## Reasonable & Necessary podcast series

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### **What should come next for the NDIS?**

Hi everyone and welcome to Reasonable and Necessary. Australia's favorite podcast series of everything you've ever wanted to know about the National Disability Insurance Scheme, brought to you by the Summer Foundation. I'm your host, Dr George Taleporos and on today's episode, we're talking to Senator Jordon Steele-John about what we need to do to get the NDIS back on track. Check it out.

Hey, Jordon. Welcome to the show.

Jordon Steele-John:

Hello, George. Great to be here with you, matey.

GT:

Jordon, I've been following your parliamentary career for a little while. I know that when you first entered the parliament, I was very excited and I was like, "Finally we've got one of our own in there," and you haven't let us down, have you?

JS-J:

Oh, thank you. Well, I'm really glad that you say that, mate. It's been a wonderful couple of years and I've just enjoyed every single minute I've been able to work alongside... as a Green working alongside the disability community to get some great outcomes. It's been an absolute joy and I'm looking forward to continuing to do it.

GT:

Yes, exactly. Now I want to get your perspective on the NDIS. There was a pretty big thing that happened a few weeks ago. You were a strong campaigner against the introduction of independent assessments, and there was an outcome that was completely, I'd say, out of the blue in terms of what I saw coming. How did you feel and were you surprised?

JS-J:

Well, I felt incredibly proud of our community, George, and the way that so many disabled people worked together alongside the Greens. From the minute these terrible proposals were kind of floated a couple of years back right up until the kind of crunch time meeting in June to put pressure on the Liberals and to share our experiences and our concerns in a way that resulted in the proposals being dropped. And I remember when the news kind of broke. Initially, I felt a little bit suspicious. Kind of like it's a trap situation, but to hear in a meeting a couple of weeks back that the agency has actually cancelled the contracts that they had given out, about $339 million worth of contracts to perform independent assessments. That they have actually cancelled those contracts means that independent assessments really are dead.

So that is fantastic. And that is a testament to, I think, our shared power as a community. The Liberals tried to do something about us without us. Tried to force these changes on us and working together between the disability community and the Greens we were able to activate and make those calls to MPs and to decision-makers and bring incredible pressure to bear in such a way that Morrison was absolutely humiliated by this result, which I think is a wonderful thing to achieve as a community.

GT:

Absolutely. The thing for me was that I had a bit of my faith restored in democracy, which shows you when this policy was introduced, it was done in a way where it was kind of decided for us and we sort of had to do all this work to say, "Hello, here we are. Maybe talk to us and see what we think." And see if that's the direction that we want to take and for a long time, the government wasn't listening to us at all. It really did change, I think, when your fellow WA person, Linda Reynolds, came in. She did really turn it around, didn't she?

JS-J:

Well, I think what happened is the more we learnt about these processes that the government wanted to subject us to, and the more the evidence that was gathered through things like the Senate inquiry process that I participated in, the clearer it became that these processes were not only not going to work, they were going to be extraordinarily harmful. They were going to fail to capture accurately, the needs of us as disabled people and they were going to result in people not getting the support that they needed to live.

And I think that that motivated great opposition in the community. The questions that we were asking, the agency and the government just didn't have answers to. I think actually the watershed moment came again when in the week leading up to the disability ministers' meeting in June, we had disabled people across the country making calls and contacting their disability ministers saying, "Go into this meeting and say, 'No, we do not support these changes. You will not change our NDIS without the consent of disabled people'," combining with the willingness of the ACT's disability minister, Emma Davidson, who's a Green minister in the ACT, to actually go into that meeting and very clearly say before she went into that meeting, that she was not going to consent.

And then that gave space for the other ministers to follow and kind of give in to the pressure. So I think once again we see the Greens and the disability community working together. It is the story of this outcome. And really the ability of our community together to wield the veto over changes to the NDIS that are not co-designed, and don't have our best interests at the centre of what they're about.

