NDIS, the disabled voice and the church

Shane Clifton

The National Disability Insurance Scheme (NDIS) was enacted into law by the Australian Federal Parliament in March 2013.¹ This article intends to reflect on the process that bought the scheme into being, focusing especially on the contribution of people with a disability. It will also discuss key elements of the NDIS vision and values and, in so doing, consider the implications of the scheme for Australian society in general and the life and ministry of the church in particular.

It is important to note upfront that while, at least potentially, I have a vested interest in the scheme, I have had nothing to do with its promotion or operation, and neither do I have any expertise in public policy. My interest arises because it was during the period when the scheme was first being mooted that I had the accident that left me a quadriplegic. In the aftermath my priority was rehabilitation, and so for many years I took little more than a passing interest in the public consultations, political lobbying and subsequent public service operations that have brought us to the point at which the NDIS is being rolled out at various trial sites throughout the country. I thus come to this topic as a non-expert, and so I am not qualified to comment on the strengths and weaknesses of the scheme or its rollout.

My reluctance to critically analyse the scheme extends to the area of my expertise, Christian theology. While there is a promising emerging literature on disability and theology, the church itself has not earned the right to speak

¹The National Disability Insurance Scheme Act 2013 (Cth), Act No. 15, 2013.
to the communities of people with a disability, at least in Australia. In 2011, CBM (the Christian aid organisation focused on disability and poverty) commissioned research from the National Church Life Survey that found that ‘the typical Australian church has proportionately less than half the number of people with a disability than in the wider society (8% compared to 18.5%).’ Among other things, the surveys identified that only:

- 75 per cent of churches have accessible facilities
- 22 per cent of churches have an active culture of inclusion
- 18 per cent of churches have statements and policies that express welcome and inclusion of those living with disabilities
- 14 per cent of churches provide specific education on disability inclusion to church staff and volunteers

These figures vary from denomination to denomination, with my own community (Pentecostalism) faring the worst. And I cannot spare myself from this critique since, prior to my injury, I’d not put any substantive thought into these problems, and knew only a few people with disabilities. In the light of all this, it is time for the church to listen rather than to speak.

The emergence of the disabled voice

The NDIS is a piece of political and economic legislation, but its real import is that it has bought disability to the front and centre of the national consciousness. In so doing it provides the opportunity to think through the cultural values that frame our identity, and inform the structures of our society. Whatever else it achieves (or fails to achieve), what can be celebrated is that the process of establishing the scheme has given a voice to people with disabilities, and so demanded that the nation listen to the things they have to say about what it means to create a welcoming, accessible, and empowering society.

More than anything else, the NDIS exists because of the potent advocacy of people with disabilities. When Julia Gillard and the Labor Party launched the scheme in 2013, Labor’s Family and Community Services Minister, Jenny Macklin, commented that it was ‘one of the best grassroots campaigns I have seen.’ It had taken a long time—more than 40 years since the proposal was first mooted. Part of the difficulty had been that Australians had generally...
assumed that the social welfare system the nation already had in place was adequate, when in fact that system had utterly failed to meet the needs of people with disabilities. As noted in the 2009 report, *Shut Out: the Experience of People with Disabilities and Their Families in Australia*:

Many people in the community believe disability is someone else’s problem. They do not believe disability will touch their lives, and give little thought to the experience of living with disability, or caring for someone with a disability. Without first-hand experience, they hold on to the belief that at least things are better than they used to be.\(^5\)

\[\text{It is true that} \] Many of the large institutions that housed generations of people with disabilities—out of sight and out of mind—are now closed. Australians with disabilities are now largely free to live in the community. Once shut in, many people with disabilities now find themselves shut out. People with disabilities may be present in our community, but too few are actually part of it. Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed, but the inequity remains. Where once they were physically segregated, many Australians with disabilities now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be noticed, they struggle to be seen, they struggle to have their voices heard. What you will read in this report is their attempt to break down the walls of silence and finally have their story told.\(^6\)

To break this silence, a variety of disability groups across the nation came together to form the National Disability and Carer Alliance (NDCA), established to campaign for the NDIS. Adopting the slogan ‘every Australian counts’, the campaign focused on amplifying the voices of people with a disability,\(^7\) organising for them to meet with their local MPs, to tell their stories, and to encourage politicians to champion their cause in parliament.\(^8\) The NDCA also interviewed people across the country, publishing their findings in *Shut Out* (cited above). Although much of what was learned was shocking, the report also highlighted the character of people who were
not passive victims of their circumstances, but rather, determined, strong, creative, and dignified. These were people fighting for a fair go. As the report concludes: ‘They have fought hard to achieve their goals. They have refused to take no for an answer.’

