NDIS Review webinar - Transcript

Moving from defining problems to designing solutions to build a better NDIS

**Ms. Natalie Wade** (00:00:04):

Morning everyone. Thank you for making the time to be part of this important event to discuss the recently released, 'What we have heard' report from the NDIS review panel. My name is Natalie Wade and I am a disability rights lawyer and advocate and proud disabled woman currently on Arabana Land in South Australia. I will be your facilitator for today. I would like to begin today by acknowledging and paying our respects to the past, present and emerging elders and traditional custodians of culture and the continuation of cultural, spiritual, and educational practices of Aboriginal and Torres Strait Islander peoples. I also extend that respect to any First Nations people here today. Today we are joined by co-chairs Bruce Bonyhady and Lisa Paul and panel members Kirsten Deane and Dougie Herd. I'll hand over to Bruce to start us off today. Thanks Bruce.

**Professor Bruce Bonyhady AM** (00:01:23):

I think I've now unmuted. Thanks very much Natalie for introducing today's important webinar. I too would like to acknowledge the traditional owners of the lands on which we're all meeting today and pay my respects to elders past, present and emerging, and I'm coming to you from Wurundjeri country in Melbourne. Thank you very much for joining our webinar today. On behalf of the panel, it's a huge honor and privilege to be working with you all through this review. As you know, 10 years ago there was a huge collective effort on behalf through, by people with disability, their families, carers, and supporting organizations to change Australia for the better through the NDIS. It was a huge and indeed unique collective effort to change Australia for the better. It's been an extraordinary journey since then. Australia has undoubtedly led the world in terms of disability policy and reform, and the world, of course is now watching this review very closely.

(00:02:36):

10 years of experience with the NDIS also means 10 years of learning that could be applied to make the scheme better. As you know, disability ministers has asked us to review the NDIS and especially look to improve the experience of participants and to ensure that the scheme is sustainable. In this report, which we launched a couple of weeks ago, we've outlined what we've heard from you. We've identified five key challenges which we think are the most significant and which the review needs to address in order for us to answer our terms of reference. The significance of those challenges should not be underestimated. They're very significant, and so we will only be able to solve those challenges with your assistance. We're grateful for all the information you've provided today, but we're going to need more help in the months ahead. I'll now ask Lisa to say a few further introductory remarks. Lisa.

**Ms. Lisa Paul AO PSM** (00:03:50):

Thank you so much Bruce and good day everybody. I'm Lisa Paul and I'm coming to you from Gandangara Land in the beautiful southern highlands of New South Wales. So far we've heard from more, let's see, we've received more than 1400 submissions and heard from hundreds of people through hundreds of meetings. In every way we've heard what people think about the scheme, and you know, the big thing we've heard won't surprise any of our listeners and that is that the scheme ranges from having transformed lives and continuing to transform lives in the most beautiful and important way possible, through to the scheme has traumatized people and the way they've been treated, particularly by the agency has traumatized people. So we've heard everything and the review has this huge job of looking at everything to do with the scheme, so not just your experiences of it, but also all the policy settings around it. So that's why we've put out the paper that we've put out that we're going to talk about in a bit more detail now. Thanks very much Bruce, and I think I'm handing to Natalie.

**Ms. Natalie Wade** (00:05:18):

Thanks so much Lisa and Bruce for those opening remarks. Within the 'What we have heard' report, there are five key challenges that have been outlined and I'm going to invite each panel member to talk us through those issues and share with us their thoughts. I'll start with Dougie if I can.

**Mr. Dougie Herd** (00:05:43):

Thank you very much, Natalie. Good morning everybody. My name's Dougie Herd. I'm coming to you from Canberra, so I pay my respects to elders, past president and emerging leaders of the Ngamberrie and Ngunnawal peoples. It's a real pleasure to be here at another webinar. I've been asked to speak about what people have called an oasis in the desert when it comes to the national disability insurance scheme. I don't know about you, but I don't want to live in a desert. I want to live in a thriving community where people with disability are respected, we contribute and we can make our lives positive, contributing and essential community lives just like everybody else. The NDIS was meant to be part of an ecosystem, is what we talk about it. That ecosystem, just to let you know, what we've discovered is that almost 10 years ago, $8.2 billion was spent on disability supports and that's grown to almost 32 billion in the 10 years since then.

(00:06:47):

But what you've told us is that there's a growing gap between what we call mainstream and community services, who have not developed in ways in which they were meant to alongside the rapid acceleration of the National Disability Insurance scheme. So that these days, 93% of all the disability dollars that are spent in Australia are spent through the NDIS, and what's what that means is that gaps have opened up in education, health, housing, transport, all of those mainstream services that are as much part of our lives as our disability support services are, and that people find it very difficult to live connected lives in which they have the rights enshrined in the UN convention on the Rights of People with Disability, realized all of the time, in all of our communities, in all of our services, people with disability in the NDIS, people with disabilities more generally, tell us that those gaps have opened up and are wider than they used to be.

