

# The NDIS is crucial for everyone - says Dr Paul Brock

Dr Brock addressed the Canberra Press Club in late 2011, with his personal story supporting the National Disability Insurance Scheme

Dr Brock, Director of Learning and Development Research for the Department of Education and Communities in New South Wales, and an adjunct professor in the Faculty of Education and Social Work at the University of Sydney, said .....

I've been asked today to speak about my own personal story of disability in the context of the need for the NDIS.

In late 1996 my entire world was turned upside down. Walking into a doctor's office feeling as fit as a fiddle with just a slightly weak forearm, I emerged with a death sentence hanging like a moose around my neck. Quote; you have motor neurone disease and quote; you can expect to live for only between three and five years, are the two sentences still burning in my memory. I was shocked and terrified.

I didn't have the vaguest notion of what this motor neurone disease was. Well I soon quickly learned that MND is an incurable inevitably fatal disease, too rarely mentioned in the media.

Typically MND progressively paralyses your arms, legs, swallowing and speaking muscles and eventually if you live that long, you end up with a mind and a consciousness inside a body capable only of eye blinking before the breathing muscles *completely* give way and you die.

Incidentally while contemporary emphasis on medical policy of prevention is important, for example the targeting of childhood obesity and cigarette smoking is necessary and admirable, it must never be forgotten that neurodegenerative diseases like MND and Parkinson's and multiple sclerosis are not currently preventable. They just hit us like cyclones, except that cyclones can usually be fairly accurately forecast.

Let me put it in a nutshell why I believe that the NDIS is so crucially important in providing the financial support and sense of security that would bring us - would bring as early as possible to those who need it. But now if somebody acquired serious disability through for example misadventure caused by a liable party, he or she have the capacity to seek financial redress through a variety of legislative or judicial means which of course is exactly as it should be.

But if the disability had either been acquired at birth or subsequently in life through some horrific out of the blue shocking disease, or other medical condition, or accident for which no compensation was received, there has been no access to the kind of financial support that would be provided by an NDIS.

Since my diagnosis the financial burden upon me and my family has been immense. As my condition has deteriorated, as I've tried to live as normal, inverted commas, a life as possible. However had the national disability insurance scheme been in place at the time of my diagnosis it would have made a world of difference to our family's financial situation and other situations.

Our expenses have risen exceptionally from year to year over the last 15 years and they are set to increase in the future.

MND was first identified in a scientific literature by the great French neurologist Jean Charcot in 1869. So I believe that it's a scientific medical research disgrace that in 2011 nobody still understands the cause and nobody has yet discovered a cure for motor neurone disease.

The majority of us die within two to three years of diagnosis. Of course there are exceptions. For example the Australian painter Pro Hart died only five months after diagnosis. I believe that's the case.

Professor Stephen Hawking is at the other end of the spectrum. In my case 15 years after diagnosis I can move my head, the top knuckle on the index finger of my right hand, waggle my knees pathetically smalley and can still speak but otherwise I'm now almost completely paralysed. Virtually live in this wheel chair. MND never takes a holiday as it relentlessly melts away my muscles.

There are about 1400 Australians living with MND, approximately 600 of us will be dead this time next year. For every death at least one more person is yearly diagnosed. It is a little known fact that MND kills more Australians every year than does AIDS. Those still living with MND are also the wives, the husbands, the partners, the daughters, sons and parents who on a daily basis provide us with care and try to deal with the short or long term drawn out grieving of watching the life of their loved one slowly being destroyed. Our friends and colleagues also share this grief.

I've already referred to NND's financial impact but even more the challenges to my image of myself as a human being have not been trivial. The physical impact of my having an incurable internal disease is obvious enough. But the emotional and psychological pressures on my wife, our two young daughters and myself are profound. I am frightened by the probability that lies in front of me and my family. We face the real possibility of eventually my being unable to speak and swallow, to be fed by a tube into my stomach, to breathe permanently dependent on a respirator, while having a fully alert mind within a vegetative body capable only of blinking my eyelashes.

In 2003 I had the privilege of meeting the inspirational Christopher Reeve and his wonderful wife Dana. Both now sadly passed away. Christopher told me that he would

regularly take researchers to hospitals and clinics in order to meet people with spinal cord paralysis like himself and neurodegenerative diseases like myself. He always concluded these visits by looking at these researchers fair-square in the eye and saying to them, quote: our houses are already on fire and we need you to put them out now.

Applying Christopher Reeve's challenge to our context today, it is so gratifying that the campaign of support for NDIS is rocketing along now. Just last night for example at a function I wasn't present, I understand the Prime Minister made it absolutely clear the Government's commitment to the national disability insurance scheme.

