NDIS Webinar: Choice and Control

DOUGIE HERD:
Hello, everyone, and welcome to the very first webinar from the National Disability Insurance Agency. Over the next hour, we’re going to discuss ideas around choice and control as they relate to the NDIS, and to the interests of people with disability in Australia more generally. My name’s Dougie Herd and I’m going to be the host for today’s discussion. I work for the national office of the National Disability Insurance Agency as the manager of our Communications and Engagement Branch.

We’re going to get started soon, but before I introduce our guest panel members, I’d like first to introduce Mr Warren Daley, who’s going to give us a Welcome to Country. Warren?

WARREN DALEY:
Thank you very much, Dougie. My name’s Warren Daley. I’d like to thank Judith Davis-Lee and Vanessa Attridge for the invite. I’d like to welcome all Aboriginal and Torres Strait Islander people over Australia today, any of them in the room today. I acknowledge the traditional owners of the land we’re meeting on, the Ngunnawal people. I respect and acknowledge their continual culture, the contribution they make to the life of this city and region.

As I said before, my name’s Warren Daley, I’m a sixth generation Ngunnawal elder, happy to give this Welcome to Country, for this web air event. The topic ‘Choice and Control’ is targeted at people who have an interest in the National Disability Insurance Scheme, which commenced in four launch sites on the 1st of July this year. The ACT will join the launch in July, 2014.

So thanks for listening to me and welcome to the land of my grandmother and mother. Welcome to Canberra, the land of the Ngunnawal people. Take nothing but pictures and great memories. Thank you.

DOUGIE HERD:
Thank you very much, Warren. And now to our discussion and the panel of guests who are going to give us their thoughts on choice and control. Catherine Mahony is from Newcastle in New South Wales. Moira Byrne-Garton is the mother of a young daughter with disability and comes from here in the ACT. And Craig Wallace, also from the ACT, is known to many of you as the president of People With Disability Australia. Welcome to our panel members.

In a moment, I’m going to ask each of our panellists to give us their take on ideas about choice and control, certainly with regard to the NDIS, but not just about the NDIS and nothing else. Each of our guests is going to speak for about five minutes, then we’re going to open up the discussion to everyone who’s online. And I should let you know that so far, we’ve had more than 1000 people registering to join this online webinar from the National Disability Insurance Agency. You’re all welcome to contribute by sending in comments or questions for the panel. You can do that now via the NDIS Facebook page or on Twitter, using the NDIS webinar hashtag.

And by the way, can I just say thanks to all of you who’ve already submitted questions to us over the past couple of weeks. So, we’ve got just under an hour here together, so let’s get cracking.

Catherine, can I come to you first? Tell us something about yourself and the sorts of things you’ve considered about choice and control as you’ve been preparing to join this webinar.

CATHERINE MAHONY:
Thanks, Dougie. I guess, firstly, I’d like to quickly commend, really, the National Disability Insurance Agency for the idea of the webinar. I think the fact that so many people are registering is an indication that there’s obviously a need for forums such as this where people with disabilities, their families and the broader community, can take some time to think about these issues to learn from each other. So it’s actually a dubious honour to be the first speaker, but it’s great to be here, so thank you.

Just to briefly tell you a little bit about myself, I have been blind since birth. I’m in my early forties now. I am, as Dougie said, from Newcastle in New South Wales and we are one of the four launch sites, which I guess I think of as both a privilege and a responsibility. It’s always exciting to go first at things and the level of interest in disability that’s been generated locally through the National Disability Insurance Scheme I find quite amazing. It’s a fascinating time, I think, to live as an Australian with a disability.

In terms of the National Disability Insurance Scheme, hopefully we get to iron out some of the little, you know, bugs in the early stages and I’m part of a group of people that are wanting to do all we can to ensure that it’s implemented in the future as well as we...as well as it can be, I guess, based on our experiences and the experiences of the other launch sites.

I don’t know whether you’ve had an experience where you say the word...you say a word or a phrase so often that it starts to lose its meaning and it just becomes a bit of a kind of a ‘blah-blah’ word. In our family, we call that phenomenon a ‘stranger attack’, where all of a sudden, you don’t quite know what you’re talking about. And I guess choice and control is a phrase that I’ve been hearing a lot and using more than ever in relation to people with disability.

Now, don’t get me wrong, I believe in my right to make choices and take control in every aspect of my life. We certainly become painfully aware, don’t we, when we’re denied our opportunities for choice and control. You know, I guess it’s a dynamic thing. In some areas of our life, we can take it for granted, we have access to it, it’s no big deal. In other areas of life, we have to fight hard for our right to experience choice and control. And certainly when our opportunity for choice and control is threatened or denied, we become painfully aware of what it means to us.

So I thought because I’ve been using it a lot and saying it a lot that I might do the obvious thing and actually look up some meanings. Don’t panic, I’m not going to bore you with a whole lot of dictionary definitions. But I did what any contemporary person does, I guess, and I went to my search engine of choice and looked up some of the meanings.

And again, just a few things I suppose that jumped out of me...at me, sorry. Obviously, choice is about the act of choosing between two or more possibilities. It can refer to a range of possibilities. I got lots of synonyms on the website and I thought, you know, just to keep myself fresh, you know, try and use some of those instead of ‘choice and control’ all the time. So I got things like ‘alternative’ and ‘possibility’ and ‘course of action’ and ‘answer’ and ‘solution’ and all sorts of things like that.

