

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

[Opening music plays]

### **Presenter**

Welcome to Brotherhood Talks.

### **Bruce**

There was always a tension and that tension remains. That is, there is the tension between trying to bring everybody in as quickly as possible. Because in the absence of that, it's unfair to have people outside, waiting and waiting. Then their desire to have - get it right the first time for everybody.

### **Woman in audience**

We've done four plans now. We're on our fifth. So - and I think it took to the fourth plan until we worked out that you actually write the goals and you bring them in and you hand them to the - and then you actually write the plan.

### **Presenter**

More than 300,000 people around Australia receive services through the National Disability Insurance Scheme, or NDIS. Another 160,000 need to be brought into the scheme. So what's working and what's not? Amanda Pagan is head of Inclusive Communities with the Brotherhood of St Laurence Research and Policy Centre. In this Brotherhood Talk, Amanda is moderating an expert panel. She begins by explaining how and why the Brotherhood came to provide local area coordination for the NDIS.

### **Amanda**

The Brotherhood has a nearly 90-year history of driving policy reform at all levels of government. Our vision and obsession is an Australia free of poverty. We work to address these things and prevent the thing - to address the things that prevent us from achieving this vision. In Australia, people with disability are over-represented in nearly every indicator of poverty. This is simply not good enough for us. We rejoiced when the NDIS legislation was announced because finally we would have significant policy change for all people with disabilities, their families, and carers. In 2016, the Brotherhood successfully was awarded the local area coordination contract in north-east Melbourne and, shortly after, extended our services into early childhood early intervention and then into five regions across Melbourne.

In running these sessions - in running these services, we've developed great insight into the real of challenges of transitioning a major policy reform from a formally state-based system to a national system. It's been a rocky but rewarding job. The joy and pride we get and experience we experience when we see major changes in life of many people with disability because of the NDIS gives us the fortitude and sustenance to keep our commitment strong. This is because our work is more than just a service. It's about working with our local communities to ensure we get the most out of the NDIS for all people with disability, their families, and carers. It's also about driving systemic reform by standing beside people with disability, their family, and carers, to get the best outcomes. For us, this means generally delivering on the vision of greater inclusion; social, economic, and political.

So on that matter, I have four wonderful panellists here to give their perspectives on where to next with the NDIS. In inviting the panellists, we tried to draw together

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

distinctly different voices and knowledge to recognise the fact that implementing good policy like the NDIS requires the best and most diverse minds. So on our panel today, we have Bruce Bonyhady, chair of the Melbourne Disability Institute and inaugural chair of the National Disability Insurance Scheme; Karen Dimmock, the CEO of the Association for Children with Disability; John McKenna, lifetime disability advocate, podcaster, and NDIS recruiter; and Sam Connor, who has a million roles that are too long to describe, but is probably most recently best known for her work, particularly in relation to peer-led work in disability and the NDIS Grassroots.

I'm going to start by asking the panel a number of quick questions about the NDIS and what their perspectives are. Then I'm hoping to really open up to the crowd to allow you to ask questions directly. So to the panel and particularly Bruce, I'm going to start with an opening question, which is - perhaps each of you could describe really briefly what you're each doing individually, through your organisations, to influence and improve the NDIS, and what you think might have changed in relation to your work since you started.

### **Bruce**

Okay. Well Amanda, thank you very much for the warm introduction. It's fantastic to be here and to be talking about where to next for the NDIS. So I'm now at the Melbourne Disability Institute. Our aim is to harness research to improve the lives of people with disability and their families and carers. We're working across the University of Melbourne, but also with other research institutes. Our vision, really, is to have much more inclusive communities, to improve the health and well-being of people with disabilities, their families, and carers, to ensure that markets that are now being available to people with disability are actually harnessed to improve their lives. To then translate this research into improved policy and practice.

This is obviously a very different role to the one I held when I was chair of the NDIA, but I have always thought that one of the differentiating features of the NDIS is the data that it's collecting and then the potential to then bring real evidence to improve people's lives. So that's what I'm now very focused on and delighted to be working with Amanda and the Brotherhood and other partners to realise that vision.