(00:07:59):

And we don't want to blame anyone or any institution for that different speed of opening up our society and inviting us in to contribute as equals, but for whatever reason it may have happened, it is clear because of what you've told us over the past five or six months, that life can be just as challenging and different in mainstream community systems and services and supports and the community generally, as it has always been for many people with disability. So what we need to do in the months remaining in this review is to ask you again to tell us how you believe those gaps can be plugged. How we can have a more integrated community service in which the National Disability Insurance Scheme is up one part of the ecosystem. Those of us who need it, those of us who depended on to get through our lives, we need to be able to make sure that the NDIS can deliver as it's meant to do.

(00:09:11):

And for those people with disability, the vast majority who are not on the National Disability Insurance Scheme with individual packages, they need to know that the community will welcome and embrace them. That community services will be there to support them. That all mainstream services will be fully inclusive. That that's the twin challenge that we all face to build in Australia in the 10 years and 20 years and beyond to come, in which we're all welcomed and included, whatever supports we may need. Back to you Natalie.

**Ms. Natalie Wade** (00:09:55):

Thanks so much, Dougie, that's a really powerful start to think of the NDIS as being a valued and critical part of Australia's ecosystem of inclusivity, that supports the Rights of People with Disability going forward. Kirsten, we know that there are lots of children that have been found within the scheme. I just want you to tell us a little bit about what's going on there?

**Ms. Kirsten Deane OAM** (00:10:21):

Thanks very much Natalie, and good morning everyone. I'm coming to you this morning from Melbourne, Wurundjeri country, so I also want to pay my respects to elders past and present and to any Aboriginal or Torres Strait Islander peoples that are joining us here this morning. Good question, Nat. What we do know is that there are now many more children in the scheme than was originally anticipated, and that's not just our finding, that's the finding of many inquiries and investigations that have come before us, and what is super clear is that the creation of the NDIS has revealed a level of demand for support for children that wasn't really well understood before the scheme started. It's really clear that we know a lot more now about the prevalence of disability amongst children and what their support needs are, than we did 10 years ago when the scheme started.

(00:11:21):

And we also know, as Dougie has just membered, that the higher number of kids also reflects the lack of support for children with disability outside of the NDIS, and like Dougie, I want to stress and everybody on the panel wants to stress that we understand why those things are happening. We completely understand why parents seek support from the NDIS. I've got to say that some of the media reporting around this issue has not been particularly helpful. Probably a good time to say hi to the journos who might be joining us here today, but I'm really, everybody on the panel, really wants to understand, just as Dougie said, this is not a matter of blame. Everybody wants the best for their kids and every parent will move heaven and earth to make sure that their kids get the support they need and have what they need to thrive, so this is not a matter of blame.

(00:12:21):

But what we've also heard loud and clear from, as Lisa said, the meetings that we've had, the submissions that we've received, is that the scheme isn't supporting children or families very well at all. The needs of children and families are not being considered holistically. There's been too much of a focus on diagnosis and not enough on people's support needs. There also hasn't been enough focus on supporting children and families in everyday settings. Things like in the home, at Kinder, at playgroup, at preschool, or out in the community, and the emphasis on individual therapy has too often gotten in the way of children living ordinary and inclusive childhoods. We've also found that some services and therapies that are designed to support children's development, haven't been based on best practice as recognized by experts in early childhood.

(00:13:23):

And that means that parents and families haven't been able to make informed decisions about what therapies or supports or services are likely to have the best long-term impact for their child and contribute to their child's development. So that's the problem in a nutshell, Nat. So what we want to know now is, what's the best way to change this picture? And in particular, we want feedback on how to design and then implement a system that supports all children and families well, not just those who are in the NDIS. How can we make sure that families are supported well so that their children can thrive? And thanks, Nat, back to you.

**Ms. Natalie Wade** (00:14:12):

Thanks so much, Kirsten, and it's abundantly clear that children are welcome within the NDIS, but we want to make sure that they're also welcome everywhere else in our communities and where they can be supported. Lisa: markets, markets in the NDIS are really tricky, slightly nerdy problem that's stalling some of the growth that we're having. Can you tell us a little bit about what you found around markets?

**Ms. Lisa Paul AO PSM** (00:14:41):

Oh, thank you so much, Natalie. Well, first of all, it's not a real market, is it? Let's face it's not really working as a market should. There's many, many, many different markets inside the scheme, and there's many, many places in which participants cannot exercise true choice and control because there's either not enough providers say in a rural community or they're not appropriate, say culturally appropriate in a remote aboriginal community and so on. So we actually have to look at the complexities of a market that's actually being treated in a one size fits all way. So the system's been set up with fee for service as the way of paying, paying for hours, but that doesn't work in many circumstances, and then it can have weird outcomes like, well, we all know about the NDIS tax. In other words, a provider that charges more because you're an NDIS participant than they might otherwise, so we've got that problem as well.

