

Podcast Series3 ep1 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 we can make the NDIS work better for everyone.

To help us work through these issues, I'm pleased to welcome Kirsten Dean, campaign director of Every Australian Counts. Welcome Kirsten.

A Thanks for having me, George.

Q I'm really excited to have you on the program because you are effectively probably the most knowledgeable person when it comes to the NDIS and that you've been there from day one, is that right?

A I think that's very kind of you to say, George, I have been doing this for a little while now, I think that would be the best way to describe it. I don't know that I'm the most knowledgeable person out there, but I have been doing it for a while.

Q So for people who haven't heard about the Every Australian Counts campaign, and I don't think that there are that many people who haven't heard of it, can you just tell us about you and your involvement and what the campaign itself was all about?

A Yeah, so people might not know that actually, the idea for the National Disability Insurance Scheme has actually been around for a really long time, it's actually been floating around since the 1970s and there was a proposal for a scheme just like it sitting in the Senate when Whitlam was dismissed back in the '70s. So the idea of the National Disability Insurance Scheme has actually been around for ages. But in its most recent incarnation, it kind of emerged around 2007/08 when it was one of the what were called the big ideas that came out of the summit that Kevin Rudd had held at Parliament House and around that time, there were a bunch of individuals and organisations who all started to meet, who all wanted to talk about this idea for an NDIS. But more importantly, importantly go, well, how could it go from just being a good idea, to how could it actually become a reality. So those individuals and organisations started to meet and say "look, we think the NDIS is the way to go, we think this would really change things for people with a disability and their families in this country, but it's so big and so complex and it's going to cost quite a lot of money, it won't get up without a fight, so what can we all do to make sure it becomes a reality?". So there were three big organisations in the sector at that time, the Australian Federation of Disability Organisations, that represented people with disability, Carers Australia that represented families and carers and then National Disability Services that represented specialist disability service providers, so they had all never worked before together. In fact, it's probably fair to say that there was a fair degree of antipathy between all of them, so they started meeting and saying, "look, okay, we want, we all agree, there are lots of things we don't agree on, but we all agree on the NDIS. What can we do to work together to make it happen?". And then they went looking for other individuals and organisations who also wanted to work

together to make the NDIS a reality, so it was out of that that Every Australian Counts was born. So Every Australian Counts formally started in 2011 and I was the deputy campaign director at that time and then basically, from 2011 to 2013, Every Australian Counts was basically a really old fashioned grassroots campaign movement that just went out and built all of the political and public support that led to the introduction of the NDIS in 2013. So from an idea that had actually been floating around for a long time, the actual period where we were actually on the ground campaigning was actually reasonably short. So to go from a good idea in 2011 to actual reality in 2013 is actually really a relatively short space of time.

Q And I remember the meetings quite vividly when we'd all meet at Parkville and get together and talk about who we thought was most likely to get across the line and I remember we had all the politicians and tried to work out who was supportive and who was almost there, and all that, and to be honest, even though it was a very short amount of time in the scheme of things, there was also a real feeling that this was a big fight ahead of us. We didn't really ever actually, well, to me and to the people who I was working with, we didn't actually think we'd done it until it came up on that big screen on Federation Square with the announcement of the type of launch and describe them, so it was actually a very exciting time because we were all not quite sure what was going to happen.

A Yeah, and I think there are a couple of things about it, the first is that the campaign itself was actually the end of years and years and years of hard-fought advocacy by people with disability and their families, for a better go for people with disability in their countries. So it was, it would not have been successful if there hadn't have been years and years and years of very hard yards done by people with disability, families, advocacy organisations, to really advance the rights of people with disability in their countries. So it would not have been successful if all of that work hadn't have been done for years and years and years beforehand.

Q It was that evidence that we'd built up over time, all that stuff that the productivity commission then and to me, the productivity report in 2011 really articulated the vision and it was an economic body that told us something that we already knew, but did it in a way that was very convincing.

A Yeah, so what was really awesome about the productivity commission report was that you had all of these hardheads, all of these sort of pointy bean counters at the productivity commission who made that economic case for why the NDIS was so important and so necessary. But what was extraordinary about the productivity commission is that they got more than a thousand submissions to their enquiry and many, many of those submissions were just ordinary people with disability, family members, people who'd never made a submission to approach any kind of government enquiry before, but who wanted to explain why this was so important to them. And I think that that was the most submissions that the productivity commission had ever had to any other enquiry, ever, and what that did was it explained the social cost of not having an NDIS. It explained the impact on real people's lives, so it gave the enquiry heart. So on the one hand, you had head with all the kind of hardhead economic analysis, but you had heart from all of these stories

from people with disability and their families, about what was wrong with the current system and what they wanted to see change. So I look back on that and report and say, if it had been one or the other, it wouldn't have worked. It was the bringing together of both of those things that made it so powerful.