### **Sam**

So probably our biggest piece of work - I belong to a disabled persons' organisation called Yellow Submarine, and we have an ILC grant. Also contracting for the Wheatbelt Health Network in WA, which is across a little area called Balladong, which is the size of Victoria - tiny area - which is around community development and getting people to understand how to access mainstream supports and services - the old tier two of the NDIS, as well as the NDIS itself. Then I also administer a bunch of social media forums and supports and peer support groups. So the biggest one, as Amanda mentioned, was NDIS Grassroots discussion, which is terrible but wonderful at the same time, which has 47,000 people arguing on a daily basis. But it's also a really good peer support forum.

So I guess, part of my role is actually creating and maintaining spaces where disabled people and their families can exchange and share information and learn about how to get what they need to be who they are. That's kind of our tagline.

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

### **Karen**

At the Association for Children with Disability, we have supported families across Victoria for nearly 40 years to speak up for their children's rights and needs. Boy, do you need self-advocacy skills in relation to the NDIS. So we're really pleased that we've been able to support thousands of families, get prepared and get ready, and learn the whole new language that is required in order to get a good NDIS plan for your child. But we've had to work a little differently, as well, and that is to work directly with child and family workers to ensure that children who are involved in child-first or child protection also get good advocacy around them, and that they are not left behind.

Because we work with so many families and children across the state, it means we get a great picture of what is happening. We use that opportunity to hear directly what is happening on the ground to then speak up. To speak up at Parliamentary forums, directly to decision-makers, to MPs, as an independent voice for children, to say, "This is what is needed," for families and children to make the NDIS work better.

### **John**

I answer this question for - I guess, three directions. First of all, I'm very fortunate to be involved when it was a start-up, the NDIS, when they were looking for the right people that had the right mindset to be part of this exciting opportunity. So about six years ago, I was part of the recruiting - and still am, which is great - and at that stage it was about finding the right people that get it, that understand why they were going to be involved, to be employed with the agency. The second angle I come at is as an advocate with an organisation called Valid, based in Victoria. They've been around for years. I've been involved in peer action groups and they're still very strong in this area, with a particular focus on supporting people without a voice, people that have [inaudible]concerned, they're the ones that drive my own professional passion, if I could say that.

So I can sit here as a proud citizen, as a person with a physical disability, but for people that do require advocacy support and for their voice to be heard, that's really important. I've been a participant for about two years and very happy living life at the moment. Little things like - when I'm out and about, I've got someone there to put my hat on. If I've got an itchy head, I've got someone to scratch it. But most importantly, this is all happening while I'm working. So there's no secret that one of my goals is to keep working. I love working and I love giving back. But it is about my disability changing and the supports I need with regards to, like I said, the hat on and off, staying warm, and stuff like that. So the really basic stuff's been fantastic.

### **Amanda**

Bruce, I'm wondering if you might be able to talk a bit about what you think is working well in the NDIS?

### **Bruce**

Well, I think to answer that question, Amanda, I'd just like to give a bit of context. Because when you read the headlines, what you mainly hear about is what's not working. So I think as we think about what's working and, indeed, later on in this discussion about what's not working and where to next, I think it's really important to recognise the speed with which this reform is occurring, the disruptive nature of it. I think - so I think most remarkable thing is how well it's going, that we've managed -

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

we've now got over 300,000 people in the scheme. Most of that has happened over the last three years. We only brought about 30,000 people into the scheme in the first three years. So I think - and there was always a tension and that tension remains. That is, there is the tension between trying to bring everybody in as quickly as possible. Because in the absence of that, it's unfair to have people outside, waiting and waiting.