(00:16:02):

And then we can see in the market in terms of how providers are going, that there's actually quite a long, I guess, continuum or spectrum of what's happening. So some providers at the most complex end often running residential services with people with highly complex needs are really worried about viability while down the other end of the spectrum, there's a bunch of folks who are probably over servicing or overcharging, and then of course there's the end of the spectrum that the minister talks about, which is the fraudulent end. So it's quite tricky to look at that whole whole thing, and then bottom line, the workers, our support workers are those central to our lives. We want them to be paid well and we want them to be trained well and we want them to be safe and make sure they safeguard us, but sometimes the pricing system works perversely too, so that some support workers who are working with the most complex people are paid less than support workers who are just in the community pretty well.

(00:17:39):

So I think that's quite hard, and we've been having quite a few conversations with the unions and workers and providers, and of course participants and their representative organizations about how the market might work better, and I think the thing we have to look at here is how you differentiate the market according to different needs, and it's not properly differentiated, and the incentives in it aren't the right incentives. I'll give you an example. All that, the plans, all our plans have got goals, but nobody is really incentivized to help you meet those goals, and those goals are not, outcomes are not measured or registered anywhere and added up to say what the scheme overall is achieving. And this is really frustrating because we know the scheme is changing lives for the better. We know it's helping carers get to work, helping participants get to work, helping participants live a good life, but you can't see that at a scheme level, so that's another problem that I see in the market. Thanks.

**Ms. Natalie Wade** (00:19:10):

Thanks so much, Lisa, and it's such an important link that you draw between outcomes of good lives for people with disability and the way in which the market is performing or not performing, as you have so clearly highlighted. Dougie, I wondered if I could come to you and invite you to tell us about words that everyone in this webinar would know all to well, and that is reasonable and necessary.

**Mr. Dougie Herd** (00:19:43):

Thank you very much. What does reasonable and necessary mean? That's a pretty straightforward question. I think there is probably not a human being on the planet that knows the answer to that question in the way in which it was conceived. I think that's the truth that we all now understand because you've told us NDIS participants who responded to the review, that you don't know what the answer to the question is. The NDIS Act was created as a rights based piece of legislation. It was intended to give people with disability, NDIS participants like me, choice and control over their reasonable and necessary supports to help equalize their opportunity to live an ordinary or good life, whatever an ordinary or good life also might be, but what people have told us is that over the last 10 years, we have over complicated some of the answers to all of those questions and we're no longer really clear what reasonable and necessary supports are.

(00:21:02):

And we need to give ourselves, we need to give all people with disability who might think about becoming NDIS participants. We need to give NDIS participants greater clarity about what that term actually means in people's lives, and we need to recognize the diversity and complexity that makes it more difficult to answer that question all of the time and for everybody. Take me as a work example. I'm a C5/6 quadriplegic. I'm paralyzed in all four limbs. I'm incontinent in both bladder and bowel. We know what by and large, we know what that means because it's pretty straightforward when you're a quad like me, I need a wheelchair. I need people to help me get out of bed every morning, to get me dressed so that I can get up into my modified vehicle, which by the way, broke down this morning and I had to call the NRMA, so my life is full of pleasure as well like everybody else's.

(00:22:05):

We need to get the supports that I need to let me go on with my life because I've got a day job. I work for an NDIS registered provider as its chief executive officer, but my life is comparatively simple compared to the many, many more people with disability than all the C5/6 quads that are in the scheme because we only represent about 1% of all the people with disability who are in the NDIS, and for people who've got more complex disability lives than I have, the answer to the question, "What is reasonable and necessary mean" isn't always as easy to work out as it is for folk like me. And what's also clear that you've told us is that the answer is not only depending on where you live. I live in the nation's capital.

(00:23:00):

If you live outside of a big city in Australia, it becomes much more difficult to get clarity about what that means. If you live in regional or rural New South Australia, much, much, much more difficult, I think, we understand. To answer the question, what does it mean for Australia's first peoples with disabilities? Because that's what we've heard from the representative organizations of a Australians with disability who come from an Aboriginal background. CALD or linguistic diversity complicates the question in a sense. What is the answer to what reasonable and necessary means? There is a gender lens through which those questions need to be answered because this may come as a surprise to you. Not everybody on the NDIS is a hairy old Scottish guy who lives in Canberra and uses a wheelchair, and we need to work together to answer the questions, what does this mean for people with disability wherever they live their lives, whoever they may be.

(00:24:13):

And those of us who've got a support need, that means we need specific assistance on any given day to get through our lives. Those are the realities that you've told us about, but the important thing that I think I'll end on is this. It's not just people with disability, their families or providers who don't understand what reasonable and necessary means all of the time. It's the people we've charged with delivering this service, and again, it's not their fault that they don't know what reasonable and necessary means. Local area coordinators and planners who sometimes struggle to do a job heroically because we've not given them the clarity they need to help us make decisions, needs the clarity that we too need as participants.

(00:25:09):

Because again, one of the things we understand is that because we've over complicated the process ,that makes things like your annual planning meeting much more anxious and unsure and uncertain than it ever needed to be. We need you to tell us what you think the solution is, to uncomplicated, reasonable and necessary so that we can make sure that it becomes consistent, fair, and affordable for the whole of Australia going on into the future, so that the next generation of NDIS participants, the next generation of taxpayers, understands what we're getting and what we're paying for when we get an NDIS package. I hope that at least lets you know what the question is we need answered and we will work with the answers you give us.

