

Podcast Series3 ep2 v1

Q: 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 about how the NDIS can better support people who have complex needs.

To help us work through these issues, I'm pleased to welcome Sarah Forbes, advocacy manager at VALID. Welcome, Sarah, thanks for joining us.

A: Thanks, George, thanks for having me.

Q: Now can I just start, this term complex, what do we mean by complex participants?

A: Well, the NDIS itself doesn't exactly talk about people as if they were complex or if they weren't complex, it's more about looking at what sort of complexity level it is to get people's services and other supports working really well for them. So what would it take to make sure that everything came together in a way that made it possible for someone to have an ordinary life, and I guess the way that the NDIS has split participants up is between people who they say would be considered the right people for the general or supported pathway, that's what they call it, or people who would be right for the complex needs pathway. So it's really about how things would come together and therefore what sort of expertise people might need to assist a participant to do really well with their NDIS funding.

Q: And this idea of a complex pathway, it's not something that was there from the start, was it? It was something that the NDIS sort of realised was needed after a bit of advocacy and a bit of jumping up and down from advocates saying, this isn't really working for our group.

A: Look, I think in some ways, that's true, they've certainly done some recent work around making it really much clearer about what the complex pathway should do differently than what say the general pathway would do. I think certainly the agency has learned some lessons from the trial they did on the general pathway which did seem to provide some improvements for that group of people. They had some really good feedback about how that worked and in terms of the complex pathway, the agency has had sort of a two stream process so that people who are in the general group from the beginning of the rollout would work with the local area coordinator and people who were considered as having more complex needs would have their NDIS planning meeting and other contact with a planner who's employed directly by the agency, so by the NDIA itself. So there has been from the beginning of rollout sort of two different processes, but the new pathway that the agency has been working on gives much more detail and puts a lot more improvements in place, particularly around the expertise of people from the agency who will be working with people who have more complex support needs.

Q: Yeah, and that's really important, isn't it, that the people who are doing the plans understand the particular needs of that person?

A: Yeah, definitely, we have had some reports from both participants and families and even services to our service that have said, the planner asked how long the person would have Down syndrome for and whether it was likely that they wouldn't have Down syndrome in the future and I imagine that your listeners, George, understand that Down syndrome is a condition that people are born with that doesn't go away. But that's not to say that people don't over time develop a whole range of new skills and new possibilities, that they won't find paid work or a home of their own. Certainly, their situation might improve and their outcomes might improve, but in terms of their condition, Down syndrome is always going to be there, so those kinds of questions from planners are a worry because it tells us that planners aren't necessarily getting all of the information they need about different types of disabilities, how they might impact on an individual and I think particularly for the people who VALID works with the most who are adults with intellectual disabilities will also have other diagnoses, so they might also have autism, a mental health diagnosis, a physical disability, they may have four or five different diagnoses and how those different types of disability needs intersect is where the complexity really sets in. So we need planners who can understand how a person would have wraparound supports in an integrated way to make sure that people's needs are met holistically. Nobody is the sum of their diagnoses and we need planners to understand both what people's diagnoses might mean, but also not to make assumptions about therefore what the person would do with their time and we have seen a bit of that, too, that people with intellectual disability are expected to exist in groups, they live in groups, they go to groups during the week, and on weekends sometimes they go to more groups. And it is really important that planners understand that people with intellectual disabilities want the same ordinary things that everyone else wants and we need the agency itself to be, to have the kind of have the expertise and training to understand what really good practice looks like in the field so that they don't ask those kinds of questions or they don't put their assumptions around what might be possible for an individual.

Q: I absolutely agree with you and I also think that there's also an opportunity for the person with a disability themselves to think differently about their life with the NDIS and for a lot of people, they don't realise that they don't have to necessarily continue living in that group home or they might not necessarily need to continue doing the day service that they don't like it. It's these kinds of opportunities that the NDIS should be offering people who currently may not be aware of that and as an advocate, can you tell us about how you help people with disabilities in terms of their access to the NDIS?