When I looked up ‘control’, I found 19 meanings on the one website. It’s a bit overwhelming, but the ones again that jumped out at me were ‘the power to direct or determine’, ‘the activity of managing or exerting control over something’ and also ‘the state that exists when one person or group has power over another’. And I guess that made me think a little bit about disability and our tradition of...how the National Disability Insurance Scheme gives us a great opportunity to try and change that power dynamic that has existed between people with disability and service providers and kind of to try and get rid of the us-and-them culture that has existed, so we can all take part in choice and control together.
I think we’re on a journey. I think that choice and control, I’ll say in my life, I’m not that good at exercising it yet, particularly around my disability, interestingly, and my way of managing my own support. That’s a bit threatening, it’s a bit hard to admit that, but I see myself as just learning, just at the beginning stages, of having what I hope will be unprecedented choice and control in my own life over, particularly, the way I receive support as a person with disability.

DOUGIE HERD:
Thank you very much, Catherine. We’re going to come back to many of these ideas and others, but I’d like to move on, if I may, to Moira, to welcome you. And can I ask you to tell us a bit about yourself and give our online audience some sense of what you think of when we mention ‘choice and control’.

MOIRA BYRNE-GARTON:
Thanks, Dougie. From the outset, I was supportive of the NDIS and as the mother of a daughter with complex needs and who uses a wheelchair, I was familiar with a disability services system that was fragmented, flawed, and that at times failed us. With this background and also as a political scientist and a policy practitioner, I engaged in the consultations on disability reform and I’m very supportive of the insurance model. That paradigm and terminology underlines the idea that the NDIS shares risks and costs.

But the NDIS is not a corrective for everything. While it can assist people with disabilities and some of their significant others with resources to facilitate greater choice and control, on its own, it’s unlikely to create the change we wish to achieve. Many of us would be well acquainted with a number of rights-based principles in disability matters. First, the slogan ‘nothing about us without us’ condenses a basic principle of participatory democracy. Stakeholders are involved in decisions.

Second, the least dangerous assumption about people with complex communication needs or apparent intellectual disability means the community should always assume that the words and actions are comprehended by people with all kinds of disability. Meaningful communication should be sought with everyone.

Third, the social model of disability rather than a medical model of disability recognises that people are only as disabled, so-called, as is the community in which they live. Inclusive diagnostic, hospital and therapy settings, inclusive education, inclusive community-based activities and inclusive workplaces are my vision for a society that accommodates and appreciates the presence and contribution of each person.

Finally, Wolfensberger’s Social Role Valorization is relevant. So that’s when people are recognised in roles that are valued. In a market society, this usually means paid employment. They are attributed more significance. So it’s particularly important that people with disabilities, including intellectual disabilities, and any caregivers, are supported to pursue their choice of career or work, however modest or part-time it may have to be. Like it or not, this would bring change in the way people with disability or caregivers are sometimes perceived.

So these ideas - involvement in decisions, the least dangerous assumption, our disabled society and Social Role Valorization - must be brought to the community at large. This would have benefits not only for the lives of people touched by disability, but for many others as well. If embraced, these four principles would bring about the choice and control I wish for my daughter and for all. People would regularly engage and communicate with her and she could participate in her life decision-making.
What are her preferred pursuits and people? How does she feel about them? Does she have a range of options for activities and relationships? Is she supported to self-determine her actions, her development, her relationships and her future? Underlying this, how do her decisions affect our family? How are our own activities, development, relationships and future shaped? While all families deal with compromise, can we obtain the support we require at times to ensure that our own life choice and control is also possible?

One way things change is through people being in relationship with someone affected by a particular policy or value. In the institutionalisation era, few mainstream community members had an opportunity to know and understand people with disability, including some of their own family members. In this era, everyone should know somebody with a disability. Knowing someone often means pre-conceived ideas are dispensed with, so each person’s life and contribution can be appreciated on its own merits. Ideally, we would have flexible workplaces, facilitating flexible work arrangements, not only for people with disabilities and caregivers, but others too.

It’s time to step away from frameworks of the ‘50s and ‘60s, where there was one typical worker working typical hours and who typically had someone else organising other aspects of their life. Employer incentives and disincentives and structural policies exist to support certain disadvantaged groups in workplaces and this should be so for people affected by disability or illness.

So in recent years, circles of support, micro-boards and intentional communities have become vehicles through which people with disability, particularly complex communication needs, can be enabled to exercise greater choice and control. They do not require governments, which cannot legislate for values, cultural change or relationships. Instead, they provide a glimpse of the inclusive community I wish to create or help create.

I don’t have time to delve into the details of these at the moment, but I encourage listeners and viewers who are unfamiliar with these ideas to search for them online, become involved and help achieve disability reform beyond the introduction of the NDIS. Thank you.

DOUGIE HERD:
Thank you very much, Moira. Much more food for us to think through over the course of the next three-quarters of an hour and can I just say thank you to everyone who has joined us, before Craig speaks. I’ve just been told that we have at least 1000 people online right now all over the country and that’s just terrific for us.

So last but by no means least, can I turn to you, Craig, and to tell us again a bit about yourself and also you and your organisation’s thoughts, perhaps, on choice and control as I welcome you to this, our first webinar.