**Ms. Natalie Wade** (00:26:09):

Thanks so much, Dougie, that was a really exciting explanation of what is reasonable and necessary, and I think it's made really clear, certainly in my mind, but I'm sure all the attendees minds that this is a question that Australia can answer, and when you do answer it as a collective, "What is reasonable and necessary", we will have the great benefit of hearing from people at the intersections, that is people from different backgrounds, different genders, different lived experiences, which is exciting. So finally, the last challenge that was identified in the 'What we have heard' report was all about sustainability. It's a big topic, it's one that's received a lot of media attention and has created a lot of angst within the disability community but I'm going to invite Bruce to share with us what the review panel has been thinking about sustainability of the scheme.

**Professor Bruce Bonyhady AM** (00:27:18):

Natalie, thank you for introducing that question. I just want to pick up your point about angst because there's no doubt that talk of sustainability is something that causes fear and great worry amongst people with disability and their families, and I just want to acknowledge those concerns today. And of course those concerns were amplified about eight weeks ago when National Cabinet announced a target for NDIS costs out of the blue, and so I do think we need to recognize that this is a topic which does lead to fear and anxiety, but at the same time, we do need to recognize that the scheme does need to be sustainable. It was always part of the original architecture and remains a key part of the architecture today, and so I'd just like to address a few issues in relation to sustainability. The first is that sustainability has got two sides.

(00:28:28):

There's a benefit side and a cost side, and too often in the current discussions of sustainability, the only focus is on the costs of the NDIS. The other side is the benefits, and Lisa's referred to some of those benefits. Kirsten's also referred to some of those benefits, and so one of the things that we need to do much, much better is to measure the benefits that are coming as a result of the NDIS, and so this is one area where the review does hope to make a very significant difference to the public discourse, by clearly identifying the benefits of the scheme and so we can have a much better informed and indeed balanced discussion around the issue of sustainability. The second issue that I think we need to address under the heading of sustainability is that in recent years, NDIS costs have just not been predictable, and we need to acknowledge that that lack of predictability undermines public trust and confidence.

(00:29:42):

And so we do need NDIS costs to be much, much more predictable, and the review is addressing this by looking at how NDIS costs are forecast and whether this can be proved to provide much greater certainty to the Australian community, but also to governments. The third point I want to raise is that the concept of a target is in fact very helpful in this context, which might sound counterintuitive given what I've already said, but if we do have a target for NDIS costs, and I do want to emphasize the term target, I'm not talking about a cap because the NDIS is a needs space scheme, but if we do have a target, I think it goes some way to diffuse the cries that we have at the moment that NDIS costs are out of control.

(00:30:45):

In other words, a target is very helpful because it is a very important mechanism by which we can give confidence to the public in relation to the good management of the scheme. The fourth point I just want to make of course, is that there's no doubt the NDIS is life changing. However, as it's been clear from some of the comments today, is it leading to more inclusive lives and are we seeing sufficient benefits from the NDIS investments? In other words, how do we maximize the benefit from every dollar of NDIS expenditures, and could the NDIS lead to even more transformational benefits and so become more sustainable in that way? My fifth point is that I do welcome the involvement of National Cabinet because the current challenges with the NDIS will only be fixed if Commonwealth, state and territory governments work together.

(00:31:55):

We also need to reengage local governments who vacated the field since the NDIS commenced. Today, as Dougie explained, the NDIS is an oasis in the desert. It needs to be built on a firm foundation of tier two supports, in which all governments have a very important role to play. The NDIS is also an island and it must change and now work hand in glove with mainstream services, health, education, housing, et cetera, and these changes are only going to be achieved through national cabinet. My final point is that it is people with disability and their families who've got the greatest interest in the sustainability of the NDIS. Sustainability, while it is currently being framed as an outcome or an objective, is best considered an outcome from a well-managed scheme. In other words, addressing the issues that Dougie and Kirsten and Lisa have raised with you this morning as part of the other four challenges that the scheme faces, and which we've highlighted in our 'What we've heard' report, and of course, solving those challenges will require your input, your advice, your wisdom, and your lived experience. Nat, back to you.

**Ms. Natalie Wade** (00:33:27):

Thanks so much, Bruce. I think that really helps to clarify what a lot of people with disability and their families have heard around the tracks about really what is the sustainability of the scheme. What does that mean and how it can be addressed? So lots of input needed from all of you from within the disability community for that. Thank you so much to all of the panel members for talking us through the five key challenges that have been identified in the 'What we have heard' report. It's now time to move into a question and answer session, which is really an opportunity to hear from all of the people in today's webinar and to ask the questions that are most important to you. I am going to ask some of the questions and direct them to specific members and gain some of their insights, which hopefully is useful, but keep the conversation going in the chat, and if you have any further questions, please also put those in the chat.

(00:34:40):

So Bruce, we're going to start with you. The question is, what is the review doing about how participants can access information about what supports are available? The current system is hard to find information and is quite confusing.

