

Reasonable and Necessary Podcast - Series3 Ep5

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 to Maryanne Diamond, General Manager of Community Linkages and Engagement at the NDIS. Welcome, Maryanne and thanks for joining us.

A: Thanks, George, good to talk to you.

Q: I'm really excited to be able to chat to you.

You and I worked side by side on getting the NDIS started a long time ago, didn't we?

A: We and many other people, George.

Q: So many people. It was a good time and now you're working at the agency. Can you tell us about what it's like to work at the NDIA?

Q: Look, it's exciting, it's wonderful to work at a place where everyone's there because they want to put in and be part of a huge social reform, so I've not worked anywhere where that mission or people are so committed to the mission of the organisation.

It's been challenging with the speed of the introduction of the NDIS and it is a whole different way of doing things for people with disability, for providers and for government, so yeah, that's kind of a short summary of working there.

Q: Right and tell us about your role.

A: My role at the NDIS is General Manager, Stakeholder Engagement, so it kind of has a couple of components. One is working with the disability community, engaging with it, talking to it, learning from the sector. But at the same time, working across the agency because there are a whole lot of stakeholders in the NDIS from government to the media, to providers and so on. And ensuring that we as an agency engage with our different stakeholders respectfully, using good principles of engagement, so kind of helping us talk to whoever their stakeholder is and learning from them as well as sharing with them.

Q: Yeah, because one of the key challenges is for people to understand what the NDIS is all about, that's what we decided, here at the Summer Foundation, just to help people to understand the potential of the scheme. And I guess that's a big part of your role, that people understand what's possible.

A: That's right and I think of people with disabilities, ourselves and all our colleagues, brothers and sisters with disability, have lived a particular way, received services from service providers, often told what we can have and what we can't have. And now we're saying to people, the choice and control is in your hands, you can set your goals. And it's not easy for people to just suddenly change the way they think and operate. And it's not simple for providers of supports and services to suddenly be ready to only hear from, and only provide services that people want. So the whole world is changing and I think it's fair to say it doesn't happen overnight, it happens over time.

Q: It sure does and we've had almost three years of the rollout and that followed the years where the trials were operating, so now that we're further down the line and we're nearly at full scheme, what do you, just reflecting on it, what's been the best and the worst things about the rollout so far?

A: I guess if I summarise it, there's a large, or a lot more money being put in to disability supports and services, I think that some terrific things at the moment are more than 250,000 people are receiving services through NDIS plans. Over 11,000 children coming through on the early childhood gateway, more than 19,000 providers of supports and services are registered with the NDIA and 1 in 3 people are receiving services for the very first time in their life. So, they're all pretty big numbers and pretty great outcomes, but they happen to come without some challenges. And I think it's fair to say that for those whose experiences haven't been so positive in getting in to the NDIS, that has been very difficult. And I think the speed at which we're introducing the scheme is one of the factors that probably contributes to that. There wasn't a workforce of planners sitting out in Australia doing something similar, so we've had to bring in the workforce. This is within the NDIA and a lot of work, it took a while. I think it'd be fair to say to get that on boarding training of those, that workforce up and running, bringing on our partners in the community, some have been, there's been a bit of variant. But I think we're addressing some of them now, but for some, that's been a really big challenge as we introduce this world first revolution to disability services here in Australia.

Q: Revolution, I like that term, and yeah, you're right, it's been a huge challenge. I was recently looking at the quarterly report and I saw that 84% of people were either happy with the scheme, so that's pretty good, but then that's the 16% left who are unhappy or not getting necessarily what they hope for. And I want to talk a bit about some of the issues that they've been facing and some of those issues relate to the speed and the lack of consistency and those things, but can we start with the issue of young people in residential aged care? We know that there was a recent announcement by the government, what's the NDIS doing to get young people out of aged care and stop them from going in?