CRAIG WALLACE:
Sure, Dougie, and I’d just like to join the others in congratulating the agency for holding this webinar. 1000 people online, that’s really, really, great. PWD has actually done a number of these online seminars over the last year now. We’ve found it a really good way to engage, especially with people who mightn’t usually engage in consultations, who mightn’t come to a face-to-face event. We’ve had some people who are actually bedridden who’ve told us that this is the first time that anybody’s engaged with us in a meaningful way. So well done for holding this and we hope that this is the start of a path of communication that uses all platforms to engage a range of people with disabilities.
People With Disability Australia, we’re a cross-disability body, we have human rights focus, we work with a lot of vulnerable and marginalised people in communities across Australia. We’re membership based, so we have a membership that actually directly elects our board and directly elects me. I also have a background in the National Disability Insurance Scheme itself. I did some work within government in the early days of the scheme. I’m on the ACT expert panel for the National Disability Insurance Scheme and I also did a research project about 18 months ago with the ACT Government that was looking at different ways that people around the world have actually achieved individualised funding and that was quite an interesting piece of work.

I’d been sort of thinking about ways into this topic over the last couple of days and struggling with it from the same sort of, “Is it a blah-blah word?” that Catherine was describing. And what...where I sort of landed on it was that, look, most of us probably feel that there are areas of our lives where we have little choice and control and sometimes they’re big things, they’re about the architecture of our lives. So do we really have a choice about whether we get up and go to work today? Well, no. Do we have a choice about whether we get the kids off to school? No.

I want you to imagine for a moment what your lives might look like if somebody insidiously, incrementally and slowly took away all of the little choices in your life. I think our lives are actually made up of lots of micro-choices. And just to give you an example, let’s work through an average day. Choosing when to get out of bed, choosing what to have for breakfast, choosing who you eat breakfast with, choosing when you want to go to the toilet, choosing... having somebody else make the decision about when you do go to the toilet, choosing where you stay, choosing who you work with, choosing how you get around during the day and at the end of the day, choosing who you actually have dinner with and who you go to sleep with.

Now, these are all choices that are taken away from many of the people with disabilities that we work with and that’s why I think choice and control, when we think about it that way, it loses its blah-blah focus and becomes a real concept in the lives of people with disabilities.

The other thing I’d want to say - and I’m not going to talk for too long because I think it’s important we get into the conversation - is that I feel that there’s a difference between choice and control. Some people want lots of choice, but they want to exercise different levers of control to be involved.

Not all of us want to be involved in the back-end administration of our lives. We don’t all want to do our own tax return, but we do want to decide who does our tax return and what the outcome is at the end of it, you know, what sort of return and what we claim. So I think that there’s some questions here about the architecture of delivery and also how people get the choices that best meet them without unnecessary bureaucracy and red tape and I hope we can get into some of that over the next hour.

DOUGIE HERD:
Thank you very much indeed, Craig. Moira and Cath, thanks very much to you too. We would... I would want to remind all of you online that if you’ve got questions or comments, we would like to hear them. We’ll get them flagged up here and ask our panellists to respond to them. I think we’ve got some themes emerging. I’m not going to attempt to summarise them too much, but getting to an idea that, as Craig put it, that choice and control should not be some kind of meaningless blah-blah term, but something real and concrete in the lives of people with disability and their family, there’s one.

I think looking at people as whole beings, which Moira may have touched on I think very clearly from her own personal experience as a parent, is terrifically helpful as a second theme. And Catherine,
perhaps, beginning us off looking at our understanding of what these terms may mean for us in our own lives are themes that begin to emerge.

But what we’d like to do now is hear from you. What do the terms ‘choice and control’ mean to you? And what will they mean into the future? Can I ask each of you to tell us what choice and control would look like in the world that we’re about to create over the next three to four years for people with disability? And if I may begin, do it in reverse order, Craig, Moira and then Catherine, tell us, you know, what does the future look like when we’ve got choice and control?

CRAIG WALLACE:
I think that ultimately, choice and control in a market economy, leverage from being able to purchase your own services. So people actually having control of that money and being able to make decisions and choices. Having the assistance to actually do that, so local planners working with them as they make those decisions. But also, for people in rural and regional areas, if you’re actually going into a community and people say, “Well, all of sudden,” you know, “we’ve got control of our own supports,” but there’s nothing to purchase, there’s a limited supply market out there, then I think that’s really problematic.

So I’d actually like to see us really growing the number of people that are seeking to access people with disabilities as a customer base, and as a valued one, including mainstream suppliers. I’d like us to move away from seeing something like respite, for instance, as being only provided in, you know, in an institutional environment that has green walls and that if you get respite effect from actually staying in a holiday cottage with the carer or your choice, then that’s a good outcome as well. So a world that is less prescriptive and also a world where choice and control can be exercised by people who we don’t usually think about exercising choice and control in your lives.

It’s easy to look at somebody like me, who has a physical disability, but what does that mean for somebody who has an intellectual disability? And Moira put it, I thought, really, really well when she said, “Don’t make assumptions that because a person can’t communicate that they have nothing to say or that they aren’t listening to what you’re saying and understanding the impact of decisions on their lives.”

DOUGIE HERD:
And, Moira, can I ask you, the National Disability Insurance Scheme will be fully rolled out to nearly 500,000 people in about six years’ time. Your daughter will be how old then?

MOIRA BYRNE-GARTON:
She will be 20 or 21.