**Professor Bruce Bonyhady AM** (00:35:03):

Well, thanks Nat and thank you to whoever asked that question. So one of the things that we've clearly seen, and Lisa referred to this in her description of what is happening in NDIS markets at the moment, is that there is not timely, reliable, accessible information available to participants in their families to assist them with effective control and choice. You cannot make good decisions, informed decisions without that information, and so one of the questions we're interested in is this particular one about how we can better inform or better ensure that that participants and their families are informed. One of the issues that we have focused on in the 'What we've heard' report is the role of intermediaries. There are local area coordinators, there are support coordinators, their plan managers, and in remote areas, their remote connectors, and a number of things are pretty clear.

(00:36:14):

The first and probably the most, the foremost, is that local area coordination, which was always meant to have a role in connecting participants to services in helping provide information has never been implemented in the way that was originally intended, but that has been implemented to a limited degree in certain locations. We also have support coordinators, but we also know from what we've heard, that support coordination is not provided equally through plans. Some people have access to good support coordination and others don't. There's also been issues raised with us in relation to the quality of support coordination, and you've then got plan managers who are also supposed to be providing information to participants. So it seems to us that there is a real confusion in this area of intermediaries. At the same time, it's very clear that many participants need service navigation. In many cases, that service navigation need is very, very complex.

(00:37:39):

And so in some cases it seems that case management, and I know it's a term that worries people, but more, let's call it super intensive support coordination is going to be needed, and at times it's going to need to look across other systems where you've got people with very complex needs who intersect with multiple systems, not just the NDIS. So I think there are number of things that we should be doing here, Nat, in order to ensure that people can make informed decisions, and it also needs important that we simplify this system because it's clearly very, very confusing at the moment as to where people should go or who they should ask, and again, of course, your views on that will be very, very helpful as part of this review.

**Ms. Natalie Wade** (00:38:36):

Thanks, Bruce. I think that really clarifies that the review will be providing community informed solutions to simplifying and ensuring that the NDIS is focused on participants and their lives. I have a question for Lisa and Kirsten. There seems to be so many problems with the planning process. It's a pretty big understatement, but I think that is fair to say. What is the review doing about that, Lisa?

**Ms. Lisa Paul AO PSM** (00:39:14):

Yep, thank you. No, thanks very much, Natalie. Yes, well, we're spending an enormous amount of our focus on this question about planning, and you can just see from so many of the questions coming through on the thread that planning can be a traumatizing experience. Planning can be a neglectful experience, planning can, et cetera, et cetera, et cetera, so even if the workers in the various roles that Bruce has just described are supportive, et cetera, it still might not work for people. So what we'd like to do is to hear from you, that's exactly why we've put it in the paper, we want to hear from you how it should look; like we actually are stripping it back in our thinking to what should the ideal look like? How can it be more streamlined, more responsive, and more humane? I've been astonished myself not coming from this sector originally that the planning system can be so disempowering, so completely disempowering.

(00:40:24):

So we really, really do want to hear from you about how it could work better, but just to let you know, the way we are looking at it is not taking so much what's there now, not that of course you'd ever throw away the foundations, but what's ideal? What would work, ideally, what would work in the dream world? So that's how we're approaching it. What we are not able to do is pick up the individual cases that are, some are coming through in the chat and we certainly hear people's stories and that's incredibly important for us, but in being an independent review, what we can do is pick those things up as themes, but we're not able to solve them one-to-one for each of the participants that raise those issues, so we totally appreciate hearing them, and we do refer them, and we still want to keep hearing them, so it's very important, but because we are not the agency, we can't always solve them for you. Kirsten?

**Ms. Kirsten Deane OAM** (00:41:36):

Thanks Lisa. Yeah, I can also see that all of the questions that are coming through on the chat, and it's probably not surprising that when you look at all the submissions that we've had on the website, issues to do with planning and local area coordination and finding service providers is the most common thing that has come up through the written submissions that we have had, and it also comes up at every single one of the meetings and consultations that we've had, so completely agree. It is an area that we are focusing on, and I guess what we've heard really strongly from you is that actually it's not really a planning conversation at all. It's actually a little bit more like, a terrible combination of a job interview combined with sort of a high school debate about what's going to be in and out, combined with probably the worst aspects of your Christmas lunch with Auntie Doris who only sees you once a year, but who's got plenty of opinions about what you should be doing with your life.

(00:42:46):

And she's not shy about sharing them. The planning conversation at the moment seems to incorporate all those terrible things, and so like Lisa says, we want to think about, "Okay, well how, again, how could we change that picture?" What is the best way for the person to collect information about you? What your circumstances are, what your disability is? What impact does it have on your daily life? What your support needs are? What do you need to get out there and achieve your goals and do what you do? What's the best way to collect that information? And then once that information's been collected, what's the best way that people can help you to get out and do those things that you've said? And as Bruce has just talked about, what's the best way to make sure that you've got the support you need to go and do the things that you do?

