

## Maximising lifetime opportunities through the NDIS

### Dougie Herd<sup>1</sup>

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Our next speaker is Dougie Herd. Dougie was born in Glasgow and he arrived in Australia in late 1999. He has broad experience with disability advocacy. He's had multiple advisory roles. He's had six years as Executive Officer of the Disability Council of New South Wales, five years as Executive Officer of the Physical Disability Council of New South Wales, and he joined the agency responsible for the National Disability Insurance Scheme last year. So, to tell us a little bit today about maximising lifetime opportunities through the NDIS, could you please welcome Dougie Herd ...

Thank you. Good afternoon, everybody. Thank you very much for the opportunity to be here and give you something of a background into the National Disability Insurance Scheme. I'm a member of the senior management team at the national office of what's called the National Disability Insurance Scheme Launch Transition Agency, which one day soon we all hope will have a shorter name. I'm joined here also by my state manager, colleague, [inaudible], from South Australia who's been at the conference for a couple of days and for us, it's a really valuable opportunity at this time to come and say something about this scheme.

I'm going to talk about how we got here, where we currently are, 11 weeks from launch of the scheme, and where and how, why we are going to, where we hope we may get over the course of the next five years. Two things before I get into the detail, first I must of course acknowledge that I'm speaking to you from Aboriginal land and pay my respects to elders past and present. And secondly, if you will forgive me, I speak quite a lot. It's my good fortune at meetings. I've never had one of these microphones on before and since the sound guy put on it my head, I've had this voice in the back of my brain going, (sings) "Billy Jean is not my lover. She's—She's just a girl that claims I am the one." And I'm really worried that I'm channelling my inner Michael Jackson. So if—if I go moon walking, backwards off the stage, you know I've completely lost touch with reality, so forgive me. But that is not what I came to say.

The National Disability Insurance Scheme, I'm absolutely sure you know some of the story around that scheme. Let me quickly take you through how we got here. The Australian Government commissioned the Productivity Commission to investigate the current status of disability, current support in Australia, and that commenced a nationwide investigation by the hard-nosed economists of the productivity commission into the touchy-feely area of social support with people with a disability, their families and others.

That report, sorry the inquiry, was the largest inquiry the Productivity Commission has ever conducted in its history and it produced a two volume, 1500 page report into the level, quality and problems of supporting people with a disability and their families in Australia in the 21st century. The key most often quoted statement from that report is the simple observation that was made by the Productivity Commission that the current system of supporting people with a disability in Australia was unfair, underfunded, fragmented and inefficient. And as a consequence of that, it recommended that we move towards a new way of supporting people with a disability and their families across the whole of Australia. One that would give to them better flexibility, genuine and informed choice, and more control over the ways in which each of us were to be supported by an industry, a sector and communities that would be more responsive, more listening, more attentive, more speedy in their responses, and, as far as we move out into the more general community, more inclusive and welcoming of people with a disability. Because, in addressing the needs, the functional needs of individuals with a physical sense of the intellectual or other impairment that significantly affected their opportunities in life, we weren't just talking about their physical limitations or possibilities.

You know, anyone can tell just by looking at me, an example to use me as a case study, that I'm a paralysed person. I happened to be paralysed in '04 [phonetic], from the chest down I have limited function across most of my body. I'm incontinent in bladder and bowel, I have limited sensation and I need assistance on a daily basis just to get up out of bed and get on with life.

But if our reform of the unfair, fragmented—whatever the other bits of the Productivity Commission report said, what the report said was true, we needed to address more than just the physical limitation. We needed to look at the way in which somebody with a disability, who needs and depends upon support, will receive that, is able to exercise control over it, and then, having had some of their functional needs met, begin to build upon their history of engagement with the community. That would be more responsive, more welcoming, more inclusive and would begin to contribute towards the shift from looking at disability as deficit, to see what people with the disability themselves brought to their family, to their street, to their community, to their town, their state and their country, and to see people with a disability as no more or less individual assets, valued for what they bring as much as for what they may need, as they contribute to the society in which they live.

And that view seems to have been endorsed by thousands of people with a disability, family members and others. Hundreds, perhaps thousands of organisations who have contributed to the debate that brought us to the proposition just 10 days ago when the National Disability Insurance Scheme legislation received royal assent, having had unanimous support, in its amended form, in both houses of parliament. A feat of political consensus in the current political climate that is commendable and for which, I believe (he says, as an Australian public servant so he should watch what he says and how he says it), a feat that I think we should genuinely celebrate the commitment, the passion and the determination of politicians to at least set aside some of their traditional divisions to do what is, I think, self-evidently perhaps, the right thing, but perhaps a little later than any of us might have wished. Because this journey didn't just begin with the reference of the Productivity Commission report or to the passing of the act last week or the week before.

You can tell from my accent that I was not born in Whoop-Whoop—regional whatever or remote Australia, wherever that may be. And so those of you who've been around the traps a bit longer than me will of course remember that 40 years ago an Australian government almost got something that looked a bit like the National Disability Insurance Scheme on the statute books of Australia. And were it not for what I believe my fellow Australians, and I now am, called, the dismissal, Gough Whitlam's initial intention to have something like this would have been realised and people with disability in their families might not still be as far back as they remain in Australia today, as they currently are.