The success of the campaign led the Federal Parliament to instruct the Productivity Commission to undertake an enquiry into the costs, benefits, and feasibility of the NDIS. Once again, the voices of disabled people were central to the shaping of the recommendations of the report, which was delivered in July 2011, and which formed the basis of the subsequent NDIS Act (2013). The power of the disabled voice was apparent in the fact that this legislation was passed with bipartisan support during a period of extreme turmoil and acrimony in the parliament (especially between the then Prime Minister Julia Gillard and opposition leader Tony Abbott). Indeed, as one reporter noted in the months of budget turmoil that followed:

The NDIS shows how problems can be tackled through goodwill and putting the national interest first. As we watch the head-butting of the budget gridlock and the glacial pace of deal breaking, we are reminded there is a better way. And as the NDIS also shows us, it’s not that difficult.

To give one final example, one year after the rollout of the various NDIS pilot projects, People with Disability Australia partnered with the National Disability Insurance Agency (NDIA) to establish the NDIS Citizens’ Jury Scorecard. This inventive project utilised ‘a process known as deliberative democracy … to ensure that the voice of people with disabilities informed the ongoing implementation and cultural change’ needed for the NDIS. While the process was limited in scope, the jury gave a relatively positive score to the rollout thus far. It noted, for example, that many of the participants of the pilot project were feeling more included in their communities, and earned a great deal of satisfaction by being able to set their own goals and aspirations and choose the activities they wanted to pursue. Many felt that for the first time they had real control of their lives. The jury also offered several recommendations for improvement.

The above narrative indicates that the disabled voice is potent. That this is so is remarkable (might we say miraculous?) given that it wasn’t so long ago that people with disabilities were presumed to be dumb and, rather than being listened to, were spoken for by medical professionals, welfare...
bureaucrats, educationalists and so forth. It might be argued that we are entering a new era, one in which the disabled voice has a unique opportunity to shape the values and priorities of Australia and create an inclusive and generous society. Of course that’s probably idealistic. One political achievement, as immense as it is, does not recreate a culture.

But if there is anywhere that this voice might find a natural home, surely it’s the church, the body of the Christ who describes the kingdom as a banquet: ‘When you give a banquet, invite the poor, the crippled, the lame and the blind ... and you will be blessed’ (Luke 14:12–13). Yet, as far as I can see, the church today is as paternalistic as any other institution—maybe more so. In my 25 years in church, I have not seen a single Sunday sermon preached by a person in a wheelchair, or by someone with substantive speech impairment. I’ve never been led in worship by a person who was blind, or deaf, or who had an intellectual disability (except in a mid-week service targeted specifically at disabled communities).

Perhaps my denomination is unique, but I suspect not. How many pulpits and stages across all denominations have wheelchair access? How many churches have Auslan translators, or make their material available in Braille? At the moment, these can only be rhetorical questions, because we haven’t asked people with disabilities and their families to share their experience of church with us, to tell us what we are doing well, and what we might do differently. We haven’t yet given them the opportunity to speak.

There are a multitude of reasons why the church has silenced the disabled voice. Principal among these is the continuation of a prejudice that is reflected in the scriptures themselves, which (at least on a surface reading) either treat disability as judgement for sin, or disabled people as being in need of charity and healing. Of course, there are other ways of reading the scriptures, and it’s not my purpose in this paper to set out a critical and constructive reading of the biblical text. The point is that paternalism has long been a problem in the church, and this is exacerbated because church leaders have come to believe that they have ‘the Word’—that they control its meaning and are tasked with its declaration. Because this is so, churches tend to speak rather than to listen.