And what kinds of help would you like to make those things happen? So like Lisa said, because this is a really big focus for us, we want to know your best ideas. What would be the best way to collect that really critical information about you? How should it be treated? And then, who and what would help you put that plan into action? Because that's the other thing that we've really heard really strongly from the review is that it's all very well to end up with a plan, but it's what happened next that is really critical and that makes a really big difference to your life. So who or what would help you to get that plan off the page and actually into action and make a difference in your life? So it is a really big focus for us, but we really want to hear your really good ideas about of all those things that are currently all mashed up into the planning process, what's a better way to do those so that you get the support that you need. Thanks Nat.

**Ms. Natalie Wade** (00:44:52):

Thanks so much, Kirsten. I think it is so reassuring to think that the review panel are going to rethink planning and offer a different way forward that really recognizes the trauma and hard yards that have been done by the disability community over the last decade, and I think that just provides such hope to everyone within the scheme or those who might like to be in the scheme at some point in their life. Kirsten, I'm going to stay with you just for a moment. Attendees are asking, "What is the review going to do about funding for ongoing capacity building?" And I wondered if in answering that, you could tell us what is ongoing capacity building? It's a bit of jargon.

**Ms. Kirsten Deane OAM** (00:45:46):

And I think we've heard really strongly that this idea of capacity building is actually one of the areas that a bit like reasonable and necessary isn't felt very well understood. And I guess there's a couple of things that I would think about with capacity building, and you would've seen in 'What we've heard so far' report and also in the comments that we're made here today. The review's got a really big focus on outcomes. We don't think there's been enough of a focus on outcomes both for outcomes from the scheme at a big global level, what contribution is the NDIS making to improving outcomes for people with disability and their families, but also what outcomes is the scheme achieving for the Australian community?

(00:46:36):

So we've got a really big focus on outcomes, but when I say that, I also think that outcomes aren't well understood and there's a connection to capacity building is that I think sometimes capacity building is treated a little bit like it's just a one-off thing that we do, and then people get better and don't need support anymore, and that's just a nonsense. Anyone who has any lived experience of disability will tell you that that's just a nonsense. So we do want to think about what help do people need to achieve longer term goals because some things that are currently funded in capacity building take a long time to achieve. So I have a daughter with Down syndrome and she tells me constantly how she wants to move out of home. Right? "No, no sledge, but I'm keen to get away from you mom", and we're keen for her to move out of home, but our experience tells us that for people with an intellectual disability to move out of home takes a really, really long time.

(00:47:52):

And people have told us through the review that the NDIA don't always treat that really well, treat that kind of capacity building really well, that with a focus on goals and outcomes, they're not achieved like this often, that sometimes it takes a really long time to achieve the goals in your plan and that you need capacity building funding for a longer period of time, so we've heard that really strongly from people. The other thing that I wanted to specifically call out because something that is super important to me and that's related to capacity building, which is support for decision making. There's a vast majority of people in the scheme, as Dougie alluded to earlier today, have a cognitive disability or need support in order to make decisions about their lives, and we've heard really strongly from people that there hasn't been enough attention to that in the 10 years since the scheme was going.

(00:48:58):

And we've noted that the National Disability Insurance Agency has recently released a policy about support for decision making, and that's a great first step, but it's what happened next, that's really important. So this is an area that we've called out in the report. We've heard really strongly from you that support for decision making needs a lot more attention and needs a lot more work to actually make it real in practice in people's dealings with the National Disability Insurance Agency. So I guess I'm going to throw it back and say we want to hear from you. What do you reckon needs to happen to make that policy and that commitment to giving people support for decision making? What have we got to do to make that actually real in people's lives?

(00:49:47):

And a particular question, how do we keep a good balance? We want things to be simple and people not to be too onerous to move your way through the scheme, but at the same time, we want to make sure that people have the time and the support that they need to genuinely have choice and control. So what's the best way to keep those things in balance? We really want to hear from people about that. Thanks Nat.

**Ms. Natalie Wade** (00:50:16):

Thanks so much, Kirsten. I think it really debunks one of the myths that floats around about capacity building in that it's not about getting better. That's not an expectation. That's definitely not a thing, and it's okay to build your capacity over the time it takes you as an individual and the scheme will support you to do that, but it doesn't mean that you are not disabled, doesn't mean you're any different and supportive decision making is a really great example of that. Lisa, I'm going to turn to you, and this is a really difficult question, sorry. Prepare yourself. How are you going to improve supports and mental health and the services that are required?

**Ms. Lisa Paul AO PSM** (00:51:24):

Yes. This is a really big issue. We've certainly made psychosocial and mental health a real core focus for the review. We have had specific and targeted consultations. We've attended a bunch of conferences like the Major Community Mental Health Conference earlier this year, and sought the views of people in and out of the scheme with mental ill health or other psychosocial issues. We see psychosocial issues as a really important part of the scheme, people with mental ill health and so on, and we also think that because the scheme doesn't do well at recognizing co-occurring issues, that there will be a huge number of people who are participants in the scheme, who are in the scheme because of, say, autism or anything else, quadriplegia, as Dougie talks about for himself, but who also have very significant psychosocial issues, and we think this is a really large number of people.