A: So young people in aged care, we know they're there, but that's not the most appropriate place. I think there are around 6,000 young people under the age of 65 currently in aged care. I think the governments, not just the NDIS, recognise this as a problem. And last week, on 22 March, we made an announcement which articulated an action plan to assist people to get out of aged care if that's what they choose as one of their goals, to ensure that the people in aged care get the services they require to meet the needs of their disability. And I know one of the goals of the action plan is by 2025 to halve the number of young people with disability in aged care, which we hope it would be greater than that, but certainly, an effort to ensure that people can choose to live where they would like to and with whom they would like to live with. And as you know, George, these are all connected with things, is there enough accommodation, accessible accommodation around in the community for people to live in? Are people getting their supports in the community they need to live the life they choose and our complex pathway, recognising that some participants on the scheme have very complex situations and complex lives, so that they need extra support in order to get those services they need. And we have a dedicated, or are working to build, a dedicated team to support these people who have good experience in government services, allied health and other supports. So, I think all of those things look promising for changing, as you say, those who

are there and stopping people going in. But there's quite a bit of work to do and across all governments.

Q: And we want people listening to know that if they're in aged care now, they don't have to wait until 2023 or '25, they have a right to be now so they should be getting in touch with the NDIS so that they can start the process of leaving.

A: That's correct.

Q: So let's talk a bit about the interfacings between the NDIS and other assistance. We know that a lot of people fall through the cracks. For example, within the health system and we also know that there's a need to make sure that people get the support that they need, even if their supports might cross from one assistance to the other. But what's the NDIS doing to make sure that people don't fall through these cracks?

A: So, the role of the NDIS is to work with other government services, as you say, health, education, justice and so on, to ensure that people with disabilities get the supports they need across all of those different areas. So, the Council of Australian Governments or the Disability Reform Council, that's all government, state, territory and Commonwealth working together to address this problem and ensure people get what they need. And I think it's fair to say, for the person with disabilities just to get the service and governments to work together behind the scenes to work through the issues of who pays for what because for a person with disability, it doesn't matter who's paying for it, you just need your services when you need them. So, the NDIS working with all governments, is addressing this issue and particularly looking at the supports people need when they need them. And governments working behind the scenes to sort out the issues around payment and cost.

Q: Absolutely, because if I end up in hospital, I don't leave my disability at the door, I need my services to continue. So, it's vital that the NDIS and the other assistance work it out between themselves in terms of who pays for it.

All right, let's talk about workforce, I'm hearing that there are some inconsistencies with the number of and availability of services for disability in regional and rural areas. What's the NDIS doing to address the workforce shortages that are emerging?

A: So, as you know, George, from the beginning of the establishment of the NDIS, the government had committed to more money being available, and services available to people with disabilities and it was also recognised that the workforce would have to hugely increase. So, double in order to meet the demand for people to get the services and supports they need, and get them when they need them, and where they need them. So, the NDIS is not a deliverer of service, we are a steward of the work being done in this space. So, some of the things that we are doing are, we recognise that particularly in rural and remote areas where there are not many people. But particularly specialist services might be required, how we can address them, working with different jurisdictions to try and get a better understanding of what works and what works well, so that we can share. We've got an industry reference group that meets, and that's made up of participants, of some providers, of industry bodies to try and work on some of these issues. So, there's a number of things happening that can only assist. But the other one we need to be mindful of and I think you'd appreciate this George, is that we need all the universities and training institutions to put people through their different courses. Because as people with disabilities, we want to ensure that those delivering our

services have the right skills, and experience and attitudes. That means that they deliver a quality service to us, irrespective of where we live.

Q: Yeah, that's right, and I think that more important than skills and experience is that the attitude word that you mentioned, people can learn skills that often added to the change.

A: I think that that's correct.

Q: As you know, we have a very vibrant online community and a Facebook group called the NDIS Grassroots. I told them that I'd be speaking to you and they sent me some postings quite a while ago, actually, more than I have time to go through today. So, the first one is about respite and that question was how will informal supports be sustainable without respite?

A: So, George, I think I'd start with saying that respite is something that exists for people who require it and it might sometimes be referred to in a different name. But we need to think about the participant, so does the participant have in their plans the means to ensure that they can participate in the community? They might have short term accommodation requirements, they might have individual plans that allow them to do things outside the home and so on, which results in the family and carers having some respite. So, I think it's about how we talk about it, so it's about, does the participant have the right things in their plan to allow them to do all these things which result in the carer and family having some respite?