Q So then the other thing is that I felt that the productivity report sort of gave us a new language that we could use. So we started talking about this as an investment and I think it really started because obviously, people with disabilities and families are going to want this, but that's not enough, right? You need the whole community on one hand and when we say, this is an investment in better outcomes in the long term, then that was the clincher, that's only up there that people who otherwise would be probably not that in favour to say, yeah, well, that's going to bring more returns than costs, then that's when I thought we were much closer to winning the fight, so to speak.

A Yeah, I think there are a couple of reasons why ultimately, we convinced the public and the politicians that the NDIS was really necessary and I think that the first reason is that you're right, that we built not just a social case, but also an economic case, it's something actually that doesn't get reported any more because we're a few miles down the track. But the productivity commission actually said it was going to cost more not to do this, than to do it, and it's funny now from the perspective of 2018, everybody seems to have forgotten that bit when they talk about the costs of the NDIS. But the productivity commission said it was going to cost more not to do it than to do it and that yes, it was an investment in people with disability and it would pay off in the long run, not just for those individuals, but for the broader Australian community. So they really built that economic case, but I think the other reason is that ultimately the campaign was successful because Australians really, really believe in a fair go, so what the campaign was able to do was, it was just ordinary people with disability and their families telling their stories, telling their story about what their life was like now, but what it could be like under an NDIS, that really brought that economic sort of investment to light. So I think ultimately, the reason that we were successful and that we got the NDIS was because people with disability and their families told their stories and they told their stories to anybody who would listen, they told them to family, they told them to friends, they told them to the community, they told them to the media, they told them to politicians and it was those stories that brought that economic framework to life. So the NDIS is a really big and complicated thing and it was really hard to get your head around, but what those stories did was explained to people what the impact was like on their daily life and what their life could really be like if they got proper support, so I think ultimately, the reason we were successful was yes, we were able to mount an economic case around what was going on in people's lives and how the NDIS would really make a difference and I think it's those stories that really convinced the public and the politicians.

Q It was those stories, as far as I remember, it was someone like Annabelle Hart (too much in the past) but I imagine that some of the most convincing pieces of, just things that were said, were the 2000 link, I remember that when people would talk about that's not okay, when people would talk about the fact that if they had a car accident that they got this level of support, but if their disability was a result of something else

that they didn't get the support, this is the fair and right thing to do and there we are, we sort of convinced people on both sides all sides of politics, so we're what? Five years on now.

A Yeah, it's kind of eight years on now, yeah, nearly eight years on now.

Q And we've got an NDIS, so cheers for that, hey?

A Yeah, and it's not, so it feels like such a long period of time for us, but actually in sort of public policy terms and social policy terms, it's kind of a blink of an eye. But it is remarkable when you stop and think where we were and then where we've got to. There are lots of problems with the NDIS at the moment and I'm sure we're going to talk about those in a sec, but it is worth remembering going, this is an extraordinary economic and social reform that we've introduced. It's not being done anywhere else in the world, there are bits and pieces that are being done elsewhere in the world, but nowhere has it pulled it together and they're trying to do this, so the rest of the world are kind of watching us kind of going, how is this going because it hasn't been done anywhere else.

Q So let's talk about today. The annual report came out today by the NDIS and I looked at the statistics, one that said that 88% of people who are in the scheme are either satisfied or very satisfied, to me, that's pretty good. The other thing, though that came out is only 71% of people understood what was in their plan and I thought, that's a horrendous statistic, so what's going on?

A Yeah, so we're travelling around the country at the moment holding a series of forums that we're calling 'Make It Work' and the purpose of the forums are to bring together people with disability, families, people who work in the sector and to look at what's happening five years on and go, well, what's working well and what do we want to see more of, but then perhaps more importantly, what's not working well and what do we want to see change? What are our priorities for change, and one of the things that's really remarkable about the forums is that most of the time, people come to the forums because things haven't gone well and they want a chance to talk about that and put forward their ideas for how to make it better. Which is great, but even at those, when people tell stories about what's been difficult or what's been challenging or what's gone wrong, everybody always says, "but I really want it to work. I really still believe in it". I really think it's changed everyone's lives for the better, but there are all these problems with it and it's really remarkable at the forums about how high support is for the scheme, despite the fact that there are lots and lots of things that are not going very well. And when we do research out in the broader community, we also find that support for the NDIS is still really high, so despite all the problems, everybody still wants it to work.

