Brotherhood Talks podcast NDIS: What’s working, what’s not? Part Two

[Opening music plays]

Presenter
Welcome to the second part of this Brotherhood Talk on the National Disability Insurance Scheme, or NDIS. What's working and what's not?

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, and then the desire to have - get it right first time, for everybody.

Woman in audience
We've done four plans now. We're 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
Leading the discussion is Amanda Pagan, head of Inclusive Communities with the Brotherhood of St Laurence Research and Policy Centre. There are four people on the panel: Professor Bruce Bonyhady, executive chair and director of the Melbourne Disability Institute at the University of Melbourne; Karen Dimmock, CEO of the Association for Children with Disability; Samantha Connor, disability rights campaigner and convener of NDIS Grassroots on Facebook; and John McKenna, disability advocate, NDIS recruiter and podcaster. We now hear from the audience, starting with a woman who expresses her frustration with a service provider.

Woman in audience
Basically, markets are supply and demand. That's how they work. In my mind, the suppliers, which are many service providers, are not - there is a - there's a lack of business mind. I can just give you an example? The supplier, or our service provider, for our son, when I was angry with him last year - or a general manager heading disability services - about to report him to the Disability Services Commissioner, or their organisation, his response to me - and then when I said, "I'm so frustrated with your organisation which I've been engaged with for the last - or my son has - 16 years, that when my son gets his NDIS package, I don't think - I'm questioning whether I would use your services." His response to me was, "That is your choice." I thought, really? That - and I said to him, "Really? That's what you're going to tell a customer?" I worked for years in the retail sector. We basically had - we - if we had our customers in our pockets, that would be gold. That would be absolute gold.

I had a service provider who basically had 16 years’ worth of service from us say to me, "That's my choice." That - you know, he soon turned his mind when I said, "Really? That's what you're going to tell a consumer - a customer? That's your response?" So I think that showed to me there's a whole lack of consumer approach that there - so many service providers are so used to dealing with a block-funded - they still don't know how to respond to markets. The other thing I would say, the customers - the consumers - don't know how to negotiate. We've had a lot of - in my mind, I've been to a lot of information about the NDIS. Lots of people have told us about how the system works or doesn't work. No one said - and this is the first time I've heard a few people a few people go, "Get in there beforehand. Learn how to write your goals. Learn how to negotiate. That's what you need to do." Because the bureaucrats don't know what they're doing. Sorry, that's just my frustration because I've been talking about this for 10 years. So that was my - that's just a comment. I mean, another comment I've got is about skilled workforce and having a good - well skilled workforce and attraction strategy to ensure that when people have packages - and people with complex needs - behaviour needs, whatever, have people who are willing and able to work with those people.

But my question to the panel - sorry, was - and I've probably asked this before in other forums, so sorry, Bruce, I'm going to bring it up again. There's - in my experience, I've heard a lot about the inequity of packages. So people who come from a more educated, English speaking background, inner east, are getting great packages. Those who are from a more disadvantaged background are getting not so good packages. Has there - is there data on that? What are we doing about getting that data, to analyse size of packages and background, et cetera, for people, so we can advocate for those in an evidence-based way? That's one question.

The other question is I'm - the other thing - and this is probably for Karen - I'm hearing a lot about that there is no - and I don't like the word respite - but out-of-home sleepovers and not going into young people's packages. I fear that when these young people get to transition into adulthood, what - that there won't be a good transition into independence. So two questions.

Bruce
So let me just answer your question on utilisation of packages and equity of packages. We - when I say we, the Melbourne Disability Institute has now been asked by the Victorian government to look at plan utilisation. We're very much looking forward to doing that work. Because I think there's a lot of anecdotal evidence that strongly points in the direction that you're talking about, that if you're well educated, you're articulate, then you get a larger package and you're better able to use it. But we don't actually know. So getting the opportunity to look at it and then - with a clear view to ensuring that the scheme is fair is something we're very much looking forward to doing. In that way, contributing to ensuring that the vision is achieved.