Q: Yeah, you're right and it's not necessarily the word respite that people will see in their plan. But people need to obviously ask for what they need to keep supporting their family members and the NDIS needs to fund what's reasonable and obviously depending on the age or on the severity of the impairment, those needs might vary.

A: That's correct.

Q: So, I want to ask about the iPad, the famous iPad. The question is why doesn't the NDIS fund an iPad if it's the most cost-effective communication device for a person with a communication impairment?

A: So, I guess what I would say is that the NDIS provides for reasonable and necessary supports for people. In general, it doesn't provide supports that are everyday purchases or things that anyone in the community uses, like an iPhone, iPad and so on. However, it does recognise and fund any apps or programs for such devices that makes them accessible for a person with disability. So, in saying that though, there have been situations or are situations where a tablet and so on, with a particular app might be a stand-alone communication tool for someone with particular disabilities and they have been from time to time funded. So, I would probably say to that question, not as a general rule, the apps and programs that are used on these devices would be funded, depending on your disability and what your needs are, but there are situations where they might be funded because of the particular communication or disability communication issues.

Q: Excellent, so what you basically said for us is that it's not about never funding it, it depends on the circumstances and the need of the person.

A: That's right.

Q: Okay, I'm going to ask now about group homes. There was a person who asked what is the NDIA doing to ensure that people are not being forced in to group homes?

A: So, I think choice and control is another big part of the NDIS and people should be able to live where they choose and who they choose to live with. I think some of this might be a bit historic where there were group homes and people felt that they didn't have many options but to live there and of course, the other big issue is, is there sufficient stock of accessible housing for people to live in? So, I would say that no one should be or no one who I would expect, should be told they need to live in a group home. We're doing a lot of work with government and the disability community and so on, with the establishment of a specialist disability accommodation reference group, which brings together participants, sector, providers, finance bodies, housing, and representatives to kind of address this issue of sufficient supply of accessible housing. We've also now ensured that people who need specialist disability accommodation upfront in their plans, that is now available so that people can go and look around and find if there's something that they can live in. All of these are really important elements to ensure that group housing is not the default. And I think it's a really important thing as we move forward and we build a market, we build accommodation that's accessible and people feel confident, too, that they have this choice and control about where they live.

Q: I think it's excellent that you said that and I think that people aren't being told that they have to live in a group home and if they want to, they should definitely ask for that to be looked at and reviewed.

A: Most definitely.

Q: The other question, the final one is about inconsistency in plans, what's the NDIA doing to make sure that people have consistency in the planning and the planners so that the decisions that are made are fair across the country?

A: I think that's a good question, George. And as I mentioned at the start of the conversation, with the speed at which the NDIS has been introduced across Australia where there's been the workforce of planners, local area coordinators and so on had to be built. And we didn't have a whole lot of people in Australia working as planners and they could just come and apply for a job at the NDIS. That workforce had to be built and grown and continues to be. We've done a lot of work in the NDIA to develop training when people join. So, training for planners and LACs, much more extensively than we had. We've been working with the Disability Advocacy Network of Australia, DANA, to develop some resources and tools for planners and LAC. And they are to be undertaken by all, on the social model of disability, on the human rights framework just to help some of those conversations be actually conducted in that human rights approach and understanding disabilities. All staff in the NDIA must do compulsory e-learning on disability rights, which I think is a really positive step and the take-up has been very, very good. So, I think that that's part of it and also the other work we've done, a lot of work in the pathways work, that means the pathways from people first approaching the agency to getting a plan, implementing their plan and plan review, I'm finding out what works and what works well. We've done a couple of pilots, one we did in Victoria last year. That's now being rolled out nationally and that is default planning meetings face-to-face, that we have a point of contact through our LAC or planner who you can talk to or go back to and we're finding as a result of people going through that process