GT:

Yes. Absolutely right. We need to give full credit to everyone that wrote to their local MPs. Everyone that spoke up and clearly sent a message to the government, and people like yourself, people like Sam Connor. There were lots of people who were very loud and very clear in their message. And I also think that credit to the States. They were very, very clear as well in wanting to understand what the whole point of was behind this, and how it would impact on people with disabilities. So collectively I think that it was definitely a team effort.

JS-J:

Absolutely, it was.

GT:

So, Jordon, I'm really keen to get your views on some of the key areas of concern that the minister, the government, and the agency have been raising. Particularly around sustainability and the functional capacity of participants. I'll start with the sustainability issue first. In July we saw the report that said that the costs of the scheme is growing and that they've been growing more rapidly than have been anticipated and one of the reasons is that there's a lot of people entering the scheme. And the other reason is that the cost of the plans are going up. What do you think of these concerns around scheme sustainability?

JS-J:

Well, I think when we're talking about our NDIS, we need to ground the conversation in a shared understanding of what the NDIS is and what it was created for. So we know that our NDIS was created to make sure that disabled people are able to get the support that we need when we need them, and those supports would be determined. This was the vision of the scheme by reference and consultation with ourselves, valuing and centreing our lived experience, the practitioners and medical folks that we have worked with for a very long time, they've given information on what our support needs are, and reference to kind of the supports that we were getting at the time versus what we think we need in the future.

So it's got to be grounded and kind of guided by those ideas, if you like. And by grounding them in those principles and kind of articulating them through the legislation, we wanted to make sure that when somebody articulated "I need X, Y, Z to meet goal A, B, C," that they'd be able to get that support. In the full knowledge that their life might change, that the context in which they live might change, or their goals might change. And as those things changes that funding would go up and down or any other direction to reflect to reflect that need, if you like.

Now, as to questions of sustainability or cost or all of these things, what we've seen to this point is the government make a bunch of, what I would characterise as scare tactic claims, really. About certain protections around how much it would cost.

And they've done the old oogedy, boogedy, boo. This is really frightening. And therefore, we need to cut NDIS supports, we need to make it more difficult to get on. We need to kick people off the scheme. So, the conversation about sustainability has arisen against the backdrop of the agency trying to get people off the scheme or indeed, introduce independent assessments.

Now, our response and my response in the parliament has been, first of all, bugger off. You should not be making it more difficult for people to get on the NDIS. Trying to kick people off the NDIS, trying to re-imagine what its original purpose was.

And second of all, if you're going to make claims around how much it's going to cost, you've got to be transparent about what are the projections that you're making? What are the assumptions that underline those projections? What are the financial sustainability reports actually saying? Not what are the cherry picked parts of them say, that you want people to see so that you can justify your fear campaign. Let's have all of it and let's subject it to independent analysis.

And at every step of the way, the government and the agency have refused to provide that information, not only to the Senate inquiries that I've been part of, but also to the ministers, the state and territory ministers, that co-run the scheme alongside the Commonwealth.

I think we need to be really focused on what did we create the NDIS for? Remembering, of course, that its purpose around giving people the support that they need to live a good life, is actually a reflection of our broader Australian community value of fairness and justice. And that there is great support for us disabled people getting those supports.

And then any and all claims made about the NDIS need to be able to be tested. The evidence provided for them need to be able to be subjected to independent analysis before we make any changes or even start conversations based on those projections or suggestions.

I guess my short answer is, George, this is a scheme that's meant to be there for everybody that needs it, to provide them the support that we need to live a good life. It's supported by our community. And if you're going to make any suggestions about how to change it, you should be willing to be upfront and transparent about the underpinning assumptions. And so far the government hasn't been.

GT:

Yeah. That is really critical isn't it? That we need to get the data and we need to fully understand the problem, if there is a problem. And one of the things that I find a little bit odd was that it was only two years ago I think, when the NDIS funding was in surplus and the farmers were being rescued from NDIS funds.