Q And the thing in the plan that I find really, really challenging is that it's often not working for those people who need it to work the most, so they're not contacts people, it seems like it's failing, particularly for people with health needs and higher complex needs around housing and support that there seem to be some issues where with that cohort, but what I'm thinking though is that you're absolutely right, that we all want it to work and that we're not that far in to it and it was a huge number of

people who have come in in a very short amount of time, we're talking about 180,000 people in to a government scheme in two years in some areas, so did you ever have a case of reeling people in?

A Yeah, I think there have probably been a few issues, one is that there is no blueprint for it, there isn't a map, so you're not copying this from anywhere else, so everything that you come up against is a new problem, I think the other thing is, is that it is a genuine start-up, but it's something new, but it's not a green field site, it has to work within existing systems, so that's always more complicated, you're not really, you are starting from something from scratch, but it's got to work within existing systems, so that's complicated. The third thing is that it is for good and for ill, it is a genuine partnership between the Commonwealth and the State and Territory governments and that has some advantages, but that has some real disadvantages and that has further complicated things and then, I think, the fourth thing and then we hear this all the time at the forums is that it's really apparent that the National Disability Insurance Agency doesn't have all the resources it needs to do the job it's got to do, so it's a pretty remarkable thing when people with disability and their families turn around and go, hey, we think this government agency needs more resources, but that's what people say at the forums because they understand that all of the delays and all of the waiting and all of the waiting, waiting, they attribute that back to there are not enough people at the NDIA and not the right resources to get the job kind of done. So I think there's a whole bunch of factors that all come together that mean that things aren't going, it is a really big number to take in and no one thought it was easy, but to be honest, it's harder than it needs to be.

Q So let's get specific. Let's say there were five things that were the big problems, maybe four, whatever number you prefer, what are they? What are the top four or five problems that you've seen in your travels?

A Yeah, so from the forums, I would say that the top things are processes. The NDIS is too complicated, too bureaucratic, too over engineered, too hard to navigate through, when there are fifty steps for something instead of just a couple, so people find it too hard to navigate their way through. And when they talk to us, they want more help at every stage of the process before they come in, while they're going through planning and then getting their plan in to action, they're just finding it too hard to navigate their way through, the language used by the NDIA is still too complicated, too bureaucratic, too full of jargon, there's not enough stuff in simple plain language that people can work with and people really believe that a. there are not enough staff and, b. the staff who are there are not particularly well trained and don't necessarily have the right experience and expertise to work well with people with disability. And that as a result, people are not getting the plans, the stuff in their plans that they need, so they're getting stuff they don't need, but they're not getting stuff that they do need and there's no flexibility to move it around and work from them, so there's a whole bunch of what I call process issues which are really burning people's crumpets and it's really, quite a lot of the frustrations at the forums is about there are issues about just how hard it is to move through every stage of the process and then there are a bunch of things about how the NDIS does or doesn't work with other systems, particularly health, but also transport, housing, justice where everybody feels that

they're getting caught in games between governments arguing about who's responsible for what and who's going to pay for what and frankly, people with disability and their families don't care, they reckon it's just about time to get it sorted out because people feel that they're being caught in these games and they're not getting kind of what they need. So there's a bunch of process issues, there's a bunch of issues about how the scheme does or doesn't work with other systems and then there's a bunch of things about whether people are really able to have choice and control, whether there really are the services and supports that people want and will work for them and whether they're able to find them and get them and there's a bunch of stuff about, technically, they call them thin markets, but it's really about are there enough services and supports out there for you to choose from and that might be a problem in a particular geography, a particular region or it might be a problem with a particular type of support that you need. So you mentioned complex needs, but people talk about I've got funding in my plan, but I've got nowhere to spend it, so in actual fact, it's all fairly academic. I've got no choice, and then the final thing that doesn't come up in the forums and that I worry a great deal about is the people who don't come to the forums because the people who tend to come to the forums are, by definition, kind of a bit more connected and have heard about the forums and are able to get there and talk about their experiences. So I'm really worried about the people who Every Australian Counts never hears from, the people who have really complex needs, the people who don't have families to help them navigate the system, people who come from an Aboriginal or Torres Strait Islander background, people who come from a culturally diverse background are people, yeah, and I worry about the people who I never hear from, which is for whom the scheme is not working well. So if you talk to advocacy organisations, they are the very people who are not getting the outcomes we want to see out of the scheme.