DOUGIE HERD:
OK. What does the future look like for your daughter in a fully rolled out National Disability Insurance Scheme?

MOIRA BYRNE-GARTON:
Now, there’s a slight caveat on that, because I think that I have some advantages that some other people might not in terms of resources and I have a degree of social capital and I’m working, so I have a degree of monetary resources. I’m very aware that a lot of people with disability, or their caregivers, are not in situations where they would have the resources to... from that starting point. So... but I certainly would like my daughter to be participating in some kind of job, however humble.
Now, while she doesn’t communicate in conventional ways and although she uses a wheelchair, I firmly believe there is some kind of meaningful work out there for her. And there are inspirational people in the broader community and I’m thinking... Sally Richards established a company delivering and collecting mail that her son also with complex needs undertakes in Canberra.

And I think that anytime somebody is seen to be making a contribution and is in the broader community, that can only bring good results. There’s relationships being built and ultimately, choice and control is going to happen through relationships and changing our community is going to happen through relationships.

DOUGIE HERD:
Thanks so much. And, Catherine, you spoke very effectively on the launch day of the National Disability Insurance Scheme in Newcastle, alongside the Prime Minister. What do you think choice and control will look like in the future?

CATHERINE MAHONY:
I’d like to, I mean, I’d like to echo both Craig and Moira’s comments as well. I think the fact that people with disability become a market force, if you like, should mean that a whole lot of new choice and control opens up for us. New ideas, new services, new ways of doing things, like respite that’s already been mentioned. The way that we think about getting the support we need, what it looks like, the who, when, the what and the how and the why of it, I guess.

I also think that, as the others have said though, it’s really important that people with disability who aren’t as able as, say, Craig and I are to speak for ourselves and to articulate our dreams and goals and aspirations, it’s really important that we don’t have yet another us-and-them thing happen where those who are less able, who may have communication and/or intellectual, you know, impairments, that they have the same opportunity as I have to exercise choice and control.

It really concerns me, I guess, in just hearing how often people say, “Oh, it’s OK for you, but it’s difficult for so-and-so because they can’t make that choice.” And there’s an assumption that they don’t know the choice that they would make and I believe that that’s an inherently false assumption and, yeah, so that’s a real concern to me, but...

DOUGIE HERD:
Thanks very much. Let’s go to a web question sent in to us by David - Hi, David - who asks this: “I’m really interested in how the agency will enable people with limited exposure and opportunity to make fully informed choices. Does the planning process of the National Disability Insurance Scheme allow flexibility to offer participants to try before they buy in a way that facilitates true individual choice?”

Panel members, you got any thoughts on does it, should it, will it?

MOIRA BYRNE-GARTON:
I think it’s an excellent question and I really liked what David wrote in there about trying before they buy, because I think for people with complex communication needs, often the only way that they can reveal their choice is through experiencing something. And I think, as a community, we’ve got to become a little bit more aware of the indicators that people provide about how they’re exercising that choice. So that means that if a care worker comes in and the... a person with complex communication needs doesn’t appear to be gelling with them or doesn’t appear relaxed in their presence, I think that’s an indicator that they’re not enjoying that particular choice and there should be other options offered.
DOUGIE HERD:
Craig?

CRAIG WALLACE:
I’d actually hope that some of the canny suppliers out there are thinking about ways that they can offer people virtual experiences to actually, you know, touch and try products and find out more about what they might do in their lives. The other thing that I think is a little bit lacking in this is that we’ve put a lot of investment into how clinicians might support people through the planning process. What I sort of find in making, you know, a big purchase of a disability-related item is that I tend to rely on peer-to-peer information. So, you know, if I had a problem with a wheelchair, I would go and ask somebody who’s been using one for a long time what that actually looks like.

So I hope we actually have some opportunities for information sharing about what it is that actually works for people. And I imagine that for people with a cognitive disability, it would be the same. It would be about what method of facilitated communication or what LiteRider actually works for them. So I hope that we actually have a bit more of that as well.

DOUGIE HERD:
And, Catherine, can I ask you not just for your own opinion about this, but maybe tell us a little bit about the... ‘cos you’re part of a peer-to-peer...

CATHERINE MAHONY:
Mm, yep.

DOUGIE HERD:
...support group in Newcastle, aren’t you?

CATHERINE MAHONY:
Yeah.

DOUGIE HERD:
You know.

CATHERINE MAHONY:
So I’m part of a group which is called Community Disability Alliance Hunter, or CDAH is our acronym. And I guess we exist, if you like, to really build upon that peer support is at the heart of who we are and what we do. So we’re run for and by people with disability and I guess we believe that that is a really, as Craig says, a really significant way to learn, to grow, to share ideas. Sometimes really simple ideas like, I’ve, of course, gone blank for an example, but just the everyday things that, as Craig said, it might be a piece of technology. There’s another person in the group who has some... who is blind as well, so we exchange stuff about our iPhones and what he does and what I do. So it is very much that peer-to-peer.

I suppose just to pick up on a couple of the other themes quickly, though, I am really concerned in terms of the launch sites that... and the ongoing implementation of the National Disability Insurance Scheme, that we make sure that people who are transitioning have that support, that independent support they need to make those choices, to know what their goals and aspirations might be during the planning. We know that there is a certain amount of people who don’t have independent support and the only support they have is coming from a service provider. And that’s no disrespect to service providers, but we know there’s a conflict of interest there.
So I guess, you know, on-the-ground feedback from the launch site is, from one of them anyway, is we have to think really creatively around how to give people that ongoing... and I like the try before you buy and I don’t think we can underestimate how challenging it is to make choices when that hasn’t been the culture in which we have operated, particularly around disability.