How do we go from having this massive underspend to having a massive overspend? The odd thing for me is, is it the plans that need addressing or is it something else around expenditure? But we'll talk about that a little bit later.

How about the other element which is around the fact that, and I've heard the minister talk about this a lot, functional capacity in self reports is going down so when you look at people who been have in the scheme since 2017, the data is showing that the longer you've been in the scheme, the lower you will rate your functional capacity. And the ministers are saying that, well, this is not what the NDIS is supposed to do. It’s supposed to lead to increases in functionality. Do these results concern you?

JS-J:

Well, I can tell you what does concern me, George. And what quite frankly makes me really bloody angry. And that is the reports that we have that we hear in my office and have heard consistently, I think for the last three and a bit years we've been in. Which is that if you go along to your NDIS meeting, or at any opportunity you have to interact with the NDIS. If you give them anything other than the worst case scenario, or if you do anything other than use every single piece of your funding by the end of your plan review period, in the next plan, your plan gets cut, or you get kicked off the scheme.

And so, people feel a great pressure to go there into their meetings always and give the worst possible scenario. And to try to use their funding in any and every way possible, because they fear, legitimately, that if they don't use all their funding or if they say anything other than, "oh my God, it's 10 times worse than it was the year before," they'll have their funding removed. Or they'll be kicked off.

So, in that atmosphere, it does not surprise me at all that when asked about your function, people would say, "oh God, it's terrible. All the things are terrible. I've not only made no improvements, I've gotten worse." Because you actually feel as though you... And you feel legitimately, by the way, it's not just, "oh, a bunch of worried disabled people. If only they trust the government."

This is lived experience, over and over again. Thousands of people would have reported to me over the years, tens of thousands of people would have shared their experience in different online forums and what have you. If you say anything other than, "I am awful, and I need more money," you get your money cut. Because the Liberals have instilled that culture into the agency. And the agency leadership have picked it up as part of their never ending quest to cut the NDIS and kick people off the bugger.

Now to the actual... The detail of the data that's released. To be honest, George, I don't trust it anymore than I trust these claims that are being made about the amount that the scheme is costing. These ideas about people's functional capacity declining were introduced in as part of the fear campaign to sell independent assessments.

And only a couple of months ago in the last quarterly report, if I remember rightly the agency specifically said, "these forms of collecting data are unreliable. And so, not so many conclusions should be drawn based on the bunch of data that we're showing you here."

And then in this report, they're saying, "oh, alarm bells. Alarm bells, people's function is declining." So I think the agency and the government, the Liberals, are presenting the information that they want to present in a way that they think will help them save their argument and sell their argument. And I think we as a community, have a right to say, "nope, this has got to be put to independent analysis."

Because at the end of the day, both the government and the agency have completely dissolved any level of trust between the community and themselves in the way that they tried to force independent assessments through. And I've told this repeatedly to the minister and the agency. We're now at a position where we cannot trust on face value anything you give us, anything you tell us.

So, if you want to make a claim about our scheme, you better pony up the data so that it could be independently analysed. And if you can't, then we'd rather just stop the conversation there. Because so far, all we've had is spin and fear-mongering from people leading a scheme that should actually be centred on, and was created to facilitate us disabled people getting the supports we need to overcome the barriers created by ableism to live a good life. That's what it was for. And that's what these people seem to have forgotten.

GT:

I was listening to you when you talk about the reasons behind why people would say or report deterioration or less functional capacity. And I was thinking, we've got a real problem here, don't we? Because if you've got this lack of trust with the government, and then we've also got the system cutting people's funding for reasons such as, I don't know, not spending it or not putting things in a positive light, then what do we do, Jordon? It feels like that will be, if an advocate for independent assessment was here they would say "oh, that's why we need independent assessments."

JS-J:

Well, I think we've got to actually challenge this whole conception that we should be measuring increases or decrease in people's functionality as a measure of success, even if we could measure it successfully. Because at the end of the day, now here's the critical thing. The NDIS is not an insurance scheme. It's not an accident and insurance scheme, it is a social insurance scheme and it must…you can't understand it without recognising that..

