

JENNY MACKLIN

DG Hi listeners, and welcome to Reasonable and Necessary, Australia's imminent 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 reflecting with a special guest about the NDIS five years on. In March 2013, the Gillard government made the NDIS law in Australia. Here is just an excerpt of some of the speech made by the then Prime Minister Julia Gillard.

JG Over the past six years, the idea of a National Disability Insurance Scheme has found a place in our nation's hearts.

In March, we gave it a place in our nation's laws.

Today, we inscribe it in our nation's finances.

The people who have gathered here today from around the country to witness this debate know what this means.

There will be no more in principle and no more when circumstances permit.

There will be launches, not trials, permanent care, not temporary help.

Disability care starts in seven weeks' time and there will be no turning back.

I commend this bill to the House.

(Applause):

DG So to reflect with me five years on from the NDIS, I'm very lucky to have the Honourable Jenny Macklin here with me today, and Jenny is known as, or by many of us, a mother of the NDIS, and Jenny, thank you for joining me.

JM My great pleasure.

DG Take me back to 2013, on that momentous day when Julia Gillard made that speech, what was it like for you as a minister?

JM It was both an incredibly emotional day and also very, very exciting. As you will know, it took a long time to get there. If you think back over the history of the National Disability Insurance Scheme, right back to the Whitlam days before you were born, we had a proposal for an insurance scheme, but the sacking of the Whitlam government happened and the Fraser government dropped the idea and it took another 40 years before this idea emerged again. And I remember very, very well, back in 2008, Bruce Bonyhady and Brian Howe coming to see me, and Bill Shorten who at that stage was my Parliamentary secretary, and they proposed that we create an insurance-based approach to disability care and support, that we get away from the crisis driven approach to disability support that had really dominated the whole state and welfare sector for the last hundred or so years. So, it really was, from that time in

2008, you would remember we had the creation of the disability and care council that Bill and I created, to really bring a whole range of different groups together, disability activists, carer advocates, providers, union representatives, bring them all round the table to start talking about what needed to be done in disability care and support. We had the creation of the alliance, which I think was one of the most critical things, recognising that over the last very long time, we've had a really fractured relationship between disability advocates, carers and providers, and I think a number of you as leaders understood, leaders in the disability field really understood, that you needed to come together if we were going to deliver a really big reform, and you did that. And, so many other things happened to make this day a reality that also just made it so momentous because it had taken such a long time, so many people had been involved, so it was incredibly exciting.

DG It was exciting and I remember vividly, I think I was speaking at the launch of the National Disability Strategy, and I made a joke and I said, I'm here to launch the National Disability Insurance Scheme, and the women in the front row afterwards said, not yet, George, not yet. You probably don't remember that as well as I do, and I'm thinking that there would've been a time when you thought maybe it's not going to work. Maybe it's too big a spend. Maybe we can't get the Australian people to accept this amount of money being spent and I know that as advocates, we would try to convince government at the time that it was an investment in people's minds. Were there times when you thought, maybe it's just still not going to happen?

JM Absolutely and I think you're right to have been nervous about it because it is such a huge reform, but there were many things that were done along the way that really gave it great momentum. So we, I talked a minute ago about the disability and carer alliance being created, many of you created Every Australian Counts, so we had this fantastic grassroots campaign that was working, not just in the community, but very, very focused on members of Parliament, telling members of Parliament just how broken the existing system is. I think that was a very, very important part of the campaign to get the NDIS. One of the things I did was take into Cabinet the proposal to get the Productivity Commission to do the big enquiry, to really do the policy and detailed work on what an NDIS would look like, and I think history will show that that was enormously beneficial to the creation of the NDIS. We had an enormously authoritative organisation delivering a report that really set the scene for how it could happen. I was very fortunate to have both prime ministers, both Gillard and Rudd supporting me and the Treasurer, Wayne Swan, but still getting \$22 billion agreed to through the expenditure review committee was never an easy task and I can tell you, there were many, many submissions that I had to take into the Cabinet room, I had to convince them that this was going to be an investment, as you say, that would transform people's lives. But, with that amount of money, of course, it's always enormously difficult, we had to find the savings to pay for it, so I needed my colleagues to be prepared to make big decisions to pay for it, they were prepared to do that, so it was a fantastically collegial effort, I think the other thing is that as you

know, in the end, it was a bipartisan agreement, so part of the excitement on the day when Julia spoke was that every single member of the House of Representatives indicated there that they would support it, that was a pretty big deal and given it was a minority Parliament, it had been pretty tough to get legislation through and here we were, getting this huge reform through with everybody on side. So yes, there were days when I didn't think it would happen, probably some of the other very difficult days were when we were negotiating with the states, trying to get the states to agree and to get them to commit to their side of the funding, but as soon as we got Victoria and New South Wales and South Australia came on very early, so we had some very good early wins and once we had some big ones, the rest came in, but that was pretty hair raising at times.