DOUGIE HERD:
OK, thanks so much. We’re going to go to another web question from Leonie Davey, who asks, “I wonder how NDIS can support people to prepare and build their capacity to make meaningful choices before they have to make decisions regarding individual plans.” So I guess that kind of...

CATHERINE MAHONY:
Yeah.

DOUGIE HERD:
...touches with your last point.

CATHERINE MAHONY:
Yeah.

DOUGIE HERD:
Moira, can I begin with you?

MOIRA BYRNE-GARTON:
I think some of this is about engendering a culture of learning to listen and learning to recognise what a choice might look like for a particular person and I am thinking particularly of my daughter and other people with complex communication needs. But I think if those small, incremental choices every day about who they interact with and what activities they want to pursue can be recognised, then later on, when it comes to working out what kind of work direction she might wish to go in, it will hopefully be a little bit easier because I’ll already know where her interests are and the kind of relationships she’s enjoying.

DOUGIE HERD:
OK. Before we quickly go to our next question, anything, Craig or Catherine, you’d like to add?

CRAIG WALLACE:
I hope that we have some work to help people actually imagine more and imagine better, so to actually start thinking outside the envelope of the services that they’ve already been receiving and there is processes like the Path Program here in the ACT, or Know Before You Go, that actually enable people to nut down their choices to a really fine level and think about, “Is this the way that I have to keep doing it just because I’ve been doing it that way for a long time?”

CATHERINE MAHONY:
Yeah, right.

DOUGIE HERD:
Catherine?

CATHERINE MAHONY:
No, just I would agree with that.
DOUGIE HERD:
OK. We’re going to go to another web question, but before we do, I’d just like to let you all know that we got 1300 people online at the moment, so that’s good news. From TK - Hi, TK - “Will carers, people with disabilities be able to choose products and services from anyone in the field, or will there be selected suppliers and contractors to use?” That’s probably a question for us, the National Disability Insurance Agency.

CATHERINE MAHONY:
Yeah, we’ll hand that one over to you.

DOUGIE HERD:
Thank you very much, guys. We ask that people who supply services, products, register to become suppliers. That’s an easy process and the quickest way to get through it is to go to our website, www.ndis.gov.au, where you’ll get detailed factsheets on how to go about that process of registration.

But we will see flexibility, choice and control enter into the decisions that people make that will lead them to go to, we believe, a broader, more diverse set of suppliers of products and we hope that that will become a real part of everybody’s life as we expand this managed market of support to people with disability.

And forgive me if I’ve not quite got that answer entirely correct, but let’s go to the next web question, which comes from Carol Peterson, who asks, “How do families feel about their family member exercising choice and control when that choice and control might present risk or goes against the family’s views?” And, Moira, you’re going to have to answer that question first...

CATHERINE MAHONY:
Yeah.

DOUGIE HERD:
...because you’re a mum and you know that tension.

MOIRA BYRNE-GARTON:
To be perfectly honest, I probably feel that tension more with my regular kids than with my limited edition kid, but I suppose ultimately, that’s where something like micro-boards can come into their own. And for those who aren’t familiar, a micro-board is an incorporated entity of people who are in relationship with a person with complex communication needs who can help parents and families determine the wishes of that person.

I see a really great future for that. I’m involved in... well, being involved, participating in the establishment of micro-boards in Canberra, but they’re quite well-established, a few of them, in Western Australia. And... one of the things that the West Australian model did a little bit differently than Canada was not to have parents on the micro-board because of the conflict of interest that is there.

DOUGIE HERD:
Catherine, can I ask you to give us an opinion and not just about parents or family members particularly, I think the question, if I may be so bold to suggest, goes to the notion of, as none of us has absolute freedom of choice...

CATHERINE MAHONY:
Yeah.

DOUGIE HERD:
...or complete control over our lives it seems to me, I think a point that Craig was making earlier. How do we get to a position in which people with disability, just like everybody else, have to deal with the same normal problems and tensions of living in a big world with complex relationships in which we exercise as much choice and control as we can?

CATHERINE MAHONY:
Mm, I think you might have... the key might be in your ‘just like everybody else’ phrase in that question, Dougie. I think that of course the needs of people with disability and the things that have to be considered, they might differ, they might be... they might seem to a family member as if they’re compounded and in some cases they may be, but I like to think that you’re right, it is, well, “What are my peers doing that don’t have a disability and what of that do I, as a person with a disability, want to aspire to and how... and what supports do I need to make that happen?”

So I think if we start from the individual, obviously, and what is, you know, typical of that person’s friends and peers and maybe their family experience if they choose to take on some of that. But I think, as you said, we all have limits on our choice and control and most of what we experience is... I think it’s far more in common with our non-disabled peers than it is different and if I spend the rest of my life getting that one message out, I’ll feel like I’ve done something. We’ve got to stop focusing on the differences and start focusing on what is common to all of humankind.

DOUGIE HERD:
Thank you very much. Craig, follow that.