A: Sure, so there's a range of ways that we do that. We have 10 people in our individual advocacy team and we take calls every day, many, many calls from people who are looking for assistance around the NDIS, sometimes they're just general questions, what is a support coordinator, those kinds of questions, or how do I choose a support coordinator? But also, it's people bringing quite serious problems to us to look for some help, so it might be around eligibility, whether the person can get access to the scheme, but for most of the people we support, it's really about a failure to understand how people's needs might be met with their NDIS plan. So maybe they didn't get

enough funding in their plan or they don't know how to use that funding effectively, those would be the kinds of queries that people bring to us often, and I suppose right at the really difficult end of things, we would get calls from people who are stuck in prison, they don't need to be there any more, but they can't leave because they can't find accommodation and they can't get a service provider who's willing to work with them just because there are not enough services around to meet all of the needs. So we're seeing issues across the board from reasonably understandable and minor concerns people have and some pretty serious service fails that are leaving people in very difficult situations. So really for us, it's about working with that individual person to understand exactly what they want and need, bringing in other people who the person trusts, and that can be helpful, and understand what the problem is, and then we work through what the possible solutions would be and we try our best to bring people to a different skill level in terms of their own advocacy by the time the problem is resolved so they feel more confident. One of the more significant pieces of work that we're doing at the moment is supporting people who live in Victorian government specialist disability accommodation who don't have any unpaid people at all in their life and who need someone independent who isn't providing services to them now to help them at their NDIS planning meeting, to express what they want, to articulate their goals and maybe to make some changes and that is one of the really exciting parts of our job at the moment is having those kinds of conversations that you were mentioning earlier, George, around, well, what if you wanted to move? Have you thought about it? This is your chance to really set that as a goal and to have people start working seriously on getting you that outcome and for most of the people who we support with that process, people without family, they are people who have usually lived a very long time in old style institutions and maybe have only been living in a group home for 10 or 15 years and in that time really haven't had the opportunity to meet with people, to get a job, to go out with a friend on the weekend to catch a movie with support that they choose. For many people, these are brand new ideas that really haven't been possible, so a lot of our work is about giving people examples of what other people are starting to do with their NDIS funding, and I think one of the really exciting things is because the NDIS is a national scheme, people are seeing examples from other people just like them all across Australia who are starting to do some really exciting and new things. They are starting to live in their own place, they've moved in with a partner and for some people and their families, that has been unimaginable, but now people are starting to see why other people are doing it, and they can see real life examples as people are starting to publish their success stories around the place, online and elsewhere, and start talking about it more in peer groups people are getting excited and we're certainly seeing that some of the work VALID does with running peer action groups where people with disabilities and other people who are interested in disability rights come together in a local area and talk about how they might assist each other to achieve goals, but also how they might improve access to the community in their own local area and they are starting to talk with each other about the kinds of goals they have in their NDIS plans and helping each other with those, but also challenging each other with even bigger ideas about how they might take it further year to year, which is really exciting.

Q: And I really relate to what you said around the fact that the people are wanting to effectively do something that they've never done before and I'm thinking that when we first envisaged the NDIS, one thing that we envisaged was the end of group homes and the idea that people could live in the community in an ordinary house whether they sort of felt that was in that community with a friend or with partner or whoever they choose and it sounds like we're starting to see a little bit of that, not a lot, but some of that from what you've said.

A: Look, I think we're seeing both. I think we're seeing some situations where people are moving in to a more ordinary arrangement, they might live with a friend or live with a partner, just like you said. We're also seeing a lot of effort put toward organisations and developers building brand new group based models and then inviting participants in and I'm not sure any of us imagined that that was going to be the way that housing and the NDIS would happen. I was certainly very hopeful that there would be a really strong focus around community living and helping people to find a house that worked well for them and then building the supports around that. It's been a really long time that people have had to live in a particular place in order to receive the supports that they needed and the NDIS is supposed to be about changing that. I think all of that is possible for people, but it relies on housing and that means that we have to get affordable housing, all different kinds, made available to people with disabilities. That means that we need more social housing and a range of other options, that people need to be able to buy their own home and then bring the supports in if that's what works best for them, we don't want to see a whole another generation of people whose only option is to live in a place where it's the only place that they can get those supports. People should be able to move around, take their supports with them, change their arrangements as it suits them and we don't want anyone trapped in a particular property type because that's the only way that they can get the supports that they need, that doesn't work, it's never worked and it's not what people tell us that they want.

Q: Absolutely, to take it back to complexity and the NDIS, and hearing that you said there've been some good examples, what are some of the situations that you've seen where it's been really obvious to you that the NDIS and how it's been implemented has not worked terribly well for people with complexity or who might be seen as having complex needs?

A: Well, certainly it starts sort of right at the beginning of the process. So, does the planner really understand the number of supports that you need and how those supports will work together? So what seems like a minor thing like, do you have support coordination hours in your plan to achieve your goals, if you need that support coordinator to be at your care team meetings or at your multidisciplinary therapy meetings to drive those meetings and make sure that each and every person involved is working towards the outcomes in a way that the evidence is telling everybody who needs to and if you don't have enough coordination, maybe the wheels fall off.