Sam
While I would never tell Mr Bonyhady how to do his job, it would be awesome if people acknowledged that if you're Aboriginal, you have a different cultural -

Bruce
Absolutely

Sam
- around disability. Also, if you're from different - a CALD background, one of the things we're really concerned about in WA is that we're hearing the language that is being used in WA for so long, which is around, "Tell them about your quest day. Tell them about the worst day of your life." That's - and it's not lying, it's just telling you about the worst day, and it's really traumatising and re-traumatising for us, as disabled people and family members, to go in and talk about the shittiest day in your year. Because we shouldn't actually have to do that. That's actually a really bad thing to do. So we should have a scheme that, as John said, it should be where we can be honest about our support needs and then be supported well within there. But I think those

cultural issues are actually a really key part of what we need to look at, is you shouldn't have to go in and use the language of burden to describe your son or daughter to actually get the support that person needs.

Bruce
I mean, that was the old scheme. The old scheme was you have to catastrophise your situation in order to get access to rare funding. This is a scheme where you should be able to talk about your best day and how we - how the scheme can make it even better.

Karen
Look, I absolutely endorse those comments around the fact that the anecdotal evidence is that - the more able you're able to advocate, the better the plan. In relation to that out-of-home residential weekend/holiday support for young people, we would certainly see that that is shifting, that there are providers exiting the market, no longer offering it, that the out-of-pocket costs for families are increasing dramatically in relation to that. Of course, it's no longer available for young people that are not NDIS participants. So I think there's three key areas of concern there and that's fairly consistent.

John
It is - and I saw everyone agree. Yes, it is very unfair with regards to the loud voices getting the big bucks, the non-voices getting not much. I still believe that it gets back to the fundamentals around - so the person who's in a residential unit, who is non-verbal, who communicates in different ways, the efforts that have been made to tap into their heart or their soul about what excites them. Can a little business be formed around that person's skills, if they have? What efforts have gone into that? We talk about marketing from a service provider's perspective but, sadly, we've got to start marketing it ourselves. This is where advocates, family members, siblings, all that, can play a role in promoting a person who - whether it be a craft or a hobby or a music - that in itself can be valued.

If you can somehow pitch that back to the agency, all of the sudden different eyes open up and say, "Yeah, I can see the value-add now." But we're not doing that. I don't think that - we've got some great supports out there, but supports need to focus on how to market the person's wishes.

John Forster
John Forster, from Noah's Ark, which is an early childhood intervention agency, but also, I have a family member who is part of this scheme. I wanted to pick up on the comments that Bruce and Karen have been making about children and propose some suggested solutions. I think one of the challenges for the NDIS is that it doesn't break things down into a life-cycle, unlike everything else that we deal with. So that we have schools and different stages in schools. Because children are going through different stages, families are going through different stages. The scheme currently - a third of the people in the scheme are children 12 years and under. So it's a huge part of the scheme. But the scheme, from my perspective, has been designed for adults. We're using planning processes which talk about all things which are relevant to adults.

So my first proposition is that the scheme actually set itself up in a different way where it can focus on, let's say, children 12 and under, so that it can develop the policy expertise and develop systems which are suited to that age group, rather than expecting people to conform to something which is - which is set up for adults.

The second suggestion I would make is that I think we've got a problem with the governance of the NDIS, when the NDIA seems to be the main driver, but it's actually also a player in the scheme, running the planning process and, as this conversation is saying, that the planning process has become a major point of difficulty for the scheme. One of the things I think which would make things much better for children would be if the state governments were re-engaged as part of the governance process. Because they are actually the critical element in terms of supporting children to have participation in a whole range of other services - families, as well. So I'd like the board - the panel's response to those suggestions. Thank you.