CRAIG WALLACE:
I just think this goes to a concept we call ‘dignity of risk’ in the disability community, which is about the idea that we all take risks and we all make mistakes along the way through. I mean, who hasn’t gotten drunk and wrapped toilet paper around someone’s tree on a 21st in their backyard? Like, and people with disabilities, look, we all learn through that risk-taking process and we... it’s part of how we grow up and become whole human beings is being able to actually make mistakes and make choices. Yes, not all of the choices that we make will be the right ones, but why should they be? Why should there be this different standard applied to disability, people with disabilities?

The other risk point that worries me is service providers who, you know, OH&S and lots of rules and frameworks around what they do, versus mainstream providers who sometimes can actually say, “Well, I can also put your light-bulb in as well as do your house cleaning,” because they’re not wrapped around in those sort of risk frameworks. I work with a lot of people with disabilities who say, “We keep getting told, ‘No, we can’t do this for you because of risk.’” And that’s limiting choice and control and I don’t support it.

DOUGIE HERD:
Thank you very much, Craig, and we’re all going to hang onto the notion that once upon a time, the president of PWD did something with a toilet paper and a tree.

(Laughter)

DOUGIE HERD:
David has sent us a web question. He says he’s interested in what safeguards will be put in place to provide protection for participants in their decision-making. I’m not going to say what will be there. Could you tell us, guys, what you think should be there? Catherine, you’re going to go first this time.

CATHERINE MAHONY:
(Laughs). What safeguards do I think should be in place? Look, I think safeguards are like everything else, we have to have an individual approach to them and so the safeguards that I might need are going to be very different from the ones that Craig or Moira’s daughter or... I know that’s sort of a... sounds like a copout answer, Dougie. I guess it just is... yeah, it’s the safeguards to ensure that people’s ability to make choices that they’re comfortable with, that they have had information about and support to make and possibly have had the chance to experience, if that is going to be what they need to do in order to experience that and exercise that choice and control. I don’t feel that’s a great answer, sorry.

DOUGIE HERD:
No, no. I think it’s a perfectly reasonable answer and I think if we think about it also in terms of the recognition that the National Disability Insurance Scheme already has that where quality assurance and safeguards already in place in the states and territories around Australia will be honoured and respected as this new system rolls out, that hopefully will give some reassurance to people.

But I think we’re also interested to hear what you, from your perspective as representatives in some senses of a broader community might think also need to be there to ensure that the vulnerable and significantly, permanently disabled individuals that we will support will be protected as they exercise their choice and control. What ought that to be, Craig?

CRAIG WALLACE:
Three things. I think that we need to start hearing, and we’ve heard some things, but we need to start hearing a lot more about the role of advocacy, systemic and individual, within the post-NDIS world. There will still be a need for advocacy. It’s going to be really interesting how we come up with a purchasable model of advocacy.

I think information is important. I’ve almost been thinking we need something like a CHOICE magazine for disability that actually rates and gives some customer feedback and says, “Well this... we tried this and it was awful and they didn’t deliver and it was over-priced,” or, “this one’s really, really good.” So information, referral and choice information.

And the third thing is I would actually say, and this will be contentious, there is stuff that we know right now doesn’t work and exposes people to hazards and I would talk about large, congregate institutions for people with intellectual disabilities as being in that domain and that we should be looking at ensuring that we don’t replicate those mistakes of the past and put people in jeopardy because of things that don’t work and expose them to abuse.

DOUGIE HERD:
Thank you, Craig. Moira, thoughts?

MOIRA BYRNE-GARTON:
Ah, it is a tricky one. As far as safeguards, the main safeguard I would like is being able to, with my daughter’s consent, change providers more easily. At the moment, we can become beholden to funded groups, groups funded by government to provide a particular service that don’t necessarily provide that service. And there’s not a lot of recourse. It’s kind of like, well, accept a substandard service because this is what’s available or go without completely. And I think that if there’s a little bit
more choice in agencies available and that, you know, the money goes with the person and a service that’s provided, that’s going to be helpful.

The other thing I think, I’m a little bit conflicted about this, I’m not sure, but I do wonder whether there should be some restrictions about profit-making entities. And partly because I think, in the past where profit-making entities have come in to deliver services formerly provided by government, there can often be a lot of cost-cutting and substandard service and not necessarily the values that are within some of the entities based on a more charitable model. Now, that’s not to say that charity is always a good thing either, but that is a little bit of a tension that I am aware of.

DOUGIE HERD:
OK.

CATHERINE MAHONY:
Could I... sorry.

DOUGIE HERD:
Catherine, on you go, you’ve got an opinion.

CATHERINE MAHONY:
Could I just quickly jump in there and say I think that the... that this new, changing culture and landscape in which we live is probably going to sort out the services who genuinely have people with disability at their heart and as their reason for being from those that are in it to make profit. I don’t... I agree with you, Moira, it’s an incredible tension and I don’t want to underestimate that and I recognise that they have a right to try and, you know, create a business, but I wonder whether we’re going to have a bit of a separation and those that remain will be those that have a genuine...

MOIRA BYRNE-GARTON:
I hope so.

CRAIG WALLACE:
Yeah, I hope so too.

DOUGIE HERD:
Well, let’s see and can I just remind you if you’re online at the moment and if you’ve got any thoughts or answers to Craig’s controversial point or the tensions that Moira and Catherine referred to, we would love to hear your comments, so send them in. I’m going to go Maricel O’Farrell’s question, “Will there be a clear separation between the provision of services and the management of funding under the NDIS? Will the same service provider manage the funds and provide support services? There is a clear conflict of interest and very little if any choice or control from the person with the disability or their family carer.”