Q: That's really interesting because I remember working in advocacy, and we had this idea of the case manager, right, who we would call, so we would ring the case

manager and they would not necessarily always do a great job, but they knew that they were effectively there to do what hopefully needed to be done regardless of whether that person had funding or didn't have funding. The NDIS has said, we don't need a case manager any more with the support coordinators and it seems that the new world of support coordinators doesn't necessarily fit that well with people who are complex.

- A:** Well, certainly we've seen a lot of problems with support coordination and it's probably one of the top 3 reasons that people would call us with around an NDIS plan. So there are 2 types of support coordinators, there's a support coordinator for someone who maybe is learning about the NDIS plan and is building their own capacity to make more decisions around how their plan will be implemented and maybe over the first year or a few years of help from a support coordinator will move on to be able to self direct their supports under the NDIS, they won't need a support coordinator any more. They might need a support coordinator to come back in at a certain point and help them because they're moving out of home and they need some more coordination for 12 months, but over the long term, they're not going to need a support coordinator every year. That's really the design of the way that type of support coordination works. And then there is specialist support coordination which is supposed to be delivered by someone with an allied health qualification and they have a much more intensive role in providing the type of coordination that you might compare to what people might have had under what used to be called case management. But the problem seems to be that support coordinators are often unsure of where their role begins and ends, so they're not sure when the NDIS tells them that part of their job is to help a person manage a crisis, well, does that mean if my crisis happens on the weekend that I have someone I can call who'll come. It doesn't seem like it means that to most service providers, but to people who've had access to particularly what used to be called intensive case management in the past, that might've been something that they had access to, someone on call who can jump in and assist them with something and we haven't really seen good published information for support coordinators or specialist support coordinators from the NDIS that provides really clear and detailed guidance to both participants and also to support coordinators. There has been lots of confusion and we've seen an absolute bunker load of it in our work, of people just not knowing what my support coordinator should and shouldn't be doing and we get lots of calls from support coordinators who themselves aren't sure where their role starts and finishes. So, we definitely are happy to hear that the NDIA is going to do some more work around clarifying the role of the support coordinator, providing some more training around support coordination so that people are really clear on both what to expect and also so that support coordinators are really clear on just exactly what they need to do. And that's really important when it comes to people who have really complex behaviour support needs and who do need a team of people working around them to make sure that they can have an ordinary life. You really do need someone there who understands best practice, who understands how to gather evidence, who can interpret those things, who can pull together the information for the progress reports in a way that really clearly explains what's happened, what's worked, what all the therapists have done,

what they say is needed for the next 12 months. You need a really clever operator to be able to do that role really well for a person who needs 24/7 intensive supports.

Q: And you also need someone who's there for the journey, yeah? So I can imagine that for people who have complex behaviour support needs that it takes a while to work out what they are, what makes a good day or what makes a bad day and that can take months, if not years sometimes to work out for the person that somehow we're not necessarily in a position where there's the workforce that's there for the long haul.

A: And I think you picked up a really important point that some of the responses that we have seen that have been very difficult for people have been an expectation that things would improve very quickly and we know that the evidence says that it does take months if not years to really work very closely with someone who needs a lot of support to be well understood by the people supporting them. And it takes a long time to work that out and make that really run well, so sometimes we've seen plans that have been 3-month plans and the person has been told that you have to reduce your 2:1 supports, you might've had 2 support workers for your safety in the community to make sure that you can do the things you need to do without putting yourself in harm's way, and the NDIA might say you've got 3 months to bring that back down to having only 1 worker in the community and that's not always realistic and really, we need to be able to give people the time they need to be able to figure out what combination of supports in what setting and what context is going to work really well for them. And one of the other big issues we've seen is where you've got people who know the person really well, they might have been working with that person in a therapeutic role, there might be a speech therapist and they've got some really good history with that person, really good rapport and they've made some recommendations around what the person might need in terms of communication support that isn't supported by the NDIS when the plan comes back. And if we know one thing about people with complex behaviour support needs, it's that getting to the bottom of how other people can understand their communication is one of the most fundamental needs people have and when their communication, when they're being heard well by people around them, people tend to have less harmful things going on. So, it is really important moving forward that we have a better way of being able to see what combination of things works for people and let people try things out and give them time, give them time to see what's working and what's not working and then try something else and give that some time, too. We can't rush change for people who have been in the types of settings that a lot of these people have lived in which is very, very long periods of seclusion and restraint and they haven't really had freedom to pursue their goals in the community and now that they do that's going to take some time until we figure out exactly how that's going to work best for that person, so we don't want to see an expectation that's unrealistic put on someone who needs a lot of time to figure things out.