GT:

What’s the difference between…?

JS-S:

Yeah, so an accident and insurance. Yeah, absolutely. An accident and insurance scheme would be ... They're usually state-based systems and you usually come into contact with them when say you're in a car accident and maybe you get a spinal cord injury because you've ended up in a car accident. And at that point what would happen is your insurance scheme would go, "all right, how much of your function can we restore using your pre-accident function as the baseline? And then beyond the point where we can compensate you or restore that function, what was the value of the function that you lost, and then we'll compensate you for it." In simple terms, we'll give you a bunch of physio, we'll pay for your operations. You will get 80% of your functional capacity back that you had before the accident, the other 20% we can't return so we will give you a lump sum payment to compensate you for lost earnings over your lifetime.

That's your traditional accident and insurance model and it has the core assumption at the centre of it, that there is a normal to which you can return as a person, if that makes sense. Whereas a social insurance scheme, such as the NDIS, are dealing with a cohort of people like disabled people in Australia, needs to be premised on the understanding that there isn't a normal to return to. The point is not to heal you to be well again because actually the barriers that you face, the impediments to your life exist because of the interaction between your impairment or your difference in the barriers in society created and sustained by ableism.

The supports you need are actually to enable you not to return to some kind of normal but actually to work towards and achieve your individual goals, taking account of the impairments that you have and the context in which you live. You might need XYZ supports to achieve ABC goal while you are living at home with your parents, for instance, and then you might want to live independently, meaning that you will need different supports that may cost more, may cost less, as you move through your life towards different goals, the purpose being to support you to achieve your goals, not to return to a normal.

And in the context of ever-changing goals within an ever-changing life context, the question of your functional capacity at a particular point is much less meaningful because you're not working to try to return somebody to a functional capacity that they had before an accident because you're actually focused on the barriers that exist in the community as a whole to that person achieving their particular goal at a particular time. Does that make sense?

GT:

Yeah, it does, and it makes sense in terms of the need ... One of the things that independent assessments were throwing out was the concept of goals and that goals weren't important, but clearly through a social insurance scheme, goals are front and centre to what you would need.

JS-J:

Absolutely.

GT:

Yeah.

JS-J:

Absolutely. The other thing that's really important in that distinction between social insurance scheme and accident insurance scheme is understanding that it actually exists for everybody. It exists for every person, disabled or non-disabled, should they acquire or have a family member with an impairment or difference, and that we all contribute so that we can all access it when and if we need, shaped towards the particular goal that we then may have as somebody that might come to be a participant in the scheme or have a child that becomes a participant in the scheme. It's much more akin to say your Medicare, or it should be much more akin to say Medicare, where we all contribute. Those who have a bit more contribute a bit more, those who have less contribute a bit less, so that if we need it that support is there.

That's the way that we think about it, we don't actually think about it in terms of how much is it costing. The focus is actually on the output for people and then we work backwards from the output for people that is needed to the revenue source and the administration that is needed to achieve that output rather than, "oh, there's only so much money in the pot, George. We can't give you that headrest because if we give you that headrest we won't have enough money for the poor children at the special school, George."

That thinking has got to be done away with because actually what we are funding the NDIS to do, through its support of people achieving their individual goals, is to tear down the barriers of ableism, created and maintained by non-disabled folks in society. If you want the thing to cost less, if that's your goal, well then get rid of bloody ableism out of the society. Make places accessible, drive discrimination out of the education and the housing system and the employment system. That's the solution, not cutting people's plans and kicking them off the NDIS.

GT:

This is where the Tier Two or the information linkages and capacity element of the scheme, the part that's largely not talked about because it's not as interesting to the media, really. But the role of ILC in connecting people with their community and addressing ableism, as you said, peer support, all of that stuff, if you invest in that you will bring down the cost of the scheme in the longer term.