It is not only people with disabilities that experience the blunt end of this paternalism. Women have also long been silenced by the church, so there is much that can be learned from feminist theologians. Elizabeth Schüssler Fiorenza, for example, notes that ‘a critical feminist theology of
liberation seeks to interrupt the patriarchal silencing of women in order to make women visible and audible as God's agents of grace and liberation. Feminist theology narrates women's experiences of oppression by the linguistic, theological, and ecclesial frameworks of the church, and insists that that the divine image is manifest in the bodies, activities and relationships of women. A theology of disability takes a similar approach and makes the same claims. It insists that disability is not a product of the fall but, rather, that disabled people uniquely manifest the image of God in their embodied actions, especially in their courage, anger, strength, joy and vulnerability. It seeks to interrupt the paternalistic silencing of people with disabilities, and claims that disability provides a unique lens into which we can see the paradoxical power of God: the strength and wisdom of God manifest through those vessels ordinarily seen as foolish, weak, and ignoble (1 Corinthians 1:24–25). In terms of ownership of 'the Word' (as if such a thing were possible), Nancy Eiesland makes the case that disability is especially representative of the broken body of Jesus. The point is that it is only when disabled voices are amplified that we are able to hear about the soul-destroying effects of our paternalism on the one hand, and learn unique insights into the gospel on the other.

Learning to listen

Amplifying voice is not just about giving people opportunity to speak, but it also means that we need to learn to listen. People with disabilities are routinely required to listen to others, ‘forced to listen to experts about their lives, instead of being listened to, not least as experts on themselves.’ This is as true of preachers as it is of the medical establishment. We are told from the pulpit about sin and its consequences, and the value of forgiveness and grace, but these are topics about which people with disabilities are experts—if for no other reason than that they are constantly needing to forgive us for excluding them!

To hear their expertise we will need to pick up new skills and examine ourselves as to whether we are open to hear. Listening is a challenge. We have a tendency to prejudge people and then to hear what we expected to hear. We are more likely, for example, to treat good-looking people as smart, and assume that those in wheelchairs, or with some obvious physical disability or speech impediment, are less intelligent, and so discount what they have to say.
Disability also has the potential to make communication challenging, so we may need to learn new methods of listening. Gerard Goggin, for example, notes that listening to people with severe communication impairments will require us ‘to indicate clearly and frequently whether or not we have understood. Listening here involves the negotiation of uncertainty—with the potential of exposure as being an inadequate, unresponsive, or uncomprehending listener.’ In facing up to the challenge, however, we get a small insight into the humility and frustration, as well as the strength and determination, that is a part of the everyday experience of people who struggle to talk, hear, see and so on.

In the concrete everyday activities of the local church, facilitating communication will require creativity. Again, churches are used to one-way communication, from the pulpit to a silent congregation. But what if the decision to amplify disabled voices generated a revolution in how we understand preaching, teaching, and sharing in the church? Is a pulpit and people seated in rows really the best way to communicate? Might replacing sermons with onstage conversation better model our theologies of the priesthood of all believers? What other forums or technologies might we introduce to hear the disabled voice and, more broadly, to open ourselves to the diverse spiritual insights of congregations as a whole?

But it’s not just the manner of communication that presents a challenge. The more confronting difficulty of listening to disabled voices is that what we hear may well make us uncomfortable. Because disabled people don’t speak with one voice, we can’t prejudge what might be said, but it is likely that their experiences will confront us with blindspots and prejudices in our own thinking and acting that will require us to face up to the need to transform our physical environment, as well as ourselves. Commenting on her experiences of listening to the stories of people for the Shut Out report, Rhonda Galbally said that ‘what I heard was both intensely moving and profoundly shocking … I came away from those consultations both angry and sad. But most of all, I came away determined.’ Australian politicians, similarly, were confronted by the stories of people visiting their offices, and by the often heartbreaking narratives presented in Shut Out and the report of the Productivity Commission, and they were compelled to take action and establish the NDIS with an annual budget of $14 billion. And while there is a strong economic case that the benefits will far outweigh the costs (not only in terms of the well-being of people with disabilities, but financially
the budget is offset against inefficiencies in disability spending elsewhere, and employment and productivity gains and the like),\textsuperscript{28} it is still the case that having listened to disabled voices, the country had the responsibility to act, even in the face of substantial economic and political difficulties.

Who is to say what similar conversations might mean for the church? No doubt something will need to be done about our facilities (why should heritage values override present-day accessibility?), and we may need to rethink access to our stage and pulpit, find ways of helping people get to our gatherings, and imagine creative technological solutions to aid communication. More importantly, we will need to ask ourselves why we’ve ignored these issues until now—what prejudices have blinded us to the injustices of a group of people especially loved by Jesus.