However, that was then, this is now, and we're moving forward. Here we are now, 11 weeks from launch. What have we got? Well, we've got an Act passed and it is, I think, I have said this before so forgive me for anyone who's here who has heard me say it before, none of it really matters to anybody except me. I don't like the term paradigm shift. I think I hear it too much in my life. I think we all wake up in the morning and think we're paradigm shifting and most of the time we're just waking up in the morning. And I think—and I think we use—we overuse such terms and the risk is that sometimes we devalue them.

But every now and again something comes along that genuinely is a paradigm shift and this I think is one of them. And if you want to get a sense of the extent to which this may be something that looks like a paradigm shift, I suggest you go to the legislation that was passed by parliament just 10 days ago because, you know, it does all the usual things that legislation does. But when it gets to the objectives of the act, the first thing it says is surprising, not, we will do good to help people with disability in their families, or we will set up a new national bureaucracy called the National Disability Insurance Launch Transition Agency. It doesn't even say we shall establish a National Disability Insurance Scheme. The first objective of the act is to contribute towards the progressive realisation of rights set out in the United Nations Convention for the rights of people with disability and that that is the first driving force that informs the law that was established quite recently by parliament.

And for me, that looks like the beginnings of a paradigm shift, because we're moving away from what, in my previous 1970s—I'm a socialist, social democratic sort of guy ~ growing up I was led to believe it was the post-war social welfare contract between people, taxpayers and the support systems around them. We were to some degree, I mean no disrespect or criticism to those that came before me, because I was part of that process too myself, but we were doing good. We were looking after people in a sometimes paternalistic way and people with disability were high on the list of people we felt an obligation to do good for and to.

But we move into a situation now where in 2013 the Australian Parliament says that what it's doing for people with disability is under the National Disability Strategy, committing itself to the progressive realisation of rights. And that seems to me to be an indication of movement in a new direction, one that people with disability and others have campaigned for for some time. And it is, for someone with my personal background, now working for four months in the APS, refreshing to find it now government policy to say some of the things that many people have said and articulated from outside government for some time.

But where are we? What are we doing now? Well, we're building this agency of ours to open the doors in just 11 weeks time. What's the plan? It's called making up as we go along. And—and why is that a good thing? It is because if it is true, as the Productivity Commission said, that the current system of support is unfair, fragmented, inefficient and underfunded, then it would be insufficient to say, 'But we'll take all that we've done before, we'll double the budget to take it to \$16.5 billion in five years from now and simply plant that arrangement in the lives of people with disability and families', because that would just look like more of the same. And if we're not doing more of the same, then to some extent we are breaking new ground, building upon the best practice that has been there in service user controlled initiatives that have existed across Australia, sometimes for up to two decades, learning from the lived experiences of people with disability in Australia and overseas, because this is not a new idea.

I have to say, without claiming any personal credit for it, that I was involved in supporting the first three people in Scotland, whoever had an independent—an independent living support package of the type we're now talking about in Australia, Wilma, Archie and a guy called Shand living in poor public sector housing in the peripheral housing estate on the outer edges of some of the most deprived parts of Scotland's capital, Edinburgh, involved in helping them set up their packages in 1988.

And so these ideas are not necessarily brand new, but we're beginning to move them into the mainstream of support, but we're transitioning from that system that has been providing support in a patchwork way to people with disabilities, and often not being able to provide support, and responding to crisis circumstances that have always been indefensible and which we cannot move into the future with, to a position where we will gradually, over time, move from that old system to a new system with the intention to empower, enable and give within a rights-based framework, people with a disability and their families more flexibility, greater choice and more control over how they control and influence the support that they've received, so that they can live better lives. That's what we're attempting to do.

How do we do it? In 11 weeks time, we open the 7 offices in the 4 launch sites that are commencing in the Barwin region of Victoria, in the Hunter area of New South Wales, across the whole state in South Australia, for kids from birth to 13, over the next three years and in the whole of Tasmania, adolescence, 16 to 20, young adults, 24 to 25, and then from next year in Canberra. As I think it was mentioned in one of the workshops, one State Government, New South Wales, has signed up to the full scheme. We are hoping, it's absolutely critical that the rest of the states and territories sign up to the full scheme also, because the intention is to build a scheme that will operate in every part of Australia. Because, as a consequence of the COAG agreement on the 7th of December last year in which all governments of Australia signed up to this joint venture, each government is committed to a program over time that will make sure the National Disability Insurance Scheme becomes real in the lives of up to 420,000 individuals with disability.