Karen
Thank you, John. I think the - as you say, the scheme is an adult-focused scheme. The importance of adult agency and their capacity to make a decision about the services and the providers that they want to use is essential. But for children, it is a different picture. I think, as Bruce has acknowledged, the rollout of the scheme has really undermined best-practiced early childhood intervention. Because the reality is that as parents with of children with disability, we are not experts. We are so informed by perhaps a swirling medical model and unknown future and what is possible, that you're very, I guess, vulnerable to suggestions and recommendations by practitioners, by qualified people recommending various services, that they can deliver. They've got perhaps the professional capacity to do that, but are not necessarily in that holistic, family-centred, best-practise, early childhood intervention approach.

So I think that is where that agency perhaps needs to be different in relation to what adults have the capacity to influence and choose, versus what should be available for children and what is available for parents to choose from.

Bruce
John, in relation to your question, I think one of the ways of conceptualising the NDIS and the way it's working is if you take, on one axis, people with high intellectual function, ability to activate their plans, and you move out along that spectrum to less capacity to activate your own plan, which could be because of age or could be because you're a child. The further you go out along that spectrum, the less well the scheme works. The second axis is family capacity. You have got families with very high capacity, able to advocate for the child, able to be hugely effective, through to families who have got highly entrenched disadvantage and having a child with disability just adds to the complexity of family life. Again, the further out that axis you move, the more challenging the scheme is. Then the third axis is metropolitan to remote.

I think we need to be thinking much more about how we deal with those outer bounds. It's very clear that where you've got a child, you cannot consider that child and its needs separate from the family context and the need of that family. I mean, similarly when you're talking about Indigenous participants in the scheme, you can't just think about them individually because they're - you know, you can't separate - their culture is that you can't separate them from their family and their community. So

I think we need to just be thinking about how - I wouldn't say the scheme needs to be totally redesigned. I think it just needs to be aligned for those circumstances, which are more common than the current thinking would suggest. So I'm very much agreeing with you about that family-centred practice.

In terms of the overall governance of the scheme, the implementation of a National Disability Agreement which would bring together the NDIS and bring together the National Disability Strategy under that National Disability Agreement would avoid the current split between the two, which is showing up in absence of - insufficient support for people with - outside the scheme. Real issues with the interfaces, with health, with education, and so forth. Also make it very clear that the governance of the scheme is joint, between Commonwealth and state.

Sam
I think there also needs to be - just in regard to transition - there needs to be a lot of engagement with disabled people, in recognition that our transition is actually quite different, often, than that of non-disabled people. So for example, if you're a young person who is medically complex - I hate this term, but you know - if you're a person who spends a lot of time in hospital, you have, I don't know, 12 different specialists and you're doing a lot of stuff, it's a really big transition going from kids' hospital to grown-up hospital. That kind of thing. So we have disability-specific transitions and they're quite often delayed because of the lack of support that we've had. That might include sex and sexuality, it might include - even just things like being included in a school ball.

A lot of people haven't had that experience because of schools being terrible. I think we need to understand what the lives of disabled people looks like a lot more when we're talking about transitions. So it's not necessarily about the idea of normalising things. But if you ask most disabled people when they moved out of home, it's not usually the same time that everybody else moved out of home. I think I booted mine out the door as soon as they were old enough, legally. You know, "Quickly, leave." But I'm probably an exception.

Bruce
But you're particularly hard, though.

Sam
I have six kids, you can't blame me.

John
Nothing to add, really. I agree with all the panellists.

Jess
Hi, my name is Jess. I am an allied health professional, so a provider here. It's not so much of a question, but I just thought I would describe my experience as a provider. So first of all, I thought I'd express my gratitude for - on behalf of the multicultural community, but also the operational community, as well, I guess. You know, for the fact that some of the issues from these minority communities are being expressed from the panel and from the audience, as well. So thank you for that. I see both adults and paediatric participants from English and non-English-speaking background. I must say that the progress and the amount of funding received by multilingual

families are essentially different - are significantly different from those who are from English-speaking background, particularly those parents who are able, highly involved and high income, and highly educated.