If we find ourselves wondering (in some cost-benefit analysis) whether all of this expense and effort is worth it for such a small group of people, we need to be reminded that amplifying the disabled voice has nothing to do with promoting the needs of another noisy minority (as if that was such a bad thing). As Alasdair MacIntyre insists:

\begin{quote}
our interest in how the needs of the disabled are adequately voiced and met is not a special interest, the interest of one particular group rather than others, but rather the interest of the whole political society, an interest that is integral to their conception of their common good.\textsuperscript{29}
\end{quote}

MacIntyre’s point is not only that we are all vulnerable and at risk of disability, but that the values learned in interaction with disability are central to creating communities (both macro, such as Australian society, and micro, such as the church) that will enable all of us to flourish together. Indeed, the reason I am arguing that we must hear the disabled voice is not principally about justice and human rights (although these things are vital), but our mutual flourishing. It may be that I’ve left the impression that the disabled voice is angry and demanding, and sometimes it will be (especially given the sorts of injustices revealed by \textit{Shut Out}). But I suspect that in churches we will normally hear joy, laughter, encouragement, and testimony to the goodness of God. The noise of disability is more likely to generate love and delight than cost and difficulty.
Independence

I have concentrated thus far on the driving force behind the NDIS (i.e. disabled people), rather than the scheme itself, and while I can’t do justice here to the complex economic and administrative operations of the scheme, there is value in reflecting upon its purposes. The scheme is directed by the vision of ‘Optimising social and economic independence and full participation for people with disability,’ and three goals:

1. People with disability are in control and have choices, based on the UN Convention on the Rights of Persons with Disabilities.

2. The National Disability Insurance Scheme is financially sustainable and is governed using insurance principles.

3. The community has ownership, confidence and pride in the National Disability Insurance Scheme and the National Disability Insurance Agency.

In all the diverse types and experiences of disability, what is shared is the struggle to negotiate dependency. This is true whether we are talking principally of impairment, where people may be dependent upon carers, medical professionals, technologies (such as wheelchairs and voice recognition software), and/or financial support for everyday activities, or the social model of disability, where people are dependent upon others to help reshape the social environment that excludes them from full participation within the community.

It is because disability establishes various types of dependency that paternalism and exclusion emerges. As MacIntyre notes, whenever the disabled are spoken of in moral philosophy books (and, I might add, on television or in the popular press) ‘it is almost exclusively as possible subjects of benevolence by moral agents who are themselves presented as though they were continuously rational, healthy and untroubled.’ The result is that benevolent charity toward the disabled, however well intentioned, ends up exacerbating the division between us and them, normal and abnormal, abled and disabled, and so has the unintended consequence of being alienating and disempowering. That is to say, we don’t think of disabled people as friends, but as objects of charity. MacIntyre goes on to describe what we should have known all along, which is that human life is always a negotiation between dependency and independency. We are born utterly dependent upon our
parents, who do their best to raise us up to become ‘independent practical reasoner’s’, people who are capable of taking responsibility for our own decisions and futures. But even at the height of our independence, when we seem to have made something of ourselves, in reality we are always dependent on our families, communities, nations and, in a globalised society, the entire world—to say nothing of our dependence upon the natural environment. And even though we rarely admit it, our bodies are inherently fragile, always at risk of injury, illness, and permanent disability, and as we age we inevitably deteriorate in body and mind. These realities of human existence are often obscured in our consumerist technological society, especially because we shunt the aged and the disabled into what are euphemistically labelled as ‘homes’, but are really ways in which we avoid facing up to our own dependency and the responsibilities that go with it. In this context, encountering the disabled voice will bring dependency to the fore.

The vision for independence is not to suggest that people don’t need help, but rather to insist that a new understanding of what constitutes help is required, one that appreciates ‘that differences are not necessarily defects and that those needing assistance have the potential to think and act independently’. There is something wonderfully paradoxical about this way of understanding the help we provide to people with disabilities, since the assistance we give intends to minimise the assistance that will be needed, and so empower people, to whatever extent possible, to take control of their own lives.

Central to the goal of independence is that we can’t assume that we know best (which is the essence of paternalism), and nor can we tell disabled people what it is that they must do. This is true of parents, experts, politicians, NDIA administrators, and pastors, all of whom will need to let go of false pride and allow people to choose their own, potentially very different, path. There is, obviously, a limit to this freedom, and a need to balance subjective well-being with objective judgements. This will be especially true for the NDIS, which necessarily faces financial constraints and has a limited set of outcomes in view. But that the principle holds is apparent in the processes that have been established, including a detailed approach to planning and assessment that seeks to identify a person’s needs, goals, and reasonable and necessary supports.