Q: And is the NDIS or NDIA listening and aware of these issues?

A: I definitely think they're aware of them. Certainly we have a lot of conversations with staff and management at the NDIA, we sit, VALID sits on a range of state and federal working groups and committees to give the kinds of feedback and solutions that we're

hearing from people would work best and they're definitely engaged in terms of thinking about what would work better. And they're making lots of changes all the time to try and work out what would be better for people and we have seen some examples where the NDIA have given people quite a long period in order to try some different things and to see what works, and we hope to see more of that so that we can try some things with people that we know are based in some good evidence. And there are lots of examples of different types of service models or combinations of supports that have worked really well for people who do have really complex behaviour support needs. And we'd like to see more attention from the NDIA around doing more of what we know works really well for people, we don't need to do a lot of guessing, we've been on this train for decades, there's lots of good evidence out there about what works well for people and we need to be able to see those kinds of evidence based strategies funded fully so that people have a real shot at being able to reach their goals.

Q: Do you have any advice for people who may have complex needs and their families and people who are supporting them around how to get the most out of the NDIS?

A: Definitely, I think one of the things that is helpful for people is to think about who could help them, so doing it alone is not a great idea. There's a lot of information that can be really difficult to understand about how the NDIS works and really, it helps to have people who can guide you through the process and help you learn how to weigh up the decisions around what you should do. So it's really important that people are in charge of making the decisions about their life and even for people who don't use verbal communications, use other types of communication, maybe they use gestures or maybe they indicate that they don't want a cup of coffee because they push that cup of coffee away from them when you offer it to them, it might be any number of ways that people are telling us about their decisions and it's really important that people have support from people who know them really well and who are committed over a period of time who can guide them through the process. So I guess tip number one is don't go it alone, get help from people who you trust and ask those people whether they can help you through different parts of the process to make sure that you feel really confident that you've got everything in the right place and you've got the information you need for the NDIS. I think the second one would be around taking good records, it sounds really boring, but it's really important. If you're trying something new in the community and you're not sure if it's worked and let's say you've started a new gym program and you are hoping that part of that process of going to the gym is that you're going to be meeting some new people, so you're not just getting fit, but you might want to meet some new people and really at the end of your plan period, you want to be able to have good examples of whether that's helping you with that or not - is going to the gym helping you meet new people or isn't it? If that's part of what you want it to do, then you can know whether the strategies that the people supporting you are using are working and if they're not working, we need to make some changes and if they are working do you want to push that goal even further? Do you want to have a role at the gym because you really like it and maybe are thinking about getting some work there? It could be any number of things, so keeping really good records about what's working and it's really important

that support coordinators are setting up those ways to capture evidence and to be monitoring things throughout the year and then to be able to produce really good reports that show what is working and what's not working. If you don't have those good records, you can get yourself in to all kinds of trouble at the end of the plan period in not being able to get what you need for next year. And I guess the last one is about keeping your energy up, that getting things right with your NDIS plan is going to take a while. We know from people's experience in the trial sites that year 1, they didn't have too much confidence about how it was all working, year 2, people started to experiment a bit more with their supports and get out a bit more in to the community and by year 3, people were starting to think about plan management and self management. And certainly we've had people with intellectual disability who over a few plans have decided they're going to try a little bit of self management or a little plan management and that's really exciting to see and we'd like to see more of that. But people have to be able to keep their energy up and one of the tools that we use at VALID to teach people about self advocacy skills is that we think of our advocacy energy in terms of batteries, so if your batteries are flat, then it's going to be really hard to get what you need. And that goes for anything in life, you need to have your batteries charged up so that you can be really effective and I think that's one of the things that we work on really hard both for our individual advocates, we use that idea, charge your batteries, and it's the same for participants and family members and others who might be supporting people. You've really got to keep your energy levels up because it's going to take a long time of improving things and pushing for things that are going to work for people and to make sure that the NDIS is set up in a way that works for everyone who it's meant to work with so that people can get the outcomes that they want and the only way to do that is to keep your energy up and to see it as a long haul project to keep going.

Q: They're excellent tips, can I add one more?

A: Please.

Q: I think that talk to other people who you admire in terms of what they have achieved and find out how they got there because chances are, they've been through everything that you've been through and they can tell you some good ways of dealing with the issues that you're about to face.

A: That's a really good tip, George, and I think we've seen some really good conversations happening where people are getting together to talk about tips and tricks and how they made things happen and it's one of the best pieces of advice I think anybody could have is to talk to people who know.

Q: Thanks for your time, Sarah.

A: No problem, George, thanks.

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, where you can find our 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.

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