JS-J:

Well, what you've got to do ... Yes, Tier Two supports are very important and we need to invest in them. I think also we need to make inclusive design part of everything. Part of the way that we design our digital place in space, our physical place in space, our education systems, our housing system. Everything needs to have inclusion of disabled folks at the centre so that as we build new things and bring new programs into the world, we're making them inclusive and accessible for everybody, as we should be doing under our commitment to certain international rights conventions, most certainly, but we can't ...

I guess my point, George, is in understanding the social model of disability and the reality that somebody's struggles related to being disabled are actually a result of that interaction between impairment difference and the barriers in society. It's actually everybody's collective job to ameliorate those barriers. Every government program should be working towards that and every state government program should be working towards that and every local government program should be working towards that.

GT:

Absolutely.

JS-J:

If there is a need to tax billionaires and big corporations a little bit more to get that done, well then let's bring Gerry Harvey in here, hook him up to a chair and suck a couple of hundred million dollars out of him.

GT:

Oh, don't pick on Gerry Harvey, come on.

JS-J:

Yes, poor Gerry Harvey.

GT:

I want to put you in charge for a second now. If you were the minister for the NDIS, what would be the things that you would do to improve the scheme and turn it into that social insurance scheme that you so clearly described? What are the practical things that you would do?

JS-J:

Yeah, great question. I think the Greens have a very clear vision for the NDIS and it begins with being very clear in what the goal is, what are we trying to achieve? We believe that we need to have an NDIS that is there for every disabled person that needs it, regardless of where they live, regardless of what their support needs are. It needs to be able to get you the support that you need quickly and its processes need to treat you with respect. It needs to be easy to access, easy to navigate from beginning to end.

To achieve that we need to do a couple of things. One, we need to make sure that we hire more people to work at the agency to bring those wait times down because we know that people are waiting too long, speaking to too many different people at too many different points because actually we've got 3000-odd people working there in the scheme that actually needed about 10,000 people to run it properly. We need to hire more people to bring those wait times down so that people can get in and get what they need quicker.

We need to make sure that those folks are trained properly and that we have an increase in the number of disabled people working in the scheme so that people that you are talking to actually get it, they have a lived experience, they have an expertise, they've been trained properly to do that work so that we don't have any more, "is Down syndrome permanent?" type situations.

Then we need to make sure that these artificial barriers that have been erected inside our scheme by the Liberals, are brought down. So we need to make sure that people with psychosocial disability, people with chronic illness, are able to access the NDIS easily.

You need to get rid of those barriers to being eligible. So that everybody can get what they actually need without this kind of, "no, no it's meant to be the health system. No, no, it's meant to be the education system." Where at the moment, that just ends up meaning it's nobody.

We need to address those eligibility criteria constraints and make sure that whether you've got ME/CFS or you've got any of the chronic pain conditions, if you've got a psychosocial disability, you can get in, get the support that you need. I don't want to hear any more about, "oh no, this is the mental health system's response."

Under a Green's run NDIS it will be clearly something the NDIS deals with. And deals with quickly and respectfully without any of this silly stigma that exists around if you have a mental health challenge.

And then finally, we've got to get rid of the awful cutoff at 65, where you're no longer able to be eligible for the NDIS and you're just left to the aged care system that isn't able to support you. So, we want to see an expansion of the age criteria so that it actually doesn't matter what age you are, you're able to get on the NDIS.

That's just a couple of things that we want to do to make sure, like I said, that everybody can get it, wherever they are, quickly and respectfully. Without having to feel like you're fighting the system that was set up to support you.

GT:

I like a lot of what you said. The one thing I would want to clarify is how do you stop…one of the things that's really important, I think, is that all parts of government and society continue to do what they want to do, for people with disabilities. And whether in the education or the health system. I don't want to go to school and this school's like, "no, you're the NDIS's problem." And go and study at the NDIS school." Well, we need to be really vigilant that all systems of government continue to... Not continue to. Start to do what they need to do to be inclusive and meet the needs of people with disabilities. How would you address that in your approach?

