

NDIS A GREAT SOLUTION TO CURRENT SHAMBOLIC DISABILITY SERVICES

BY SUE O'REILLY

In common with the vast majority of Australians in any way affected by disability, I thought from the first moment I heard about the proposal for a national, no-fault Disability Insurance Scheme that this would be the best possible way to transform our shambolic, wasteful, inefficient and inequitable disability support system.

And the more I heard and read, the more convinced I became. The fact that this proposal has attracted an utterly unprecedented outpouring of support from every sector of the community involved with disability services – people with disabilities, carers, disability service providers and senior public servants at both federal and state levels, as well as politicians from every major party – further convinced me of its merits.

Thinking about who, if anyone, might oppose the idea, the only people I could imagine even attempting to argue against it were perhaps a handful of compensation lawyers. But even if they wanted to, their naked financial self-interest in retaining the current system would be so obvious, I doubted they would dare.

Of course, heated arguments were likely to break out about the details of how such a scheme would work, if and when the Rudd Government finally gave the green light for the feasibility study necessary to design such a complex, far-reaching reform. But who could possibly oppose it in principle?

The answer has turned out to be: Erik Leipoldt.

Now, I must say I admire Erik for his undoubted personal courage in arguing against a proposal that has not only captured the imagination of pretty much every other single person in Australia affected in any way by disability, but one which also offers so many of us the one ray of hope in another bleak and hopeless landscape of stress, exhaustion, poverty and despair.

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But while I admire his courage, I'm afraid I cannot say the same about the case he attempts to construct in opposition to an NDIS.

Erik says, for example, that “no insurance premium can buy anyone the status of a valued person”, and that “money cannot buy love”. These statements are both so self-evidently true, one wonders why anyone would even bother making them – particularly as no-one, for one second, has ever suggested that an NDIS is about buying “love” or “the status of a valued person”.

No, the NDIS is about giving people with disabilities and their families the means to buy far more basic, prosaic things – like wheelchairs, and therapy, and respite services and hoists and shower chairs and quality educational support and computers and wheelchair-accessible cars and houses in which adults with disabilities can live as independently and self-sufficiently as possible.

The NDIS is not about “love”, but about this extremely wealthy nation finally introducing a properly designed method of funding all necessary support services for people with disabilities and their families; about this nation finally breaking free from a chaotic, crisis-driven model of disability service provision that demeans millions of people with

disabilities and their families by treating them as pathetic charity cases, and which instead enshrines all the basic services and equipment essential for day-to-day living and maximum independence as a fundamental right.

Of course, an NDIS, in whatever form it finally takes, will not be perfect, just as Medicare is not perfect. Nothing in this world is. But, as Churchill once said: “Many forms of government have been or will be tried in this world of sin and woe. No one pretends that democracy is perfect or all-wise. Indeed, democracy is the worst form of government, except for all the others that have been tried.”

Imagine, for just one moment, what Australia's acute care medical and hospital system would be like today if not for the introduction, some 25 years ago, of our universal health insurance scheme, Medicare. For all this scheme's faults and failings, would you want to live in a country where access to doctors and hospitals depended either on how wealthy you were, or if poor, the willingness of doctors to treat you as a charity case?

The answer, I imagine, is no. Yet that is exactly how Australia's non-acute, or chronic, medical, rehabilitation and care system treats people with disabilities and their families. If you are very wealthy, or entitled to some form of workers' compensation or motor accident cover, or you are awarded huge damages by a court, then you can get the services, equipment and support you need. If not, you languish on government waiting lists for years, or beg for help from charities. Your chances of living in poverty, of being unemployed, of suffering from depression or some other form of mental illness are appallingly high. We should all be deeply, deeply ashamed at the public policy failures over decades that have abandoned Australians with disabilities and their families to such a Third World support system.

As Bruce Bonyhady says: “Where is our outrage?”

In Erik Leipoldt's case, the answer appears to be directed at those trying to do something to come up with a solution. Apparently, his preferred approach would be that rather than doing something practical now to relieve the poverty and despair in which so many people with disabilities and their families live, we all focus instead on campaigning for “priceless attitudinal change”.

