine. But when you start pushing financially, people on a financial point of view, and you say to people, look, you will have to share this house with someone else and then we'll give you the SDA funding, that is absolutely wrong. Because it takes the focus off the individual and what the person could be doing. There are many people who would be saying, I just want to live on my own, I don't want to live with other people, so they should be supported to do that. The other point about having SDAs for people, a number or more than one person living in a house, for some parents and for some people, that might appear to be a good thing. But it's continuing the status quo of what was there before the NDIS actually started and you end up, even though it's not a group home or a larger facility, it has the capacity where you end up in the place where you've got "that's the house where those two people in wheelchairs live" which is different to saying, "that's where Jack and Tom live", that's quite different, so the focus does change.

Q: Yeah, and I'm thinking about the fact that the whole, the fact that we refer to it as specialist, the word specialist already rings alarm bells for me and then we say accommodation, we're talking about housing, right? We seem to have brought in to the NDIS a very antiquated terminology and when we're talking about SDA and we fought for the NDIS because we wanted something new, something different and obviously something better and that's obviously what you've advocated for your son. So, I tend to seek your advice then on what would you say to other people who are embarking on this journey or who are having some challenges around their plan and getting what they need? What have been some of your secrets or tips for getting some good outcomes?

A: My first suggestion would be to actually do some preplanning. Now it's interesting in that people seem to think of an NDIS plan as the plan of what was given to you and this is what you're going to base your life on. With my son, what we've actually found useful all the time, is we do some preplanning. We have a discussion with him and we work out what he wants in life, so the goals are something that we hadn't actually been focused on years ago, we were

just working from day to day. So, the goals in the NDIS are a very positive and a very powerful thing. So, it's important that people actually know what their goals are and they actually, they can work on goals. Some which may be achievable, some which might take even a little bit longer. So, for my son, he has difficulty in a whole range of things, for some of the goals, he may never achieve them, but they're still goals that he worked towards because whilst you're taking, you're aiming for big steps. If you take smaller steps, you may not necessarily get there, but you'll be in a far better place next time, so it's that preplanning and goals that you work through and the other part of that planning is that you need to think outside the square. Think of what not necessarily is, but what might be. And part of that journey from my perspective is looking at what everyone else in the community does and basing what you want for yourself or for your son, or for your child or for your brother and sister, with their... in discussion. Base that on what everyone else in the community does. Because of that, that's the starting point, what does everyone else do on a day-to-day basis? What are the things they enjoy? If you say what am I missing out on, you might not even get to the stage of realising that there are things out there that you can even consider. I remember when we, my son, moved in to an area where he currently lives. I went down and I met with a lady from Community House because our focus for him and his focus had been on community-based activities because they're much more powerful than group activities, they're things that what other people do. In group homes, for example, sorry, in community houses, they do things like they have get togethers, they have film nights, they have walking groups, they have common interest groups and so on. But we went down and met this lady and she knew why we were coming and the first thing she said to me, she said, "Les, I know why you're here", she said, "but I have to tell you in this area, we have nothing for people with disabilities", so I paused for a second and then I said to her, "that's okay, just tell me what you have for everyone else".

Q: Yes, absolutely and isn't that the problem that there is that view that if you have a disability that what you need is different or special or in some way, not part of what other people would want to do?

A: That's true and to this lady's, to her credit, she immediately got it and so that's actually captured the life of where he is now, but all of that is documented and put together and the last one, so in fact, I almost take disability out of the equation when I'm exploring the options in that regard, so this became the focus of a document that we started putting together. It was initially probably only a couple of pages, as part of that documentation, we also work out how are you going to do these things. So if you're going to talk about communication, supporting someone to communicate, then what are the things you might do with that? So what are some of the outcomes? Some of the outcomes might be if the person likes writing and likes language, for example, it might be I'm going to write a book this year or I'm going to join a writing group or a very simple one, I'm just going to go in to the forest or the areas of the country where I really love being, and I'm going to come back to my home with lots of ideas. So these things have all been documented and put down so that when we actually had our planning meeting, this was the information we gave to the planner of the NDIS. But I had actually also gone the next stage, which is probably not an easy task, but that was I managed to get a hold of the line items of the NDIS so I had a pretty good idea of where that was all sitting and I understood the costs. I understood what the costs were per hour because we're working with our own organisation. We also had not a bit, we also had a very good idea of

what it was going to cost, so let's just think of a figure. Let's just say if the final cost was going to be say \$178,000, that might have been what we knew that we were aiming for. When the plan came back, if it was a \$100,000 less, we then had a document that we could then, not challenge, but actually go back to the NDIS and go for a review of it to say that the information we've given you... is not right - this is not based in the information we gave you. So that gives you a really very powerful document to work on that review capacity, if that fails as you are probably aware, the next step of course might be to go to the tribunal. That same document is equally powerful to go to the tribunal because once they saw that, they would have to ask the NDIS the question: why did you ignore this?

Q: Has it come down to the reasonable and necessary value for money and has it caused the person to be part of that community and not place unreasonable requirements on paid informal supports and all those things?