For example, with my adult participant, who I haven't actually signed into my caseload yet because they live in the outer region of Melbourne. They only speak Mandarin and I just - I just cannot travel three hours a day, return trip, to see them. They asked me, "Well, can you refer me to any other providers who speak Mandarin?" I said to them, "Not anyone I know in Victoria who can see adults, who can provide you with that service that you want." Mainly because of the difficulty of entry into the adult field. I want to say no to them but, as a provider, I feel really bad. Because it's not sustainable for my business, but they really need the service. I'm the only one I know who could provide to them. I'm not sure if there are any suggestions or solutions to that?

The other example is for early intervention. For a family who can't speak English at all, or read anything, they are about to have their plan reviewed and they don't know what to do in the - with their plan manager. The thing is that I'm taking on the role of - writing down the goals for them and asking them, "What would you like? What's important to you beyond communication, speech, and language?" Because this year, for their funding, they only see me less than once a week for a child who is non-verbal, moderate to severe intellectually disabled, with challenging behaviours. That's just not enough to see any changes, really. They're finding it hard to do home intervention when I'm away. So that's - I don't even charge them a travelling fee because they really need the help.

So I'm not really sure if there's any solution to that. The only thing that I can think of this maybe have this sort of forum in communities that - you have a lot of multilingual speakers and family participants. I'm just looking that people around me - no offence - but I don't see any people who are - oh, what's the political way of saying this? So I ask the question because I want to be the voice for them. I see the struggle -

John
There's too many locals here. Too many locals. Got it?

Jess: Oh, yes. Yes.

John
I'm with you, sister.

Jess: It's good to see participants, though. What I'm trying to say is, is there any chance that this sort of forum can be translated in another language? Or - yeah, with…

Sam
We're all so white. What do you do? Could I just ask what kind of allied health professional you are?

Jess
I'm a speech pathologist.

Sam
Oh, you're a speechie. Are you engaged with any tele-health initiatives over here? Do you have telehealth?

Jess
No, no.

Sam
So we're starting to - so because I work in a health centre in WA, on a contract, they're starting to use tele-health. Because of the distances in WA, there's a whole bunch of investment that we've had for quite a long time around infrastructure and massively big screens of people and videoconferencing material. The deaf community have been using it right well - and Skype - quite well for a long period of time. So I guess, one of the suggestions that I have is actually around the use of technology. Maybe engaging with the actual - with the health sector. Also, the educational sector, to see if you can use some of that infrastructure in order to deliver services outside the region without physically travelling.

Jess
That's [inaudible]

John
If you'd like to see me afterwards, I'm happy to help.

Jess
Yeah.

Conny
I'm Conny Lenneberg, 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.

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. So you write that first bit and you do all of that. So that's just my advice and I've helped a number of people with that. I'd just also ask the sector to keep on thinking about the importance of data for transparency and power. So far, we've really had a situation where we haven't been able to access - we're talking so-called anecdotally all the time. We know this is happening, but if we have data we're actually able to tell that story much more easily. So I think the sector needs to rise up and make that case. Often researchers just look like we're just trying to promote ourselves, which we probably are.

But the other comment I have, and I think Sam brought it up earlier about the planning process, is the issue around legal literacy. This, for me, is - I'm not trained in law and I find it absolutely perplexing. As we are presented, both as employers and the legal issues around that, but - and what our - what our legal requirements are there. The second is as we sign service agreements, which are increasingly getting complex. In some instances, move liability back to the - to the participant or their nominee. We don't - and Bruce and I have talked about this many times. I know the Office for the Public Advocate has also looked at this a little bit here. So I think this is a problem that's waiting to blow up, really, and could really undermine some of the issues. So I'd be interested in the panel's views on that.

Sam
So many thoughts. I think data, absolutely. A million percent. I think the NDIA are collecting a lot of data that probably is very relevant to the NDIA and not necessarily to the rest of us. That needs to be with transparency and accountability, as well. I think also, we should be informing research agendas because this is a really important part of this. The legal literacy stuff, I think people being well versed in consumer law is a massive issue. Also with our rights and responsibilities as employers is a massive issue. Absolutely agree with you that we are going to be the ones who are going to be penalised when things go wrong, and quite often are. I guess, the thing that's of value now is that with this increased level of peer support that a national scheme has brought about, we don't have the same kind of culture that we've had with competitive funding systems where all of us were too embarrassed and ashamed to tell all of our friends that we had funding.