DG It was a bit of a snowball effect, wasn't it?

JM It was, yeah.

DG Yeah, and you mentioned that part submission. I remember, probably the amount of work that went into a submission for that, and thinking that this is the key, we need to convince the economists that this is a good idea because we've won people's hearts, and we knew that it was the right thing to do, that we needed to convince them that it was the financially responsible thing to do, and I remember when those two big green books arrived in the mail, I don't know how that came in the mail...

JM I was going to say, you should've read them online.

DG And what was obvious was that we have convinced the financial submission as well and there were some very, very clear policy directions in that report that said that this was the right time, that if we continued with the old system, it would cost us more in the longer term; and that Australia would benefit from this.

JM That's right, and you'll remember that one of the key findings that so many of us repeat over and over again was that the old system was broken, they had some horrific examples of how people with disability were being treated under the old system. I take my hat off to the people who worked on the Productivity Commission inquiry, but also you'll remember that they had an advisory group and one of the people who was very, very important was John Walsh, and his contribution I think should go down in history as absolutely critical to the success of the scheme.

DG Yes, as it does, Jenny.

JM Thank you.

DG Then, and then there's now a member of the board of the NDIA, which is fantastic because we can have the voice of people with disabilities on the board, it's very important.

JM Yes.

DG So it's now five years on, can you believe it? It's five years on. Julia Gillard said, and I quote, "there will be no more in principle, there will be no more when circumstances permit". Now we have, however, it must be reasonable and necessary which is part of the legislation. Do you think that five years on, we've achieved what the scheme set out to achieve? Are we on our way?

JM I think we are on our way, let me just go first to the quote that you have from Julia Gillard, that there'll be "no more in principle, there'll be no more when circumstances permit", and I think the thing that people with disabilities should be very, very pleased about is that that commitment has been met, that every government in Australia, Commonwealth, State and Territory is fully committed to the National Disability Insurance Scheme. It is fully funded, there haven't been any cuts to the scheme, so this idea about "in principle" or "when circumstances permit" has not happened and I think we should all be very, very pleased about that, that's a really, really big thing for such a huge transformational reform. Now that doesn't mean that everything that's happened is good, obviously, there have been some people, and I'm really thrilled to hear that your personal circumstances are an example of a positive outcome in the NDIS, and there are many, many other individuals and families whose lives have been transformed, but unfortunately, there are many, many problems, there are many problems and we shouldn't shy away from that. Probably the thing that distresses me most is the culture that seems to really permeate the organisation, it's very much more bureaucratic than I would like to see, I would like to see a much more person-centred organisational culture. So, if there's anything that I find really frustrating and that makes me angry about what's going on, is that people can't have an ongoing personal relationship with people in the NDIS, in the NDIA, in the agency, that they don't feel that they've got that personal association. Many providers are very frustrated with their relationships with the agency, so it's that culture that I think, more than anything, that needs to be improved. I know that the leadership of the agency understand this and they're trying to deal with reforms to what they're calling the pathways, the way you get into the NDIS, the way that you work through. Whether they will make sufficient changes makes it a bit hard to say at the moment. There is obviously a serious problem with the government imposing a cap on the staffing of the National Disability Insurance Agency, we're going through this huge transition, lots of people need to get in to the scheme, we don't want any delays, we want people to get in, so it's a crazy time to have a cap on the scheme, and we also need, of course, to make sure that the staff are adequately trained, that they're able to deal with the huge range of different types of people who are going to need support. We get a lot of complaints come to me, particularly from families of people with very, very complex needs, people who otherwise end up in jail, people who otherwise end up homeless, people who have very, very complex behavioural issues, mental health, so there are many, many problems, there's no doubt about that, but also, we've got to keep our sights on the good things that are happening for people, too, and just keep trying to address the problems where we find them.