I’m going to try and give you an answer from the scheme’s point of view in a minute, but I’d like to ask our panel members to give us their thoughts on what ought to be the case.

CRAIG WALLACE:
Well, I hope so. I mean, the first landscape is very much pre-Disability Services Act 1986, where you had one service provider potentially having control of the accommodation, the employment supports, the respite supports and maybe you could even die there as well. So having the whole service wrapped around a single person is a point of danger for us.
However, the other reflection I would make is that for some people who choose to completely un-bundle, those people will be providing, managing and being their own supports and also hiring informal supports around themselves. So there needs to be shifts by degrees and some nuancing in this and I suspect it’s a hard question to answer and an issue that the agency is probably still working with.

DOUGIE HERD:
Righto, Catherine?

MOIRA BYRNE-GARTON:
I don’t really have anything I think I can add to that one, sorry.

CATHERINE MAHONY:
I just think it’s crucial that there... I mean, it’s my opinion that it’s really important that there is separation from service provision and fund management. I’m, you know, I’m not... I just, yeah, I think there’s all sorts of inherent conflicts and I think if we want people to have genuine choice and control, then that to me almost feels like one of the safeguards we were talking about before.

DOUGIE HERD:
OK, well, I hope it will be clear to people that in this process of transition in which we move from block funded arrangements to the many non-government organisations that are currently providing support to people with disability and their families, we will move, over time, as quickly and as reasonably as we can, to build a sustainable service system that supports people to a position in which the primary relationship will be between the individual with disability and the agency that supports them through a personal package of support and that that conflict of interest, should it exist, will be removed so that it doesn’t interfere in the natural relationship between people exercising choice from a range of support providers, some of whom will continue to be, many of whom will continue to be, the support providers that currently exist, but that it won’t be possible to be both a provider of support to an individual and a fund manager of that individual at the same time.

The power we seek to create, which the legislation has put in the hands of those individuals, is an individual packaged plan that is developed, mindful of all of the relationships in an individual’s life. They will control and determine for themselves with the advice of others, independent advocates should they so choose to have those in their lives, that will allow them to exercise the choice that they need and want.

But we do have to say to individuals that it takes time to get from the system we currently have and which operates for many people with disability to the fully fledged rollout of the National Disability Insurance Scheme and we don’t apologise for the time it will take us to get to that new arrangement because we get only one chance to make this big reform work.

We will work together, people with disability, family members, support providers, the provider sector, the governments of Australia, to try and make sure that we get this big reform right and that’s why we will see it develop incrementally over the next few years. But we are moving inexorably to a position in which that choice and control rests with individuals supported to the best of our ability to do so.

We’ve got another web question? EI, thank you for your question, “Is choice and control really only possible through people with a disability becoming purchasers and/or consumers?”
CATHERINE MAHONY:
No.

MOIRA BYRNE-GARTON:
I was going to say no, yeah.

DOUGIE HERD:
Catherine thinks not. Tell us why.

CATHERINE MAHONY:
Because choice and control is, as I think we’ve said before, is about most, you know, we want to exercise it in most aspects of our lives and we’re always thinking about all dimensions and I guess what we were perhaps saying was that as people with disability have greater opportunity to exercise choice and control, then that may influence some of the commercially available and sort of paid for services that we access. But it can be around choosing between, you know, which friend you want to have some informal support from and that doesn’t have anything to do with purchasing a service.

DOUGIE HERD:
Craig?

CRAIG WALLACE:
Wasn’t it Thatcher that said, “There’s no such thing as community, there’s only families and the economy”? Well, I’d actually disagree and say that there’s community in the middle of that as well. In terms of it just being about purchasing and consuming that creates choice, I think the NDIS needs to be exploring a continuum of options. So not all people are going to want to completely unbundle and deal with the backend business of becoming a consumer and purchaser and hiring their own staff. But people might want things like arrangements where they’ve got an account of money that’s actually brokered and managed by someone else and facilitated that they can purchase from.

The principle, though, of power and control, in other words, being able to in some way hire and fire and sever the service if it’s underperforming is the key bit that makes the NDIS different to what we’ve got now, in my view.

DOUGIE HERD:
Moira?

MOIRA BYRNE-GARTON:
I agree with what you’re saying, Craig, and I agree with you, Catherine, as well. I think that there are a lot of ways in which people can exercise choice and control outside of consuming and purchasing. And when it comes down to it, if with the right supports in terms of community, as you were saying, Craig, there’s no reason you couldn’t live on a little self-sufficient hobby farm in, you know, in the middle of the country somewhere and not engage with any services at all, but grow your own veggies and, I don’t know, live the good life. But at the same time, I do think an important aspect of choice and control is if you choose to engage with the economy, to be able to make purchasing decisions and including over disability equipment and services.

DOUGIE HERD:
OK. And if I may add, again I hope I don’t get this wrong, that I think it’s useful to remember that this is not just about seeing... or it’s not even at all about seeing people as simply purchasers or consumers. I think it’s no accident that the Parliament of Australia, when it enacted the National
Disability Insurance Scheme legislation, set out as the first objective of the legislation a connection to the United Nations Convention on the Rights of People with Disability.