Then the desire to have - get it right first time for everybody. This was always a juggle and it remains a juggle. There's still 160,000 people to bring in. There's obviously the need to refine and improve the scheme. So I just think that context is really important. In terms of what's going well, I think the most exciting thing is the innovation that's happening. The fact that people do have control and choice, the fact that there is a market out there. I was at an event in Sydney on Monday night, where Remarkable, which is an incubator of start-ups, was showcasing the latest six organisation - start-up organisations. It's just remarkable what people are doing. So for me, the thing to scale up is this innovation and this creativity, and to spread the news around this so that people will can say, "Well, that actually suits me. This is what I could be doing - or this is what my son and daughter could be doing."

### **Amanda**

Fantastic. This question is really, I suppose, for Karen, Sam and John. But I'm going to start with Sam on this one. With the NDIS, what do you think should be changed? Perhaps it isn't working as well as it could.

### **Sam**

I just had my answer ready about what was working well. Yeah. I think - well, it's probably a bit of a halfway answer. I think the thing that is really exciting is disabled people and their families realising they have rights for the first time. Actually, the peer support that's happening at the moment, where people are having discussions which involve not just things like community tourism. So we're talking about the value that we might bring to the world when we're actively involved in things. I think, obviously, reform takes a long time and attitudes take a long time to change. That's something that also needs to change, that we need to stop thinking about disabled people as commodities. We need to stop thinking about us as burdens and pitiful objects of welfare and charity, and as citizens that have the same rights as everybody else to be part of things.

So I think the thing that needs to change on an operational level is - not even so much having - having disabled people work - I think the agency is doing reasonably well with having disabled people employed and family members employed in the agency. But I think they need to get a lot better with looking at how they can ask disabled people and families how decisions that they make are going to impact on people. So even things like, when you're building an ICT system, the idea of having a primary disability is actually crap. So there's a lot of us who have more than one disability. So as somebody who's autistic and ADHD and is mad and then also has muscular dystrophy, I can't go, "That thing is more important than everything else," because it depends on where I am and what I'm doing. So I think that lens of disability being put over everything that the agency does is something that needs to change.

### **Karen**

I'm going to give some very specific examples. I think there are some families here today who would like to ask about the waiting times that they've waited for their

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

child's early intervention planning meeting. We regularly hear waiting times of 12 months or more and this needs to change. I do acknowledge that the Minister has made an announcement about this and we wait and see what the stop-gap measures result in. We also hear from families across the state who have waited an incredibly long time to get assistive technology for their children. That's technology that would make a difference to their child's capacity to participate in learning at school and in family life. I receive four-page emails detailing every step a family has undertaken to get their child's wheelchair. This needs to change.

I think that early childhood intervention plans need to influence practice. We know what works best for children. They do best when supported by their families, when participating in ordinary childhood activities, such as playing with others, and when participating in quality early childhood education. Yet we hear so often about the stress that families are feeling about whether they are choosing the right therapy and the right therapist. There are many vested interests influencing their choice and I think it is really important that the plans themselves point towards what is best practice.

### **John**

I believe it's about how we communicate information back to the staff at the NDIA. At the moment, they can get good news and bad news from the media. But I think there's also a third option - another way to receive information, and that's in, I guess, creative forums. So that when you're a planner or a LAC or whatever your role is with the agency, you are hearing a bit more from people with disabilities in a different environment. Because we all look at media and we react media and say, "That's a good news story," or, "That's a bad news story." What about the middle stuff? How are staff hearing the middle stuff? How are they getting feedback about how they're performing? I think there needs to be a bit more of an emphasis, focusing on the supporting of staff.

Because at the end of the day, the staff at the NDIA are nice people, but they just - I think Bruce has said - they've been thrown in really quickly. They do their induction training, that's fine, but it's not just about the induction training. They need another way to receive positive and realistic and honest information about how things are travelling stop

### **Amanda**

So on that, I guess I'm interested to hear that we talked about much more opportunity to have codesign policy, more opportunities to have information flowing in two ways. Are there other things that are missing in the NDIS that you think should be there that are similar to that?