Q: Absolutely, yeah, and what's clear from what you said is that there comes a rare theme really around how the NDIS is implementing it, it's, the policy itself is a good policy, yeah, Reasonable and Necessary shows some control which really seems to be fundamental to the legislation, but somehow when they're involved governments and lots of them, then they're all involved in implementing it and start making up lots of rules and all sorts of hurdles that you need to get over and make lots of excuses and sometimes that's a problem, yeah?

A: Yeah, so that's what people say at the forum, so we held one in Geelong a couple of weeks ago and there were a couple of families there who, there was one family in particular who was just so striking to me, they just, they said, look, the NDIS had really changed their son's life and they were such big supporters of the scheme, but they had to go to the administrative appeals tribunal to get the right supports in the plan, but they were such big supporters of the scheme because it had really changed his life and the lives of everyone around him, so for me, that kind of summed it up which is we all want this to work and the fundamentals are right, what we're not getting right is how it's been rolled out.

Q: So go that person of the 71% who didn't understand their plans, what's going on there? I can sort of relate to this because I think that people get this funding and they're confused by lots of jargon words like support coordinators and capacity

building, core supports, there are lots of words that you need to learn in order to understand what's in your plan and considerable, and what's a considerable, and what's an OT, and we've almost made up this whole language of NDIS that unless you know it, you're going to look at your plan and say "I don't know what to do with this".

A: Yeah, I think that's right, so what people say at the forums is that they really feel that they're on their own and that they're left to kind of navigate this whole bureaucratic kind of maze on their own. So they want more help, both before they go in so they know what to expect when they're in there, they've had a chance to think what their, it's even a bizarre conversation you have to have with somebody about what, George, what are your goals and aspirations, so it's a very odd conversation to have sitting in some government office somewhere. So they want more help before they go in so they know what to expect and they have a chance to think about what would, what they need and what would really make a big difference to their life, then once they're in there, they want that process to be easier and simpler and to be dealing either with a planner or a local area coordinator who they feel really understands disability and treats them with sort of empathy and respect and really listens to what they have to say, and then on the other hand, when they get through the other end and they get a plan, they want someone to help them put it in to action, so at almost every single forum that we've held so far, one of the things that people have asked for is not just more help, but people reckon that it would be a good idea to get so everyone gets support coordination in their first year or two years. Because they just want somebody once they get this piece of paper in their hand to go, what's next? What am I going to do next and there are even really simple things like the language in the plan doesn't match the language in the portal, which doesn't match the language in the price guide. So if you're trying to line up all your ducks, all those things are called different things in each of those formats, so even a really simple change that could be done is make all those things line up, so if it's called something in your plan, make it, call that in the portal and make it call it in the price guide so you know where you're at because really, people want to do the right thing, but at the moment, it's too hard to work out what that should be. So I think that, what would be devastating after all of these years would be to get to the end of rollout and get everybody in the scheme and get everybody going and find that not much had changed, that for me, that's what worries me the most because we didn't just fight for the NDIS so that people could get appropriate support. We wanted that, we wanted people to get more support and we wanted people who never had support before to get it and that was an important part of it, but we also wanted things to change. We wanted people to be included in to their communities, we wanted them to have the chance to move out of home, to get a job, to do the stuff in the community they always wanted to do, to get out there and be part of things. So what would be devastating is if we go through all of this process and get to the end of it and find well, yeah, people have got a bit more support and that's really good, but nothing looks very much different. That would be terrible and that's the missed opportunity and that's what also people say at the forums, so yep, we've got to fix up all this process stuff, but we should never keep our eye off the bigger picture, which is what's the change we want to see and are we really getting there and people are really worried about some of the crackdowns at the moment that actually

we're going in the opposite direction and we're not getting the change that we want to see.

Q: And it's around those outcomes around citizenship, community participation, socioeconomic involvement, all that stuff that was in the original report that we need to see outcomes in those areas, and we know that part of that is going to be people adapting to change, services evolving, services, if people can have more funding, and all the services are the same, then it isn't the same right? So it's really about the sector evolving as well and evolving in a way that provides the kind of support that we know is going to lead to good outcomes, so I think that will take a while and I don't think we'll see that by the way and I think that it's remiss of me to say that maybe it will be a ten to twenty year process.