This movement has been both a top down and bottom up campaign. The bottom up movement has been driven by countless numbers of people with disabilities themselves and we've just listened to a champion advocate for such a scheme, Rhonda Galbally. And those parents or guardians or partners or sons and daughters or other family members or friends who have been providing care for them in one way or another.

Top-down there's been leadership from the Productivity Commission and the Commonwealth Government and the Alliance to which Rhonda referred. The agreement of support from NDIS, in principle, at the recent COAG meeting of relevant commonwealth, state and territory ministers, represented - or was - the ministers advised the leaders - represented a very encouraging beginning. The campaign has been vigorously led by the campaign director John Della Bosca.

As far as the Commonwealth Government's future implementation of the Productivity Commission's report is concerned, speaking both personally and as vice president of the Motor Neurone Disease Association New South Wales, I would like to suggest that the Government might exercise some flexibility on one particular matter. Of course it would not be the first time that a government has exercised flexibility in implementing a report.

Indeed the Commonwealth Government has already exercised flexibility by indicating that the final year of national rollout, with all the current and new clients to be receiving into our services, will now be brought forward a year from 2018/2019 as stipulated in the Productivity Commission's report to 2017/2018.

I believe that by excluding from the NDIS anybody who acquires a debilitating disease or condition when aged 65 or over, the commission may have inadvertently disqualified that relatively very small number of previously healthy people who will have the tragic misfortune of being diagnosed with a rapidly progressive neurological disease such as MND at age 65 or over.

For example I'd be confident that the commission would not have been aware that of the 259 people known by Motor Neurone Disease Victoria to be living with NIND in that State, 126 were diagnosed when aged 65 or over. Therefore of the approximately 600 people diagnosed with NIND each year, we can estimate that almost 300 will be aged 65 or over.

While many of these people will have their needs met by the aged care system, many others may require services from both systems to meet the needs caused by their rapidly accelerating physical disintegration. Remember, the majority of those diagnosed with MNI die within only two to three years, during which relatively short time their physical deteriorating is catastrophic.

Therefore the financial demands made on NDIS for those people would be for a relatively very short period so it would be admirable if the Commonwealth Government's legislation could consider providing such a safety net flexibility for people diagnosed with MND and other neurological diseases when 65 or over.

Like Rhonda, I've got great optimism for the campaign that it will succeed. But only because of its intrinsic goodness as public policy. Not only because of the power and efficacy of the top-down and bottom-up leadership already displayed. But also because I believe that our Australian people will throw their support behind the campaign. Why? Because the NDIS appeals to many aspects, what we like to think of as the Australian character. Not all features of which of course are unique to Australians.

We like to see ourselves as cherishing, indeed assisting upon, a fair go for all. As our magnificent tradition of volunteerism continuously demonstrates, Aussies reach out generously to those who need a hand up. An equitable, assessable quality NDIS would at long last provide a fair go for those who have not been able to have access to the kind of financial support that others, often experiencing similar disabilities, have quite rightly been able to access.

The NDIS will provide tremendous financial, emotional and psychological support to enable many with disabilities who have not been able to enter or re-enter the workforce, to join or re-join the workforce and contribute more effectively to the economic social and cultural capital of our great nation.

It would also partially, or in some cases perhaps fully, free up people caring for their loved ones at home to enable them to re-join the paid workforce in some degree as they choose.

Such an insurance scheme would provide a boost to national morale as Australians would take pride in the provision of assistance to those among the more challenged of our community and will also feel more secure themselves about their future and that of their family. But we must avoid any unnecessary delay and as I said before I was so heartened to hear of the Prime Minister's commitment last night.

Of course there are still questions to be asked and answered. For example is there a government commitment yet to a timetable for legislation to be introduced into the Parliament? These are not -these are legitimate question, I don't know the answers to them, nor are they to be merely rhetorical.

Will the Government be prepared to be flexible in its implementation of the Productivity Commission's report to admit the kind of safety net flexibility - safety net flexibility 1 mentioned earlier?

What financial commitment will be expected of state and territory governments? How much bipartisan or should I say in our contemporary political climate, multi-partisan political support can we continue to be confident in the NDIS? I'm not aware of any evidence to the contrary but it's a question that must continuously be asked. In particular of course where do the coalition parties, the Greens, and the Independents and the Federal Parliament stand on this issue?

To conclude: many lives and the basic rights of many people depend on a properly established equitable, accessible, quality national disability insurance scheme as soon as possible. To reiterate Christopher Reeve's vigorous assertion; our houses are already on fire, and we need and I feel confident that we have, we need the political leadership in this country to set about putting out those fires now.

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