### **Sam**

There's just this enormous list, really. So I think some of the things - I have an intersectional interest in disability and violence. So I'm involved the royal commission stuff at the moment. One of the really obvious gaps for me is around not just this idea that we're - that we're vulnerable people, that we're marginalised people, and that we should be able to be supported to identify our own safeguarding. I think that's something that the NDIA could do really well. So I think that's a really obvious gap, especially for people with complex communication needs, who aren't necessarily supported by family. If you lived in an institution your entire life and you live in a government-sponsored group home and you're about to be a royal commission

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

participant and be supported by an organisation, that kind of stuff, who's going to support you to enter a redress scheme? But they're the sorts of intersects that we're going to have coming up.

But I think that - I think that there's some really big opportunities that we haven't necessarily looked at because of the speed of the rollout, but also the amount of appeals and the operational issues that we've had with the rollout so far. So there's a whole bunch of those gaps that we could be looking at. I think also, employment is huge. We really need to start - if this is actually going to be an investment-based scheme which is going to return back to community, then we need to look at how people are going to be supported in their day-to-day jobs and be - have their rights upheld. They shouldn't have to fight to work. So we should be encouraged to build skills and we should be encouraged to be able to take part in employment. There also needs to be some work done outside of NDIA to change the attitudes of employers, so we can actually get jobs, right?

### **Bruce**

I think the intersection that Sam is talking about - these intersections are really important. Whether you're talking about the intersection between the investment approach and risk of violence and abuse. So capacity building should be partly about building that capacity to self-protect, those developmental safeguards. There's obviously the intersection between disability and Indigeneity and a number of these things. I think the other point, just picking up what John said, and others have said, is we've all known that the agency has been operating under a staff cap, that there's been inadequate staff training, not enough time to train the staff given the magnitude of the task. I mean, those things just need to be fixed and very, very quickly. Because otherwise, the effects just compound. If plans are poor then it leads to more appeals, it leads to more rework, and then you actually don't catch up.

But in terms of what I think needs to really change is we need to look outside the NDIS, to tier two. That there is just insufficient funding there. Over time, that will make the NDIS unsustainable. But above all, it's unfair. At the heart of the NDIS is fairness and equity. So the idea that there's 460,000 people that are going to get \$22 billion at full scheme and then you've got 4 1/2 million people - other people with disabilities who will share something like \$200 million is just - or \$46 per person - is clearly highly problematic. So that new National Disability Agreement to set above both the National Disability Strategy and the NDIS, I think, is an essential reform if we're going to make the NDIS sustainable, but also be fair to all people with disability.

### **Connie**

I'm Connie Lindbergh, executive director of the national social justice group, the Brotherhood of St Laurence. I hope you're enjoying this episode of Brotherhood Talks. If you'd like to learn more about our work to find solutions to the complex challenges presented by poverty in our prosperous country, have a look at [bsl.org.au](http://bsl.org.au).

### **Amanda**

I'm actually always interested - in a complex implementation like the NDIS, there's always something that gets done that doesn't quite make sense. So I'm wondering if there's anything you can think of that comes to mind, where you think perhaps that should be stopped and something far better should replace it.

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

**John**

Stopped or tweaked?

**Amanda**

Either/or, John.

**John**

Because I think we often complain about the planning process and that's a start for a lot of people. Now I appreciate that there are some boxes to be ticked when going through the planning. But once again, we're getting - the problem is the sorts of negative feedback about the planning. But do those staff get the opportunity to say, "Let's modify the process. What's missing? What's not working well? How can we improve it so it is more inclusive?" On this point, I just want to quickly talk about the fact that the multicultural community - I don't believe that we're hearing that word enough. If we look at the population - I don't know what it is, I don't know what the numbers are, but I'd like to see more of an emphasis about our multicultural community being involved in this whole journey with the NDIA. I think it's a huge gap and we're failing really badly there.

**Karen**

I'd like to talk about perhaps some of the unintended consequences. I think, often, complex public policy impacts on the lives of women in its detail. I have concerns that the rollout of the NDIS and the implementation of plans which, with children, largely sets with mothers, actually reduces their capacity to work. I regularly hear from mothers who have reduced their work hours, gone casual, can't contemplate commencing paid work with their child returning to school, because of the implementation of their child's plan. Implementing a plan is a life admin on steroids. I think there is also really complex interplay between the NDIS and accessible childcare and accessible before-and-after school care. Children do do best when their parents are working. I think we need to stop and look at what is the impact on the NDIS on that?