the number of plan reviews being requested has dropped in those ones. So, some of those changes in the pathways are for people that their experience has made a difference, and also the recognition that a standard pathway isn't the right way for everyone. So, people as we talked about before, have more complex situations. Some people might be needing to go through a different pathway because they have psychosocial disability or they might be children with hearing impairments. So sometimes, depending on a whole lot of circumstances, it's been recognised that people need to go to a particular pathway and then they work with experienced, trained people in that speciality to ensure they get the best plans they can. And our whole plan review team is now being centralised. It used to be done out in the regions so there was variation, I suppose just for people because of the nature of how that was done, we've got a centralised team now who are doing that and I think we'll find a lot more consistency as a result of that.

Q: I think that's fantastic because we want people to have a consistent and reliable NDIA, regardless of where they happen to live and that's why we advocated for the NDIS because we wanted fairness across the country.

A: That's correct, George and also the portability of the NDIS, so that if I'm born in Melbourne and currently get my services in Melbourne, if I, for whatever reason decide I want to go and live in WA or Queensland, that I take those supports and package with me rather than go to the end of a queue and wait for my turn in a new jurisdiction.

Q: Absolutely. Look, I'd like to end on a positive note, I want to ask you when we're done with the rollout and we're full scheme and all these implementation problems have been ironed out, can you describe for us would the NDIS look like for you in your mind?

A: Okay, I think the 460,000 people with disability estimated to be eligible and will be receiving a plan and implementing their plan. I think is pretty exciting I think the fact that 1 in 3 people we experience at the moment are receiving services for the very first time is also exciting. That people are benefiting from our information linkages and capacity building part of the scheme. So, it's not those who receive packages, but another big part of the scheme is that word, so for people who have a disability, but are not getting packages, they will benefit from the work that's been done through that side of the NDIS because of a more inclusive community. I would see that governments and interfacing services or services other than the NDIS, are all working together and that it's pretty transparent, or it's not known by us as people with disabilities, when we receive services who pays for it or who is delivering it, but it's there and available to us. So all of those things are pretty exciting and I think we will have got through the issues of establishing, setting up and scaling up such a big program, that it will be consistent across the country in what you can expect and what you receive. And I think, George, just to kind of end on, I think it's a really important thing to note that for some people who were involved in the trial sites in Barwon and Hunter, I think, back in 2013 to 2016, many of them now are receiving fourth or even a fifth plans and what our data tells us in our first year or maybe even 2, they often just or often receive the same services from the same service providers that they have already received for years. But by the time people got to their third and beyond plan, they had the confidence, they had the information, they had talked to people, heard about what else is available and had made significant changes in what they received and who they received it from, so I think that tells me that it takes a while for

people to have that confidence, knowledge and that the market response to what people want, not just what they've traditionally provided.

Q: Absolutely and I know that people are doing some great things through self-managing their funding and often, that's where innovation and doing things differently often comes around.

A: That's right and I think self-management is a great example of the choice and control at its height where not just are we choosing and controlling what types of services we get and who from, but we're managing, we're confident enough to manage every aspect of our plans, so I think that's pretty exciting, too.

Q: Thanks, Maryanne.

As we say farewell, are there any final words that you'd like to say to our listeners?

A: Well, other than it's been terrific talking to you, George, as usual, yeah, and I think there have been lots of successes as we've rolled out a huge change in disability supports for all of us as people with disabilities, for those who provide our services. But we've still got a lot of challenges ahead and the NDIS is taking them on and working with the community to ensure that what we do is demonstration of a leading scheme that we can all as people with disability have confidence in and be proud of.

Q: Absolutely and one day, hopefully, we'll have Maryanne Diamond as CEO of the NDIA.

A: I don't think so, but thank you, George.

Q: Thanks, Maryanne, thanks for your time.

A: No problem, 'bye, George.

Q: 'Bye. 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 website where you can download our transcripts, previous episodes and the latest info on the NDIS.

Sadly, this has been our final podcast in the third series.

Keep your eyes on our Facebook page for our next series.

Until then, I'm Dr. George, and stay well and reasonable.

END OF TRANSCRIPT