Because you don't want to tell your friend, whose kid has got higher support needs than your kid, that you've got a big package. Because why would you? That would make you a horrible person, right? It's like bragging about your BMW. So we didn't do those things. Now we do. We're a lot more transparent as disabled people. I think that's extended to sharing knowledge about pricing and being able to engage with those systems a lot more. I do think, as Bruce said, there needs to be more invested in tier two stuff and in investment in disabled people to be good employers and - yeah, consumers of services.

Karen
We speak to a lot of families who are asking, "Well, how do I assess whether this support worker is going to be able to offer quality, safe service for my child?" Then I enter a service agreement, as you say, and actually, it can be - if you do have questions about quality, it can be overwhelming to know, "Well actually, how do I exit the service agreement?" It is such a legalistic - and so much of that pressure comes back on participants and families.

John
I just want to go - peer support. We're hearing a lot today but, don't forget, there's peer support, but there's also different categories with peer support. You have parents, you can have a with an ID, people with mental illness. So you're allowed to do some shopping when trying to find the right peer group that is going to work for you because it's - I think it's really important. You've just got to get a feel for - is this group itself going to be able to talk my language? We talk about the CALD community, same thing. Let's get the old-fashioned conversation going within consumers.

Bruce
I think Anne's point about data being power is quite central to this discussion. I mean, I think a lot of what we've talked about in the planning process - it's an unequal information, unequal data. So I think we've just got to go back to the core underlying principles of the NDIS, which was about empowering people with disabilities, about

being fair. Data is absolutely central to that. So making that data available, so that people - there is equality of power in the relationship, making that data available so the scheme can be refined and improved. Making sure that there are - the information in contracts is transparent, so people really understand what they're signing up to. All of these things need to be put in place for this scheme to deliver as intended.

So I think we're in a position where we're now identifying these issues. The six-year journey we've been on has taken us to a point where we're now relatively clear. If I talk to people and I think - listen to the discussion on this panel, there's enormous consensus around what needs to happen. Now we just need to make sure that those key areas are addressed and that we are - that everyone who is a participant in the - with disabilities and their families and carers are actually co-designing and involved in these processes. So that, again, that reinforces, or underpins, a move to a much more equal relationship.

Roland
Hi, my name is Roland. I have a son who has a disability. But I want to ask a wider question. My question is: How motivated do you think this government is in willing to improve the NDIS? Now the key for that is - you talked about the cap to staffing [over talk] [laughter] that's happened before. You've talked about - I don't know if you've talked about the $3.9 billion that was repurposed for the drought? The $1.6 billion shortfall where they said that not as many people brought up the scheme as possible. So as a quick announcement of that, we asked for a trike, for our son to be more inclusive. We didn't get it. So we had to get it through the Lions Club. He's actually being enjoying it, it's fantastic. So my question to you is: Given the overall lack of confidence in public institutions, both here and in the United States and the United Kingdom, how motivated do you think the government is actually willing to improve the NDIS?

Sam
I like that I just got handed the mic.

John
Well done. Congratulations.

Sam
The loudmouth activist type who always has political views. So as activists, we are bipartisan. We don't necessarily always express our political views, except when we're ranting. So a lot of us are a little bit despairing in the wake of the election. A lot of - you know, disenfranchised people and a lot of minority groups have a bit of a sense of despair, I guess, that a royal commission is less important than franking credits, that kind of stuff. I think we need to - I think there is a possibility for that to be turned around, in terms of them having an understanding that this is an investment scheme and it's about investing in us. So the problem is, I think, cultural.