**Sam**

I think there's some wider things around us as a society stopping things, as well. So then that translates down to - for everybody who is working within the scheme and around the scheme and the partners, is around, A, medicalisation of disability and not looking at it as a social construct. Then B, also the issue of us being regarded as burdens. So we were famously called, "X-dollars burdens," on the front page of a newspaper. You see this every day. In the NDIS Grassroots group, we have people saying, "Is it reasonable and necessary to go and get my legs waxed? It will cost me \$15." There are 250 comments from people outraged that you possibly could get your legs waxed. Then it goes into this thing of - okay, well, all the men who are disabled in these places actually go and get shaved every day. What does that look like? So - but some of -

**John**

And waxing.

**Sam**

- comments - yeah.

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

### **John**

Please. Please.

### **Sam**

So - that, as well. So some of those - some of those things are really judgemental, where people are saying, "Well, nobody looks at the legs of disabled women anyway. Why should we pay for your Brazilian?" Well, you know, it's going to be asking your support worker to do your Brazilian otherwise. Is your support worker actually going to wax things shut that should never be shut? So these are actually things that - they're very practical things, where we need to start losing that whole thing around judgement. We've just had a few cases that have gone through AAT around things like transport and air flights for people and paying for people who are travelling a lot for sport and that kind of thing, for them to be supported in wheelchair sports. Then we need to lose all of that. We need to stop looking at disabled people as a burden and as a - this is not a welfare scheme.

This is a scheme that is intended to reduce the financial burden on the country and actually enable us to be able to return to work and for people to be able to get into jobs and for people to be able to contribute equally and reduce a whole bunch of other burden on other areas, like mental health, if we do that. So it's a bit of a broader thing. There's some very specific things that need to be stopped, as well, around practices. Especially around gatekeeping around advocacy. There needs to be some things that uphold capacity to disabled people and families, to be able to get the help that they need to engage and negotiate within the scheme and navigate the scheme. So - yeah. I could probably list about 50 things that the NDIA need to stop doing right now, but we have told them all of those things and they're working on it.

### **Amanda**

I think another curious thing is, with any disruptive thing like the NDIS, where it's actually moving from one big system to another big system, inherently there's some things that existed in the previous system that were good and are subsequently risked during that transition period. I guess, I want to hear about what those good things were that you think are really at risk now.

### **Karen**

Look, I do have an example, and that's, I guess, a very distressing type of call we get from families who have a 'good plan', in inverted commas, but who have an adolescent son with high behaviour support needs and who can't get support workers. So none of the providers will work with them and their child. This is incredibly devastating for the young person and for the family. The market doesn't always provide. I guess, that's something that has been lost.

### **Sam**

Just to add with that idea of cherry-picking, we have issues in the country that are massive around - not so much cherry-picking, but the markets and also think bit providers who are withdrawing services from that area. They might have delivered aged care and disability and now they're saying, "Well, it's not financially viable for us to do that because of the costs involved in WA and in transport." So I think we've also lost a lot of the small values-based organisations. In WA, we had the family-led organisations. They were all WIFs and GIFs and MIFs. They were started a billion years ago by families for their children and they've emerged into things. I think a lot

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

of those organisations weren't connected with good business practice because they'd never had to be. They didn't have great cash reserves or bad debtor systems. A lot of them have really not been supported to engage in that business market. Yeah, so I think that might be at risk. Then also the number of people who are actually available within the scheme. Yeah, available to support us, especially in allied health, is a massive issue.