A: Yeah, and I don't think anyone thought we were going to see that straight away, but what you've got to make sure is that you don't, you've got to be worried about inadvertent consequences, so you've got to make sure that when we're trying to fix up this process stuff and get the fundamentals right that you're laying good foundations for the change you want to see and you've got to make sure you're sowing good seeds and I think what people are worried about now is that actually, in sort of clamping down on some things, we're going to get some perverse outcomes, so that's not what we want to see, we want more choice and control, more flexibility, more getting out and doing the stuff we want to do, not less.

Q: And when I see that there are certain disability services not coping under the NDIS, ok well, maybe they shouldn't survive after all, we want to see transformation in supports and we want the fact that people have told us now that they can take their money that the money's attached to them, that they'll take it to their outcomes and not where there just happens to be a free spot that was under the old system, so I think the foundations are there and it will take some time for this to roll out and to start delivering on the promises, or whatever you call it.

A: Yeah, and I also think, so there's change that's going to happen on both sides, right? There's change on the side of providers to not do things the way that they've always done them, but there's also change on behalf of people with disability and their families. It's a really big deal to go from being told, just be grateful for whatever you get to right, you're in the driver's seat now, you can dictate terms, you can say what it is you want, explain what it is you want and then go out and find someone who will do that for you, it's a really, really big change in mindset and again, I think that we haven't invested enough in people with disability and their families to help them along with that journey, there were people who were busting their boilers for the NDIS to arrive and just for them, it couldn't come fast enough and they were off, but for a whole bunch of people, this has been really, really hard and really difficult and in my view, we haven't invested enough in them to help them make the most of it and we won't get the kind of change that we want to see on the provider end if we don't invest in people with disability and their families and that's one of the things that I really strongly believe that they talk a lot about the market, but they focus a lot on the supply side whereas I'm really worried about making sure that we invest in the

demand side so people really can be those really bolshy, well informed, articulate consumers who can go out there and get what they want.

Q: Informed consumers, yeah?

A: Yeah, because that's what you're, but that's a really big deal from having waited for years on some State government waiting list and finally getting to the head of the queue and saying, well, this is all we've got, so this is all we can offer you, it's a really big deal to go from that to kind of the NDIS and that's why I think sometimes people don't understand their plans, but also aren't using all their funding because it's just really overwhelming.

Q: Just as a final note, we're coming up to the election, what can people do with the election tied in to the democracy is a time where you can try and really sort of have a say, right? Do you have any advice around what our Ministers could do around making sure that they could make it work for people?

A: So we're, so elections are a bit of a double edged sword, right, because on the one hand, they are a really good opportunity to kind of bring up the issues that are really important to you, on the other hand, they're very noisy and they're very highly contested spaces, so they can work for you and they can also work a bit against you, so one of the things that we're doing with the forums is that we invite local MP's along to every forum, both State and Federal because we want them to hear from the people who live in their electorate, their own local communities about what's working well and what do we want to see more of, but also what needs to be fixed, so one of the things that we do at the forum is that we talk about what the problems are, but then we also spend a good half, three quarters of an hour at the end of the forum talking about what are the solutions and we brainstorm the solutions and when we first started holding the forums, we were trying to come up with a top five solutions, things that we wanted to see change. Our record is now thirty one, thirty one things that people want to see change with the NDIS and they're all really great, practical, eminently sensible, workable ideas that people come up with and what we do is we say to the local MP's, here, none of the problems that you've heard about today are not fixable and here, here are our ideas on how to fix them, and then we kind of say, go away, you go back to Canberra and you be our champions, you make this happen, and if the MP's can't make it along, we write up the forums and then we send it to them so they've still got a record of it, so even in the absence of an election, our focus really is keeping up the political pressure to get these problems sorted, our first message is always we want the NDIS to work and here's the way that we think that it can work, so we'll be doing the same kind of thing in the lead up to the election which is, we all want it to work, our very strong message is that we're really behind this, but we're five years in to the scheme and some of these things, it's time for some of this stuff to get sorted out.

Q: That's a really good time to end on. Thanks, Kirsten.

A: No worries,, thanks for having me, George.

Q: That's all we have time for on today's episode of Reasonable and Necessary brought to you by the Summer Foundation.

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We also really love hearing from you, so please
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Until next time, stay well and reasonable.

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