A: Yeah, absolutely, but it's also the conversation that you have, so it has to be a positive conversation. But it also has to be a collaborative decision making, that's one of the things that we learnt. My son went in to a regular school, he moved from a day training centre, which was totally segregated, he moved from there at the age of about 30 years old and he went in to his regular school with full support from the education department, now that wasn't an easy road. But that whole journey, and this was another organisation we'd started years ago, that whole journey was based on collaboration and talking to the people who we were working with, understanding how people can become victims or people can become supporters and working through that whole process of working collaboratively together to come up with a decision. That's where the NDIS or some planners don't get that, let me say there are some fabulous planners in the NDIS and there are some who just need a lot more training and don't get it, but there are some who have come from the system who will never, ever get it because their whole mindset is based on the lowest common denominator.

Q: Yeah, and I think you've given some excellent advice there, do your research, pre-plan, documentation, have it all written down and I think I'd also add to that the importance of talking to others who've been through that journey, which is sort of why I have people like you on the program because I think that we can learn a lot from each other in effectively understanding what can work and what we might need to do to achieve what we need.

A: Cool, absolutely, can I just come back a few steps, we talked about the SDAs before, can I just reflect a little bit on that in the NDIS as well?

Q: Sure, Les.

A: Part of the journey, too with the SDAs, in fact, we do have a couple of people who are living in two separate units, so this is a model that's actually working well for them and this model is these two units are going to go under the SDA where they'll give additional supports to ensure that the supports will be ongoing and so on in this house. Now one of the people moving in to this house had a planning session and regrettably, the planner who was working with this individual actually thought that we were talking about SIL, which is Supported Independent Living, which is a model that they use for people with intellectual disabilities. And that's where they bundle a whole lot of people together, and it was the wrong planning approach, but the planner actually got in touch with me several weeks after the meeting and she asked me if I could put a quote in for SIL. Well, I said, "no, we don't do SIL because it's

not what our organisation believes in as being appropriate for people, it's not what we do", and she was insistent. So I said, okay, "send me the details on SIL and I'll have a look", so she sent me the details and it was a dot by dot spreadsheet, if you like, of what happens during the day of when people go out and what people do and what they don't do and so on. And I said, well, "I can't, I'm not going to put a quote in based on that, I'll just send what the quote is what I always have done, but based on the home help support during the day and the evenings and the social and community activities that people might be involved in", which is what we've done with our son and with other people. And I put a quote based on that just for support staff to assist him to work, for this lady to live in this unit that had already been set up. I received a phone call a week later from someone from the NDIS from the top area who actually asked me some questions and said, "why is your quote so cheap?" Now that was bizarre, because that to me, it almost sounded like a lot of SIL quotes that come in are very, very expensive and I can see why that would be when you start looking at we're going to factor in every second of everyone's life. It does become expensive, but it actually goes over the top. It's far cheaper for people to focus on the aspects of home support and social and community access, they then come in to these houses, wherever the house might be, it might be an SDA, it might be a flat that they use to rent somewhere or a house down the road that's got a proper rent, or it might be a community house. My son lives in a house which actually is community house-based, so he pays 25% of his rent, sorry, he pays 25% of his pension, so that means the other 75% of his pension can actually go on things like electricity and living expenses and food, etc, etc. So, that to him, is a far better outcome whereas people who get caught up in this other notion, and I'm flipping back to the SIL because this is just one of the things that there are sort of parallels that go through there. The SIL funding is not necessarily based on giving people a life outside of their home and from what I'm hearing, some of the SDA funding options might be very, very similar and they may not have the option to do the things that they might really want to do every day of their lives. Some people have had support through whether it's SIL or SDA, and they're only allowed for example, one day a week, to go out shopping.

Q: Which is not right because that's not what the NDIS is about. It was about community and social and economic participation and all those things about legislation, which is why I will always tell people to go back to the NDIS act because it's all there, it's all in writing.

A: Yep, and this approach, also this is where it's quite disturbing in that it's been based not so much on what people really want or what they need in their lives, but it's based on not on the expectations on them being able to be individuals, but based on how much money can we save and so on, so one's got to be very careful of that.

Q: It sounds like you've had some bad outcomes for your son and for your family. I know you've given me some tips, but is there a final message you want to leave us on? Yeah, a final message, final words of wisdom.

A: Well, and this is not something that everyone can do, but I guess looking, I think certainly looking at what *could be*, as opposed to *what is*, is probably a good way of defining where your life might go, looking at what you may wish to do in your life and basing it on what everyone else does as a starting point will give people cues as to what might they be able to do. And going on the basis that I guess as a parent, you're told at a very early age when you were a child, it's usually diagnosed at an early age that the expectations are sort of fairly low

and it's very hard to leap out of that hurdle and come to the next step up. So I think looking outside the square, and having some confidence that you can, sort of, move forward and give someone, your child a far better life. Through supporting that individual, that person, sorry, to maximise their capacity in many ways, is far more powerful and just accepting their status quo.

Q: I think that's an excellent point to end it on, so thank you so much for your time, Les.

A: Thank you, George.

Q: 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 which is at Building Better Lives you can find all previous podcasts and transcripts.

We also really love hearing from you, so please leave your comments and suggestions for future episodes. Until next time, stay well and reasonable.

END OF TRANSCRIPT