### **Bruce**

I think two things that have been lost - one relates to early intervention, which Karen's talked about. We have lost family-centred practice here. I think this is a huge issue, both for the future of those young people, in terms of optimal supports for them. We are so far from best practice that I think it is a huge concern. Ultimately, I think it's also a concern in the sense that this is a very - the current practices are highly medicalised, rather than a social construct. So I think if there was one thing that I could - if I could wave the magic wand and stop, it would be the current predominant approach to early intervention and a return to family-centred practice. I think the second thing that we're in danger of losing is the glue. That in a highly individualised system, all those things that hold societies together, that make people - that contribute to people with disabilities being part of community, where there is some risk of that been lost. It applies, I think, at the provider level, where providers previously were very responsive under the block-funded model of give and take.

If something needed to be done to support someone, they just did it. Whereas now, under an individualised model and where the pricing is quite tight, the capacity of providers to do that has certainly been eroded. We don't have a highly responsive approach in terms of plans being reviewed that would enable that to be dealt with through that system. But more broadly, when you look at what local area coordinators are doing, which was always about building the glue, they're not building the glue. The planners are - the KPIs are very focused on planning numbers. So we need to move much more to that community capacity building, relational sort of model, that then contributes to restoration. I hope, ultimately, greater social cohesion, greater inclusion than we had in the old system, which clearly did not see people with disabilities as full citizens. So that aspiration of full citizenship is what we need to not just aspire to, but to achieve.

### **Sam**

Can I just follow Bruce through?

### **Bruce**

I've just waited -

### **Sam**

Just look so scared instantly. So Bruce and I, you may be able to tell, probably wouldn't be friends in real life if not for the disability sector, kind of thing, because - very different life and different people. But you know, Bruce became a bit of an activist in WA because - lobbying for WA to be part of the national scheme, so was a very good ally in that fight. One of the things, I think, was that we've had an LAC system for 30 years in WA. Nobody actually came to WA to ask disabled people and families what the LAC system looked like, what it worked like, and what the issues were. So in WA, Bruce found out quite quickly that we had a very paternalistic model, where there's not been any capacity building for disabled people, because of

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

where we've come from. But WA is very, very good at telling people that we are fantastic. Correct? So it's great to hear Bruce yelling at people on radio.

**Bruce**

I didn't yell. I was quiet. I was my normal, calm self, but made my point.

**Sam**

So I think that's actually attention that everybody else needs to look at because when - so I went to Bendigo very early on, and Geelong, to talk to people about, "What is your idea of what LAC is going to do?" Because some of the things that we didn't have - because we had LAC, was that local - we didn't have local government doing anything over there. So there was some things that you may have lost that - in roles that other people might have done, that are no longer being done, especially in New South Wales where everybody just exited from everything. Where it's supposed to be picked up by LACs. If anybody had asked anybody in WA who was a receipt of services, they would have said, "Actually, all of the LACs -" there is a former LAC over there with pink hair "- massive caseloads of people." You might have 70 or 80 people over this enormous geographic region and most of those people never heard from their LAC. So there was - there's those sort of issues where - yeah, I think we need to unpack all of those things and histories a little bit more, to look at where we're going forward.

**Bruce**

If I could just add - sorry, Sam -

**Sam**

He's going to defend him -

**Bruce**

- but if I can just add, I think another - that Sam just touched on is local government. One of the things that, I suppose, I never thought would happen would be that local government would withdraw from all disability service provision. So if there was ever something you would have thought would - might encourage local government to become more involved, it's the NDIS. It's about local communities responding and supporting members of the community in the community. So I think that whole social inclusion, community involvement is a lot of work and a really important element that we've got to get right.

**Amanda**

I guess, I wanted to turn the conversation in a slightly different direction from here. One of the opportunities, I suppose, of the market is - has the ability to see choice and control come to fruition. But what we see over and over again is markets are incredibly complex and don't always deliver quite what they expect they might. I guess, I really want to talk about - or want to hear from you what you think it would take and what kind of advocacy landscape we would need to actually really harness markets effectively?

**Bruce**

It's an easy question, John.