How does this shift take place? Well, you know, Merryl will tell you better than I, if you ask her. Over the course of the next two weeks you conduct hundreds of job interviews to try and get people who are going to be the planners, the senior planners, the local area coordinators who will work a broader community to make it more inclusive, the accountants, the administrators, you know, the people who will answer the phones to make sure we can open the doors. You get a bunch of guys in hard hats to knock down the premises that are currently becoming our offices, which is sometimes problematic, you get a place in Launceston and you get an office in [inaudible] then start the work, send the guys in, you discover asbestos and you go back to the start because you have to find another location and that's—this is a really good indication of how smoothly this well-oiled machine is running. Our state manager gets the keys on Friday the 28th of June and we open the doors on Monday the 1st of July. So we're all hoping, believing, absolutely trusting that the IT guys have got the system ready to go in that weekend, because we don't have an opportunity because the Prime Minister was absolutely clear when she spoke to the chief executives conference of National Disability Services. She said this ain't a trial. This ain't a pilot. This is a launch. And my uncle, you don't need to know this, but I'll tell you anyway. My uncle, I know about launches because my uncle worked as a riveter on the Queen Elizabeth the II in the Clyde [phonetic] seat and I understand that once you launch a ship you can't bring it back up the slipway. We're going on the 1st of July. We—Please, don't—come back on the 2nd of July and we'll see whether or not that happens.

It will, because Merrill's responsible for operations. I'm just responsible for talking about it. But we're telling the people of Australia in a way in which we hope they will understand that we don't perform magic. Things won't shift overnight. It's not an unfair, fragmented system on the 30th of June and perfect on the 1st of July. But we are telling people that this shift is coming and that it is irreversible and there are reasons for doing that. It is to give to people with disability the dignity and respect that they deserve.

And in my abstract, which I hope some of you have had a look at in the program, I've—as is usual with me—set out a set of questions and given no answers because some of them aren't known. But if it is true that we are going to spend \$16.5 billion of public money in five years' time,—I don't know. I have no idea what \$16.5 billion looks like. I understand it's a lot of money. I don't know if it would fill this room or just occupy a tiny little corner if you brought it in \$50 notes. So I have difficulty getting my head around it sometimes. What I do know though, because Patrick Marr [phonetic] who's the Chief Operation Officer of National Disability Services used this comparison. It's about the same as the annual income of Qantas and I understand that's a big company with a lot of influence and say in what goes on in Australia. The difference between the National Disability Insurance Scheme and Qantas is that Qantas took 103 years to get to \$16.5 billion worth of income. We're going to do it in five. So there's no pressure there upon anybody!

But what we're going to do is to those 9,000 people with disability in the launch sites in the first year, the 26,000 people with disability in the launch sites over the first three years, and then the 410,000 people who will be supported by the National Disability Insurance Scheme using a system of individual packages, person-centred approaches, creating possibly 410,000 cost centres, because people will increasingly take genuine real control over not just their money but their plan, who supports them and how they are supported. We will increasingly give to those people the wherewithal to take greater control of their own lives, to be the authors of their own destiny.

But all of that sounds fine to me and I'm absolutely sold up, not just because it's paying my wages and the mortgage I've got on a house in Canberra I didn't own two weeks—two months ago, before I moved to work for the agency. It's because it's absolutely the right thing to do to help us realise those rights. But the problem is, as you know better than I, how do we make sure that if Dougie Herd's a guy with a disability supported by the National Disability Insurance Scheme living in the Inner West of Sydney with a vast range, even in this under-funded fragmented system, a vast range of non-government, government and other services around him, how do we make sure that if Dougie decided he wanted to go off and live in Wilcanya in New South Wales, or Broken Hill if he had a child who needed a speech

therapist where you cannot get a speech therapist for love or money, it doesn't matter what enticements you send out there, it is almost impossible to get someone to take a job, never mind someone who loves a hour and a half or two hours or four hours or six hours drive outside Broken Hill? How do we build equity, consistency of support, equal access to support across the vast range of an Australia that you know much better than I about its problems of providing support where the market is, to use the jargon, then?

The pillar upon which we build the hope that we can achieve that and part of the paradigm shift that matters is the final thing I'll make reference to, which is we shift power. Currently the power relationship and the ways in which we support people with disabilities and their family exists between the funder and the service provider, many of whom do excellent work. The paradigm shift we're engaged upon is to make sure that people with disability and their families, through the funding mechanism, through their ability to control their own plan, through their ability to make decisions and to enter into new relationships of a new type, which might mean that your neighbour becomes your support person, that you might, if it is absolutely necessary and there is no alternative, you might find some circumstances in which it's absolutely right for some of your support package to go to your auntie, your uncle, your brother or somebody down the street that you may be related to, because they can give you the support where and when you need it, rather than waiting for six months for someone to fly in from Sydney.

That's the way in which we will increasingly and progressively build this new system. We will trust people to be authors of their own fate, to make decisions about their own life and having made those decisions to exercise real control over how those decisions are realised, where they live, when they need them and the way in which works for them as individuals, with a rich cultural background that may be different from this white Anglo Saxon Protestant guy speaking to you now. That's where we're going. We will need your help to get there and if you want to talk about it in your local site, your local state, make sure you contact the National Disability Insurance Scheme in each of the launch sites when we open the doors in the 1st of July. And if the phones are too busy that day, give me a call at our National office in Canberra and I'll see if I can answer your question.

Thank you very much for your patience. It's been a great pleasure.