DG Because you mentioned this about the staffing cap, that their original idea was that the funding would be spent on people with disabilities and that we wouldn't want a huge bureaucracy, so I'm just thinking, too, and our listeners might think that we don't want more and more of the bureaucracy, will that keep the NDIS or the agency focused on delivering funding to people?

JM Sure.

DG What would you say to them in terms of the staffing cap?

JM Well, I think the staffing cap should be lifted, it's been imposed by the government. Of course you want as much of the money spent on services for and supports for people with disability, but they're not being used if you've got a long queue of people who can't even get into the NDIS on time because there just aren't enough planners to meet the demand or you can't get through on the phone or you can't get your emails answered or all the other myriad problems that exist because there just aren't enough staff or the staff don't understand people's complex needs, they don't understand the importance of doing outreach. It's one thing for people who are able to advocate for themselves and get in there and get a good plan for themselves, but it's quite a different story if you're living on the street, you've got an intellectual disability and mental health problem, behavioural issues, you don't like bureaucracy much, you're not going to come in the door on your own volition, we need to be making hard decisions to make sure those people get support as well as those who can advocate for themselves.

DG And the other thing that we see is a lack of housing, I know it's very, very early on in the scheme, but we really need to see a lot more housing for people.

JM We do.

DG What do you think could be done to address that?

JM Well, there seems to be an enormous number of blockages as you're very well aware of, in the provision of housing. You're definitely right to say, as we know, there's a huge shortage of housing, but it's not only that there aren't enough houses, we don't want the same type of housing as was provided in the past, we actually want to really honour the promise of the National Disability Insurance Scheme, which is that you should be able to have a choice, so everybody shouldn't be expected to live in an old-style group home. For example, if you want to live with your mates in an apartment somewhere and get the support that you need delivered in that apartment, then we should be able to make that happen, and all the other different types of options that people are going to want, just like the rest of the community, so there are problems with making sure that people have got a range of choices, that we don't fall back into the old models, that those people who are prepared to invest in housing for people with disability understand that, so that they don't actually just go and build the same

old thing, so I think we've got a huge range of people who need to understand that people with disability have got just as much right as anyone else to have a choice of housing.

DG And I think you're absolutely right, that there was a promise there that we would replace the broken system, and I think part of that broken system was the old group home models that we know from the enquiries and the work particularly around abuse, but these are not necessarily the best places for people.

JM That's right, that's one part of it and you're absolutely right and another big part of the promise of the NDIS was to older parents, people in their seventies and eighties who are very worried about what's going to happen when they pass on, if their sons and daughters are still living with them. They're living with them often because there just hasn't been any other housing available. There's been, so there is an enormous shortage, both of housing, but also appropriate housing, housing that people with disability themselves will want. So I would say, I've been saying this to the Department of Social Services from the time I was still a minister: get on with it. Make some decisions, make it happen, it's a massive area of demand.

DG And we know that the NDIS wasn't meant to solve all the problems in terms of housing, we know that there's a need for the National Disability Strategy, for example, to do its work, it's a whole of government issue, isn't it?

JM Well, the National Disability Strategy, of course, was meant to cover all areas of government activity: justice, education, health, all the different parts of life where governments provide services and supports to people. And we know in many, if not all of those areas, people with disability don't get a fair look in. You go to hospital, you don't get looked after appropriately, you have to take your own supports in there – you're rolling your eyes – obviously, personal experience.

DG Yes.

JM So, the list goes on. We know what happens in the justice system, that's why we created the National Disability Strategy and unfortunately, this government's really just let it sit, sit and rot, frankly, they haven't done anything, they haven't made any effort to make sure that different parts of government keep up their end of responsibility to deliver to people with disability.

DG And you're probably not too far away from being in government again.

JM Never get ahead of yourself.

DG Let's say that you're the next in line for the government, what changes can we expect? I know that you will obviously spend some time reviewing and consulting and making sure that you understand what the problems are, but what can we see, can we expect to see some changes?