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

### **John**

It's easy, but how long have we got? It's quite a simple answer: get people with disabilities involved in the market, in the design, in the whiteboard. Let them be involved in the planning for this. Okay, I think - and let's - and not getting off topic, but let's talk about family values. I think there's been a risk - not risk, but a negative side of all this is where you've been natural supports with families, where families have had buy-in and been involved. They've actually - actually, some families have taken a step back because, "Okay, the NDIA is here now, what's my role? Wife/husband/sister/brother?" So that's a bit sad. So I'm - I'm going back to your question, but as far as the marketplace, it is about involving disabilities at all levels, even those people that behave - sorry, that communicate at different levels. Make the effort to tap into their brains. They have a brain, they have likes and dislikes. Just got to be a bit more patient about how they communicate.

But they can guide what the market needs, instead of people for with lots of qualifications about a marketing person, "This is how it should look." I think we're just forgetting the value that we've already got now. We've got six years of experience already, so I think we need to champion how we're receiving feedback.

### **Sam**

Yeah, the idea of codesign and coproduction, the checking in through that whole process. You have a white man in a city designing something then it's going to be designed for white men in cities. It's not going to be designed for Aboriginal people in remote communities, in prison, you know, who might also be transgender and have 15 different intersectional identities and specific needs that are tied into their identities, as well as being disabled. So it's about having everybody in the room when you're designing those services, I guess, and looking outside of us just being regarded as commodities. If people are going to get smart about marketing, it's not about having big white buses with big stars on the side. It's about actually making sure that things are very universally designed, I guess, so that all people can take part and it's suited for all people.

It's a difficult, difficult thing to do, but I think a lot of the market has been very limited and very narrow and it really needs to take a bit of a good, hard look at itself and go, "Actually, these are customers with money." We need to actually design our products in the same way that anybody else would.

### **Bruce**

Look, I think that the points being made about universal design are really important. So if you design for disability, you design for all. So the more we can embed people with disabilities in design processes, both products and services, I think the better it will be for everyone. But also, as I think about markets, I think there are real questions here about information asymmetries. How do we ensure that people with disability can actually get the information they need on the services they're prospectively looking at purchasing? How do providers get feedback on quality so that they can improve their services? These are very opaque markets that we're dealing with. I think one of the issues we've clearly had from the outset scheme is that there is no one really responsible for market stewardship that might have taken a more holistic approach to these issues.

## **Brotherhood Talks podcast NDIS: What's working, what's not? Part One**

So I think that urgently needs to be addressed. But then I think the final thing that's really important is the whole platform on which the market sits and the transactions happen are - we've touched a little bit on the agency IT system, which clearly is not fit for purpose, hasn't been fit for purpose since it was first built by Centrelink. So that just needs to be fixed so that the sorts of transactions, the sorts of market things that need to happen, can happen, in a way that facilitate control and choice, and people can actually see a plan before it's sent for approval, so that they actually know what's in it.

### **Amanda**

So I'm laughing because he's so salty. He wasn't five years ago.

### **Bruce**

Yeah, but we're sort of - we're still having the same conversation, aren't we? So - yeah. But I think now is the time - there are reasons where things have to happen because you're trying - you're on a tight timetable and all those things. But now we've just got to get this basic architecture right.

### **Sam**

Also, there's untapped markets, as well. So like, workforce, you know? This is huge. The unions haven't worked out that we're employers yet, which is cracking me up. So there's a rather wonderful disabled woman in WA called Rachel Delaporte, who's just about to start a micro-business which is around teaching other disabled people to be able to manage their supports and services. But in that stuff around hiring and firing and IR knowledge and Occupational Health & Safety - and there's a lot of people who have got held knowledge. Because there's a lot of quadriplegics out there who have actually been managing their own supports with their payout for the last thousand years. You know, so we do actually have held knowledge. So I think this is a bit of an untapped part of the market, as well, and we need to start looking at the lived experience and held knowledge of disabled people and their expertise and how we can - yeah, and strengthen that.

### **Bruce**

Make it in available and accessible forms that people can actually get a hold of. Yeah.

### **Presenter**

That's the first part of this Brotherhood Talk on what's working and what's not working with the NDIS. In the next episode, we continue the discussion as we hear from people in the audience. They share their experience as participants and service providers.