I don't have a huge amount of confidence that that's going to be a quick and easy turnaround, but I think that if we can start positively profiling where things have gone well and where - and doing some economic modelling, especially - which sounds really awful. But looking at what it looks like when somebody is in hospital for two years because they can't actually get housing, how much does that cost you and the government? What does it look like if a person with psychosocial disability is accessing a whole bunch of other supports around homelessness and drug and alcohol and around - you know, all of these other things? How much is that person costing you, rather than just being supported well within the NDIS to get the support that they need? So I think it's a doable thing. I don't have a great deal of confidence that it's going to be an easy, doable thing, but thank you for that question.

John
Thank you for answering.

Sam
But I'd love to hear Bruce's opinion.

Bruce
Well, I suppose, a couple of comments. I mean, the first is that the support for the NDIS has been all parties, all governments. We would not be where we are today without that and without all the work that was done in the lead-up to the NDIS. So the fact that this scheme has been able to just continue to go ahead across multiple governments and even - and even greater number of prime ministers and premiers and state governments, I think, is testament to the work that the sector did to build national community support. I think we've got to particularly pay tribute to the work that every Australian counts and the work they continue to now do to ensure that the scheme delivers as intended. So I think that's the backdrop. I think it's really quite remarkable, what we've achieved.

When you think about other countries, like trying to implement this in the United States with its 50 states, it's just not - you could not conceive of this happening there in the way that it's been able to take place here. I think the question now is: How do we ensure that the difficult bits get done? That this scheme is truly transformative in the way that we've all - everyone wants it to be. That does come down to things like data and research and codesign and coproduction. But it also comes down to the support and the championing that we get from governments and from their officials. I take enormous heart from the fact that following the election, Prime Minister Morrison chose to identify the NDIS as one of the three things that he wants his government to be known for. Since the election, he's held at least two face-to-face meetings with people with disabilities and their families and carers. So he is now championing this scheme in a way that, frankly, we haven't seen since Julia Gillard.

So that championing, I think, gives me great hope that this scheme will deliver. You know, it's - he's - the Prime Minister's obviously been affected by his personal experience, the fact that he's got a brother-in-law who is a member of the scheme. He's seen what it's done. His brother-in-law has got MS. If it were not for the - in the pre-NDIS days, he would have got nothing. That sort of acquired stability, you got nothing. So it's been transformative in his family life and I can see - I think he can see how it can be for all Australians now and in the future. So that, I think, should give us all hope. We should - you know, we should utilise that environment to make sure that our voices are heard and the priorities that have been discussed here and are being discussed in lots of places, become the priority of government.

John
Well said, Bruce. [Audience applauds].

Sam
We didn't say inequity and xenophobia once. That was great.

Sophie
I feel like that's a good place to end, but I'm going to squeeze in a last question anyway. I'm Sophie. I'm from the office of the Public Advocate. Thank you to the panel and thank you to people in the audience for sharing their experience and their questions. I wanted to home in on a comment that was made, which I wrote down as, "The ability for people with disability to identify their own safeguarding arrangements." I wanted to unpack that vision and, I guess, know how to strike the balance between a universal safeguarding environment and something that's more tailored.

Sam
So we have a big disparity between disability and family and domestic violence, that - as you know. So that sector just says, "There's for those people over there," and, unfortunately, there's not. You're it. But they're not inclusive of us. So we think that there's a lot of translatable work that's being done in the family and domestic violence sector. Of course, disabled women who experience abuse are still disabled women, but you also need to recognise that disabled men are at higher levels of abuse than non-disabled men. I think if you're looking at what it might look like on the ground for people prior to them going in for their planning, I think that idea of assisting people to identify where they might be particularly vulnerable.

If somebody breaks into your house and you're going to show them the layout of the house and show them your new iPad, then that might be something that's going to - but you might not recognise that that's going to be a vulnerability, do you know what I mean? So this is actually about involving people around supporting that person to - not just look at it diagnostically, but also consider the other factors, that people might not have any awareness that people might be dangerous, because they're autistic and they don't have great, you know, skills and understanding that sort of thing. People who have been institutionalised for a long period of time and they've not really had any experience in saying no to things. You might have over-familiarisation with your body because you've in receipt of personal care for your entire life and you might not be aware that you're being physically abused.