(00:52:50):

So this is one area we are not only is this scheme really important and the way the scheme recognizes conditions that are permanent but can definitely flex up and down in presentation, but can significantly disable someone over the course of their life. At the same time, it's this classic issue where there is actually support outside the scheme. There's probably more support in mental health, dare I say, than in some other areas, but that's not to say there's nearly enough. And so you don't want to have the two systems, the health system and the community oriented, socially oriented NDIS working against each other. You want them to work with each other and they should be working much better together than they're now.

(00:53:48):

We can also, in the NDIS, actually learn some lessons from the mental health sector itself, so I used to chair Headspace, the National Youth Mental Health Foundation, and one of the things that's really striking in that wonderful system of supports is the amount of peer support. So people with lived experience supporting other people with psychosocial disability, and I think we could be making use much more of making more connections amongst people with disability in the community, better connections into the community and so on, so there's just some of the reflection on psychosocial, but please rest assured this is an important part of our focus.

**Ms. Natalie Wade** (00:54:44):

Thanks so much, Lisa, that's really helpful. I just wanted to note to everyone that we are running a little bit short on time, but the quality of questions and conversation is really valued and important, and so we're going to take up about another five to 10 minutes of your time. Obviously if you need to get going, please feel free to do so, but we hope that you can stay with us and hear the end of the conversation. Bruce, I wanted to come over to you and ask on behalf of attendees, they've said that we keep hearing about how much the scheme is costing. What is the review doing about making a more affordable scheme?

**Professor Bruce Bonyhady AM** (00:55:34):

Thanks, Nat. Look, I just want to start in a sense by reiterating something I said earlier about sustainability, and that is that we can't just look at the costs of the NDIS. We actually have to also look at the benefits because what's affordable actually does depend on the benefits. And we've heard about how transformational the NDIS is. And in a number of the things we've talked about today, we've talked about how it could be even more transformational and therefore produce even greater benefits. But if I just focus for a moment on the question in relation to costs, the NDIS was designed to support approximately one in 50 Australians. We know that one in five Australians have a disability. And because of what happened when the scheme was introduced, which was that all governments put all of their funds essentially into the NDIS and weakened the supports around the scheme, it's now this oasis in the desert.

(00:56:49):

So if we want a sustainable scheme, that desert has to be watered, there needs to be much, much better supports for people outside the NDIS. And I would argue that it is simply unconscionable what is happening today if you are not in the NDIS because only one thing is certain, and that is that you'll get insufficient supports or no supports, your disability will worsen, and at some point you'll need to have the NDIS. And so it's the exact opposite of what we're trying to do with an insurance scheme, which is to maximize lifetime outcomes and minimize lifetime costs. So this issue of tier two is absolutely essential to the sustainability of the scheme. It's particularly prevalent in certain areas, for example, in mental health where they're insufficient community health supports, but it's also particularly acute when it comes to children.

(00:57:51):

And one of the consequences in relation to children is that because they're not much better supports in natural settings because emerging developmental concerns are not identified early enough or as early as possible when the brains are most plastic, these kids are coming into the NDIS later with higher support needs. So I can't emphasize enough that if we want an affordable scheme, there needs to be this firm foundation of tier two supports. It's a bit analogous to what we have with motor vehicle accident schemes. They invest in roads because safer roads equals fewer accidents. Tier two for the NDIS are the safer roads, the motor vehicle accident compensation schemes. But the other key point is the one that Dougie touched on, which is... And this of course reflects what you have told us. You've told us that planning is inconsistent, that reasonable and necessary is not being implemented consistently and fairly.

(00:59:06):

And so we believe that if processes can be... If we can clarify what reasonable and necessary is, much better, we can then ensure that reasonable necessary is implemented well. We will have a much more sustainable scheme than we've got today. As we know, the way it's working at the moment, is that control and choice is actually quite restricted when it comes to implementing a plan. And we think that control and choice should be amplified when it comes to implementing that reasonable and necessary budget. And then of course, as Lisa and others have pointed out, it's about quality supports. It's about a well qualified workforce in the case of mental health, just to return to where Lisa was in the last question, it's the implementation of good recovery processes, those sorts of things that go to the heart of an insurance scheme and investment approach, which needs to be implemented well, and we hope that'll be the outcome from the review. Thanks Nat.

**Ms. Natalie Wade** (01:00:23):

Thanks so much, Bruce. That's really helpful on a really tricky area of affordability in the scheme. Dougie, I wanted to come to you and ask, will in the review provide solutions to improve the quality and safety of support, including the training of support workers?

**Mr. Dougie Herd** (01:00:47):

Thank you very much. Quality and safeguarding is absolutely essential to the success of the National Disability Insurance Scheme. I think the first thing we should acknowledge and say is that we recognize that the Royal Commission will publish its report after a two year review and that the whole of Australia needs, all governments need to pay attention to what the Royal Commission says about quality and safeguarding. What we need to make sure, is a couple of things, if I could say them in this way.