- JH Well, I think there are some serious issues that have to be fixed, the housing one we've just spoken about, the culture I've already made reference to, a couple of other big issues, though, that have not been addressed and need to be that would be a priority is the workforce. We've just seen the Productivity Commission enquiry come down really reminding us that this is both a huge opportunity for people to get great jobs in the disability sector, but we need to make sure that people are encouraged and trained to be able to get the jobs, that they are going to be available. And I've been very, very frustrated that the government's been very slack, frankly, at making sure that people know about the opportunities in the NDIS, know about the huge demand that's coming through for people in the disability sector, and of course, the reason we need more people is people with disability haven't been getting the support they need and that's why the old system was broken. People who gave examples to us that they were only getting showered two or three times a week because they just didn't have enough support, so there's a huge range of job opportunities and I think this government's really dropped the ball on making sure that the workforce is ready for this big expansion. I also don't want to see a hugely casualised workforce where people aren't properly paid, we need a workforce that's probably paid, where it's a great place to work, people with disability want workers working for them who are well paid and happy to do their jobs, well trained and equally, the staff themselves need to know that they're going to have a career and have a future in the disability sector, so I think this is a huge issue that really, in addition to the others we've already talked about, really needs to be resolved.
- DG I think you're absolutely right that workforce is critical and if we don't have the workers, there's no point in having an NDIS, is there?
- JM Well, a lot of people are finding they're just coming round to getting their second plans done and they're losing money because they haven't been able to spend their first plan, and one of the reasons they haven't been able to spend all their money is because they can't get the services that were in their plan. Now that shouldn't be a surprise to anybody, it's new, the new providers need to come on stream, there are shortages of the workforce, what we don't want to see is people's plans get cut just because they can't get the services, it doesn't mean they don't need them, that just seems to me to be terrible short-term thinking, so that would need to be fixed.
- DG Absolutely, but it's a \$22 billion scheme, and you're talking about attracting more people to the industry, if you increase people's pay, you pay them better, then our listeners might think, does that mean less services or smaller packages, but the pay of \$22 billion is what it is, and it's a complex issue.
- JM I beg your pardon?
- DG It's a complex issue, when you look at the workforce taking people.
- JM It is, but when the Productivity Commission did its enquiry, it didn't base the costings of the scheme on paying people badly or making sure that people got less than they

needed, it costed it on the basis of looking at what people would need and making sure we had a properly paid workforce. So we've got to be able to do both and we don't want to short-change the workers and we don't want to short-change people with disability, we've got to be able to do both.

DG Absolutely and just the last thing I wanted to ask was if you had the chance to do it all again, not that you'd ever want to ...

JM Well, I don't need to, fortunately.

DG Hopefully not, is there anything that you would've done differently in terms of making sure that the NDIS was as good as it can be?

JM We shouldn't have lost the 2013 election.

DG I knew you'd say that.

JM I think what it demonstrates, what the whole story of the National Disability Insurance Scheme and its creation demonstrates, is that very, very big reform does take a long time, it really took all of the time, from 2008 to 2013, to build the case, to build the evidence, to create the campaign, to get it successfully through the government and then through the Parliament, and then of course it's taken since 2013 to 2021, it will be before it's fully implemented, and there's not another reform I can think of that's taken that long. So it's, and it will need that time for it to be fully implemented right across Australia, given the extra time in Western Australia particularly, so yes, it's been an enormous project, if you like, but one that I'm incredibly happy that I had the chance to be part of.

DG Well, thank you, as someone who is personally benefiting from the NDIS, thank you for all that you did.

JM Well, can I just say, before you finish, George, I want to say what a great advocate you were, people like you, Rhonda Galbally, Kirsten Dean, fantastic advocates who it would not have happened without you and the others doing.

DG And can we mention Lesley Hall?

JM Lesley Hall, an absolutely outstanding advocate who passed away far too young, fabulous, I can remember her coming and seeing me in my Parliament House office with her very clear agenda, always very, very clear. Lesley was about what needed to be done, but all of you, all of the advocates, I could list another so many, but I just wanted to say to you personally how important your role was.

DG Thank you, Jenny and thank you for joining us on the show.

JM My pleasure, thank you.

DG That's all we have time for on today's episode of Reasonable and Necessary, brought to you by the Summer Foundation. Don't forget to check out our Facebook page, Building Better Lives, for all previous podcasts and transcripts. We also love hearing from you, so please leave your comments and suggestions for future episodes. Until next time, stay well and reasonable.

END OF TRANSCRIPT