So I think there's some inherent risk factors. If you look up developmental, corrective, and preventative safeguarding, and then map it across to the stuff that's being done in the more gendered spaces, I think there's potential for that work to be done in the preplanning process, that you could actually bring to the planning meeting. Does that help?

Amanda
I'm afraid we're pretty much out of time and I really wanted to give the panellists a chance to do a - have a final reflection. But just turning to panellists, I suppose, I just wanted you to think about perhaps your final reflections and the future of the NDIS and one or two things you think you really want to say about it. Starting with you, Bruce.

Bruce
Okay. Thanks, Amanda. Look, my final reflection about what next is I'm optimistic.

I'm optimistic because of the unity that we've had in the sector and that we continue to have about what needs to happen to improve the lives of people with disability and their families and carers. I'm optimistic because I think the data that we need to refine and improve the scheme will become available. We haven't specifically mentioned it today, but there is work by the Australian Digital Council, which is a subcommittee of COAG, to create what they're calling a National disability Data Asset, that will bring together all of this data that we'll need in order to ensure the NDIS delivers.

My final point is that while we are all caught up in the day-to-day issues of the NDIS and what's not - particularly what's not working, the world is actually watching what's happening in Australia, in terms of disability policy and the NDIS with enormous interest. With a view to try and take the lessons of the insurance approach to their country. Because we are the only country in the world which is dealing in a highly strategic way with the fact that people with disability are living much longer, the capacity of the community to provide informal care is declining. So one of the countries that has approached us and we're about to start modelling the economic and efforts of increased investment in disability, and effectively model the NDIS, is India. So just imagine what this could do in a country like India.

Sam
I guess, I'm also optimistic. We don't hear as much about the successes of the scheme as we do other things. But for me, self-management and people with disability being able to be supported to actually be in charge of their lives and be authors of their lives for the first time is actually incredibly exciting. We really haven't had a disability rights movement in the same way that other countries might have done, in Australia. So we're part of international movements. So we're quite behind in that regard. So for me, as a disabled person who is also a participant, one of the amazing things is - I'm a Scout leader, doing a Scout vigil where we stand around a memorial all night at Anzac Day with a bunch of 10-year-olds. I can actually employ - I only employ disabled people. I can employ another disabled Scout leader who can do the things that I can't do and pay them a decent living wage.

These are the things that I think are going to be transformative because they're actually assisting us to actually be alongside of other people in community. That's where the things - that's where things are going to change, I think.

Karen
My optimism comes from thinking about the children that we are supporting now and what their adult life will look like. I hope that the NDIS means they have access to housing of their choice, that they get a job, and that they lead an ordinary life, with them making the choices that they want to make. On my most optimistic day, I hope that the NDIS statement that it makes around the elimination of restrictive practice is also carried through to other areas, particularly schools.

John
My reflection is we have to be positive. We can't be negative. If we're going to be negative, that's going to hurt everybody. So let's get this right. We've got to think positively. It's still got a long way to go. We've had some great comments around the CALD community. We'd like to see more youth involved. These young people, get them talking it up. We have to talk it up. Bruce, thanks for sharing about India. I think that's pretty exciting. I think let's - we all watch the news to see what happens around

the world. But we can't sit here and say, "Oh, dear." It is still new. We're not going to get it right for another 10 years, but there are some great stories out there. It's not perfect. But in my closing remark, it is all about those people who do not have the John McKenna voice. It's those people who communicate in different ways. Respect those people as humans. Thank you.

Amanda
Can you please join your hands to think the panel.

Presenter
This talk took place in July, 2019. It was co-hosted by the Brotherhood and the Melbourne Disability Institute at the University of Melbourne. Brotherhood Talks is a podcast by the Research and Policy Centre of the Brotherhood of St Laurence, working toward an Australia free of poverty. Find us online at bsl.org.au/brotherhoodtalks. Join the conversation on social at #BSLtalks. Production by Aysha Zackariya and me, Sharon Lee. Music by Lee Rosevere. Subscribe in your favourite podcast app for more episodes of Brotherhood Talks.