My understanding of that, I believe the agency’s understanding of that, is that we wish to move further towards a position where people with disability and their families are understood to be whole human beings with rights of citizenship that attach to their existence and that sometimes will purchase, sometimes will consume, but that we’re not reducing individuals to those simple mechanisms. It’s about meeting the reasonable and necessary supports to allow people to have better social and economic outcomes for participation in a society that is more inclusive.

We’re beginning to run out of time, which is unfortunate, but we’ve got at least one more question that we’ll try to squeeze in from Peter G, who asks this: “Choice and control still seems to be a difficult concept when people labelled with ‘challenging behaviour’ are concerned. What do you think?” And if I could add to that question, this dimension also from a questioner that submitted in advance: “How will people with communication difficulties express their needs, goals and wishes within a choice and control framework?”

You three, give us an answer. Catherine, you’re going first again.

Catherine Mahony:
OK. I might at least take the first part and maybe we can share it between us and I’ll keep it brief. But I suppose I think we have for a long time underestimated the link between some of those, quote, ‘challenging behaviours’ and the complete restriction of choice and control that people with disability have experienced, particularly but not limited to those congregative, large congregative settings that Craig spoke about before. I actually heard a person with an intellectual disability be very clear about the fact that she had been barred from a particular centre because she was frustrated and she chose a particular way of expressing that frustration that wasn’t appropriate in that centre. But she was very clear, “I did that ‘cos I was frustrated and angry.” And so I think it can, in some ways, be as simple as that.

The challenging behaviours, why are there challenging behaviours and what can we take, what can we learn from those challenging behaviours about the goals and aspirations and dreams and desires of that person expressing them?

Dougie Herd:
Thank you. And briefly, guys, ‘cos we’re running out of time.

Craig Wallace:
If I may?

Dougie Herd:
Yes, please.

Craig Wallace:
I actually think one person’s challenging behaviour is another person’s way of communicating what’s going on with them, whether it be, you know, underlying pain in their lives or whether it actually be the fact that they’re constrained in a place and with people that they don’t want to be. In terms of people who need communication assistance, I would say we should be asking, well, just being unable to be understood doesn’t mean that you can’t communicate if you’ve got the right supports. So we ought to be investing in things like facilitative communication and communication devices and also gaining different understandings about the way that people communicate.
And for some people, in some situations, acting out in what other people might call challenging behaviours for them feels like the only way out of a really bad situation. It’s their way of communicating.

DOUGIE HERD:
Moira?

MOIRA BYRNE-GARTON:
And I would just support what Craig and Catherine have said. I would also just add that I don’t think we should underestimate the try before you buy or experiential concept of ascertaining people who have complex communication needs’ preference.

CATHERINE MAHONY:
Yep.

DOUGIE HERD:
OK. We’ve got one last question, which we’re going to have to answer quickly. Can I just say, as you’re giving your answer, you should probably know that there are 1500 people online waiting for the answer. Handmade Features asks this question, “Do you think we’ll be able to move beyond group thinking for people with high support under an NDIS?”

MOIRA BYRNE-GARTON:
I’m not sure what the group thinking is, so I, yeah, can’t...

CATHERINE MAHONY:
I’m not sure if...

DOUGIE HERD:
If I understand the question, it is will we get to a point where we stop thinking of people as the stereotyped members of diagnostic categories and groupings, particularly as that might relate to people who have what we understand as high support needs? Will we get beyond that to see them as individuals?

MOIRA BYRNE-GARTON:
I definitely hope so and I’m very hopeful of that.

CATHERINE MAHONY:
I don’t want to think about a world where we don’t get beyond it, to be... that’s a bit dramatic, but that’s how I feel.

CRAIG WALLACE:
I really hope so and I think one of the problems in the debate around things like congregate is that it’s been conducted almost in the wrong order. We’ve been talking about models and choices for people with limited choices and limited income to support those choices and we ought to be able to now have that, you know, discussion about more varied choices for people now that we’ve got the decent support. We shouldn’t be trying to, you know, we shouldn’t be fighting on the 10% when we’ve still got the 90% to win.

DOUGIE HERD:
OK. I think that’s a unanimous ‘yes’ from our panel. We’re going to have to wrap up. I think it is safe to say we could’ve kept going here but we can’t, so we’re going to wind up. Firstly, I’d like to say a very sincere thanks to our three panellists for being the first panel for an NDIS webinar. I’d like to thank Brett for his Auslan interpreting, without which we couldn’t have conducted this session. And I’d also like to thank all of you who’ve joined up to watch this webcast or submitted comments and questions before or during the event.

I’m really sorry that we couldn’t get to all the comments and questions during this session, but, you know, 1500 of you, that probably sets up a bit of a queue. We’re very grateful that you’ve been here.

We’re going to publish some of these questions and answers in a response that we’ll place on the website for those that we haven’t had time to get to today. Could I just say that if you’ve missed part of the broadcast or would like to view it again, you’ll be able to do that by accessing the video, text and audio on the NDIS website, that’s www.ndis.gov.au, and stories from NDIS participants are also going to be available on the website and we will keep updating them as we get more through the scheme.

Finally, can I just say that our second webinar is planned for Tuesday the 10th of December and that the theme will be in keeping with the theme for the International Day of People With Disability celebrated just a bit before that. So we’re looking out for... we’re asking you to look out for more details on our website over the coming weeks.

That’s it from us. See you all next time. Thank you very much for participating.