JS-J:

Yeah, absolutely. So the other two things the Greens are going to talk about and we are talking about, ahead of this election is the need for two fundamental changes. We need a proper national disability strategy that encompasses all of what you've been talking about and makes sure that there's a realisation that actually, confronting ableism and breaking down the barriers it created is every department's responsibility, so that you don't get that buck passing.

And that looks like actual, tangible, measurable commitments. For instance, an Australian public service employment quota of 20% in the Australian public service for disabled people. It looks like anactual plan, like a step-down plan to eliminate segregated education and ensure mainstream inclusive ed for everybody by 2030, in line with the Australian Coalition of Inclusive Education's outline for that goal.

So we need to do that. Need to stopped being this sloppy, motherhood statement, dominated nonsense document that everyone goes, "oh, isn't that lovely? We'll put it up there on the fridge." That attitude to the disability strategy. We need to get rid of that attitude.

And then, the second thing we need to do is we need a disability discrimination act with teeth. We need a new DDA. It's 20 years old now, or more than 20 years old now. And it is not the legislative... What it does at the moment is it forces you as a disabled person to pursue an individual issue yourself. And then the most it can do is make you conciliate with the party that's subject to the discrimination. And then that settlement doesn't actually set a precedent necessarily. We need a disability discrimination act that enables the disabled person to make the complaint. And then not have to take on the emotional and physical labour of pursuing that complaint.

Meanwhile, the commission takes on the discrimination issue, drags the corporation to the table, kicking and screaming, forces them to make changes, and then those changes result in a precedent for the affected industry or particular issue.

So those two things working together. A concrete plan with measureables to which people will be held accountable if they're not met. And a DDA with teeth will, I think, drive some of those changes you're talking about.

GT:

Thanks, Jordon, you’re absolutely right. The National Disabilitiy strategy & reforms to the DDA are essential to improve outcomes for disabled people.

I want to end with this question. What's it going to take to get Senator Steele-John to be our next prime minister?

JS-J:

Oh, dear. I can only imagine the look on some people's faces at that idea in the Labor Party and the Liberal Party. It's quite funny. Look, I think that we have an incredible opportunity in the aftermath of our wonderful demonstration of power as disabled people in defeating independent assessments to now look at the NDIS and the disability policy space generally that we want to see.

And I think that by... Well, really, to be honest with you, George, I'm really quite excited about the federal election. Because it is in many ways closer than many people think. I think that the Liberal Party is very much on the nose. The Labor party need a bigger swing than I think they will get to win government in their own right. And even if they were to win government in their own right, I think their track record on some disability policy stuff isn't too great either.

And probably the ideal outcome would be the Greens in shared balance of power. Meaning that we would kick out the Liberals, but still when it comes to the NDIS, we'd hold the balance of power as to what changes are that we need. And that's how we'd actually get it done together. I think that's what really excites me.

That and the idea of being able to be in a position after the election to refound our NDIS, to fix the issues that have developed through 10 years of total mismanagement. And also, to address those other things that are outside the remit of the NDIS, that are so vital to create an accessible and inclusive society for everyone.

GT:

Yes Jordon, very interesting times coming up. Jordon thanks you, you've been great to talk to. And I really look forward to seeing your political career go from strength to strength. You really are a fantastic advocate and you have my full support. Thank you Jordon.

JS-J:

Thank you so much, George. And thank you for the work that you do. You've been an invaluable source of information over the last couple of years. I've really appreciated your help and guidance at times. And I really look forward to continuing to work with you to get some good bloody outcomes for our community.

GT:

Thanks see you next time.

JS-J:

Cheers, George. See you.

GT:

That's all we have time for on today's episode of Reasonable & Necessary, brought to you by the Summer Foundation. To be notified of future episodes, don't forget to hit the subscribe button and the notification bell. Thanks a lot team. And until next time, stay well and reasonable.