Yes, attitudinal change towards people with disabilities would indeed be a wonderful thing, and would make a huge difference. But why is this an either/or argument? Can we not all continue to fight for attitudinal change, while at the

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same time also supporting a universal, no-fault insurance scheme that would provide essential services, equipment and day-to-day support for all Australians with disabilities?

Erik is fundamentally mistaken too in asserting that the NDIS is “all” for people with disabilities. Actually, it is also for their families, many of whom now have to care for a person with disabilities from the moment of birth and then for five, six or seven decades afterwards – until either the carer or the person with a disability dies – because currently, there is no alternative.

Most significantly of all, however, his fears that an NDIS would just “entrench things as they are done now and the change we really need will still be out of reach” are completely baseless. In fact, nothing could be further from the truth.

As things stand now, we “consumers” – whether people with disabilities or family carers – are pretty much entirely powerless when it comes to deciding where and how the billions of dollars allocated by governments or raised by charities in our name each year are spent.

If all government funding was instead to be allocated to each disabled individual, in some form of trust account accessible as and when needed, the changes such a reform would bring about would be little short of revolutionary. Instead of being forced to accept what we are offered by bureaucrats and charity administrators on a “take it or leave it” basis, we consumers would have vastly more power and control than we do now. →

It is this sense of utter powerlessness – springing at least in part from having no say or control over the quality or quantity of support services offered – that can, I believe, play a major role in driving a tiny minority of parents to the extremes of killing their disabled children, as Robbi Williams discusses.

Generalisations, I realise, are dangerous, and those few parents who do kill their children probably do so for a whole range of complex reasons. But as the Julia Farr research identified: “People in the above situations often

children all around Australia – and when I say “children”, this includes adults in their 40s and 50s – I’d have to say I’m actually genuinely amazed and surprised that the death rate is not significantly higher. I think it is a huge tribute to the resilience, fortitude and stoicism of Australians that so many carers in this country manage to keep battling on, decade after decade after decade, with the burdens imposed on them; burdens imposed not because their children are disabled as such, but because the disability support system in this country is just so appallingly inadequate.

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report being beset by the chronic, unremitting pressure of their circumstances. Typically this can be accompanied by a sense of fearful, anxious hopelessness about a future where things do not change for the better. As time passes, the weight of these feelings can become heavier, especially if people have unsuccessfully tried to find assistance and relief.”

As things stand at present in Australia, Robbi Williams can only make suggestions to any parents contemplating murdering their disabled children such as: “Let the government know you are there. Publicly-funded government services... can give you nothing if they do not know of your existence and your circumstances. Seek information that can help you, because information gives you greater control.”

But what if that information, when you get it, is that there are simply no services available? Or that there are, but there’s an interminable waiting list for them? Or that you or your child don’t quite meet any of the convoluted eligibility criteria for the particular service provision you need?

Is that sort of “information” going to make a desperate parent feel more or less like killing their child, would you think?

From my personal experience, observations and conversations with many scores of parents of disabled

And the thing is: it doesn’t have to be this way. There’s nothing sacrosanct about Australia’s current disability support system, as even Erik Leipoldt admits. Why not scrap a system that has just grown in a completely higgledy-piggledy fashion over the past five decades or so, without any proper planning or design, and start afresh? After all, it’s not as though we could end up with anything worse!

In his critique of the NDIS proposal, Erik states: “Of course, you can’t really insure against disability, just against some of the financial costs”.

And that’s quite true. An NDIS is not actually going to prevent children being born with cerebral palsy or spina bifida or autism or intellectual disability. An NDIS is not going to stop people developing multiple sclerosis, or being felled by a stroke, or diving into the surf and breaking their neck, or falling off a skateboard or anything else that results in severe and permanent disability.

Equally, it’s quite true that disabling attitudes can’t be insured against. And it’s quite true that social attitudes towards people with disabilities need to be radically and fundamentally transformed.

But why is any of that an argument against an NDIS?

Beats me. 🌀