(01:01:26):

First and foremost, the supports that any person with disability relies upon, need to be safe. We need to be safe because every single Australian has a right to live their life in safety. We know that those rights are not always upheld, not always realized all the time in all circumstances. And so we need to make sure that we've got a skilled workforce that understands the rights that people with disability have to live safely, that they understand the individual personal circumstances of all the folk that they're providing support to and that they can deliver supports that are safe psychologically, culturally, and in terms of the day-to-day practice.

(01:02:12):

That doesn't mean to say that everyone has to have a degree in how to provide safe supports to people with disability, but where people are providing supports in home or in the community, they understand what it takes to support a human being, to exercise choice and control over their own lives. We need to ask questions about how the framework of overseeing all of the providers registered or unregistered that provide supports to people with disability can have an appropriate light or heavier touch to make sure that the higher the risk of any individual support for any individual person with a disability, that those people who are going in to provide the supports, know what they're doing, how they're supposed to be doing it, not just in a functional sense, but in terms of the respect and dignity and rights that people have to be treated fairly, reasonably, safely by those funded to give them supports.

(01:03:21):

But we also want to think about supports more broadly. We want the future to be one in which participants have strong natural safeguards as the protection that any of us as human beings need in our lives. Families where we have families, communities in which we live, understand and respect the involvement, the life, the experience, and the community participation of people with disability who will have a wide diversity of experiences and disabling conditions. We want people to live in safe communities supported by providers and workers who understand and can match the needs and preferences we have as participants for the ways in which we will be supported and where we need intensive safeguarding. We need that to be done by a framework of safeguarding organizations that can both be responsive and can act as quickly as possible to make sure our needs are met, but also that we all understand that people with disability do that- a term I don't particularly like personally, but I don't have a better one, so forgive me for using it, that we all have a dignity of risk.

(01:05:00):

That to live a normal life, an ordinary life, a good life means that we take responsibility as much as we possibly can for the decisions that we have to take in our own life with supportive decision making where that is required and necessary, but in communities that value us as individual human beings with rights and ensure that where and when we need the support that we need, they're delivered by the best possible quality of support providers that we can and that recognize their responsibility is to ensure that we can achieve our right to safety in an environment in which we can also participate as equals.

**Ms. Natalie Wade** (01:05:51):

Thank you so much everyone. On behalf of the panel, I'd really like to thank everyone for being here today. People with disabilities, their families, people that provide them with valued supports and people within the sector that are advocating for a rights-based future for all Australians with disabilities. The video of today's session will be available on the website, and the answers to your questions will be put on the website in the coming week. So if we didn't get to you today, don't worry, we're absolutely going to come back to you. It's really important to continue the conversation beyond today, and so please take some time to watch the videos on the website that detail the 10 areas of improvement and provide your thoughts on how we can make the NDIS great for all Australians. Thank you again for your very valuable time and apologies for taking up a little more than we were meant to. Have a great rest of your day. Thanks so much.

**Ms. Lisa Paul AO PSM** (01:07:01):

Our what we have heard report outlines what you have told us needs to change. 10 years ago, you came together to fight for the creation of the NDIS. It was a collective effort to change Australia for the better.

**Professor Bruce Bonyhady AM** (01:07:18):

It's been an extraordinary journey since then. 10 years of experience also means 10 years of learning, that we can use to improve the scheme. You have told us how the NDIS has transformed your lives. NDIS funded supports are making a difference.

**Ms. Lisa Paul AO PSM** (01:07:36):

You've also told us how complex and costly the processes in the NDIS are. Navigating the system is leaving participants and their families exhausted and stressed.

**Professor Bruce Bonyhady AM** (01:07:48):

Our 'what we have heard report' details 10 areas for improvement we would like your feedback on.

**Mr. Dougie Herd** (01:07:54):

How can we empower you through the planning process?

**Ms. Kirsten Deane OAM** (01:07:58):

How would you define 'reasonable and necessary'?

**Dr. Stephen King** (01:08:01):

How can the market be better designed, structured, and supported?

**Ms. Judy Brewer AO** (01:08:04):

What is the best way to support children with disability and those with emerging concerns?

**Mr. Dougie Herd** (01:08:09):

What is the best way to provide supports for those not in the NDIS?

**Ms. Kirsten Deane OAM** (01:08:15):

How would you build better outcomes or goals into your plan?

**Ms. Judy Brewer AO** (01:08:19):

What does good service from someone helping you navigate the NDIS look like?

**Dr. Stephen King** (01:08:23):

How should outcomes and performance be measured and shared?

**Ms. Judy Brewer AO** (01:08:27):

How should the safeguarding system be improved for a better NDIS?

**Mr. Dougie Herd** (01:08:31):

How should housing and living options be improved to build a good life?

**Professor Bruce Bonyhady AM** (01:08:36):

We're now moving from the discovery phase in our review to look for solutions. We need your insights to help answer these big questions.

**Ms. Lisa Paul AO PSM** (01:08:46):

You can send us your ideas and have your say through our online survey at **ndisreview.gov.au.**