Beyond the NDIS, it is readily apparent that negotiating the balance between dependence and independence is notoriously complex and utterly
particular. Parents face the greatest of challenges in helping to transition children with disabilities into adulthood, and I am in no position to suggest the best way this can be done, except to note that (relative) independence is the ultimate goal. Of course parents are likely to be more aware of this than anyone else, because they really do listen to the aspirations and goals of their children. And while parents and families won’t always get things right—and so also face the danger of being paternalistic (by definition)—they are more likely to understand the subjective desires of their loved ones than anyone else, a fact that has political significance. Empowering people with disability is likely to involve equipping families[^37] and, at the same time, free disabled people from always having to rely on family support[^38].

In terms of other communities such as the church, again I’m in no position to presume to know what supports might need to offered (except those that pertain to my own disability). What is certain is that people with disabilities and their families will know what they need from us. More significantly, what we should be looking for is not ways in which the church can be benevolent, but rather ways in which we can empower disabled people to contribute to the life of the church. Indeed, rather than speaking of dependency and independency, we might better refer to interdependency, which highlights the mutuality of giving and receiving. If we make the effort to share the ministry of the church with people with disabilities, we will discover the beauty of interdependence, and have fresh insight into biblical metaphors for the church, such as the Pauline reference to the church as the body of Christ in which each member brings a vital contribution (1 Corinthians 12). In this vision of the church we learn that every member is spiritually gifted and a conduit of divine love[^39]. As Jean Vanier, founder of L’Arche communities, observes, people with disabilities have profound lessons to teach us. When we do include them, they add richly to our lives and immensely to our world.[^40] Reynolds observes similarly that:

> Living out our interdependency is a source of genuine good. It entails caring for others—represented by a range of disabilities—as essential not only to our own flourishing but also to the common good of the communities in which we flourish. Human solidarity is not found inside the cult of normalcy, but rather in sharing space and welcoming each other vis-a-vis a condition of vulnerability[^41].
Choice

The NDIS frames independence by reference to a choice. In practical terms, this means that participants are given the opportunity to choose what supports are needed and who will provide them.\(^\text{42}\) There is widespread discussion in the literature about the challenges this will present to participants, administrators and service providers. There is some concern, for example, that service options may be limited, especially in regional areas.\(^\text{43}\) Some commentators fear the speed of the transition to a new system, and whether staff working to implement the NDIS will have the training and experience needed to help people with disabilities to understand the opportunities and responsibilities that go along with the freedom of choice. There is also apprehension about the ability of people, especially those with intellectual disabilities, to make independent decisions—although this concern does reveal incipient paternalism.

There is certainly irony in the fact that a collective campaign of disabled people created an NDIS based on individualist notions of human rights and a neoliberal framework of ‘a choice-driven, market-dominated economy of services’.\(^\text{44}\) The danger is of a ‘superficial appearance of increased liberty—within which agency and choice are co-opted into an expanded market rationality’,\(^\text{45}\) particularly since neoliberalism assumes the priority of the rational autonomous individual that is potentially problematic in the context of disability. This leads some to suggest that the NDIS offers consumer choice in the place of rights and full participation,\(^\text{46}\) as well as concerns as to whether a neoliberal strategy will ultimately lead the state to move away from its welfare responsibilities.\(^\text{47}\)

For now, it’s enough to note that this choice is what people with disabilities asked for, and early reviews of the rollout suggest that they are feeling empowered as a result.\(^\text{48}\) It is also the case that all of these concerns are matters that will need to be taken up by the NDIA and its interlocutors during the course of its rollout and development. To a certain extent, the NDIS itself will only ever be able to do so much. It is, after all, an insurance scheme constrained by political and financial realities, and focused on funding disability supports. More important than the specifics of the scheme is the potential for attitudinal and cultural changes that might accompany its rollout. It would certainly be an achievement if engaging with disability caused the cultural values of individualism to be reframed by notions of interdependence. Fears about neoliberalism might be offset if Australian
NDIS, the disabled voice, and the church

society came to appreciate and embrace the diversity of our abilities and our interconnectedness. As suggested earlier, these are themes that are (or should be) central to the identity of the church, and it is precisely here that the church has opportunity to speak to and even challenge and reframe the society of which we are a part. Of course, this will only be possible if we model what we preach.

Endnotes


11. It is sometimes considered preferable to say ‘people with disabilities’ because the phrase ‘disabled people’ or ‘disabled person’ seems to define a person by their disability. Given that what we are talking about, however, is social exclusion, the label ‘disabled people’ describes the fact of disabling experience and recognises the collective identity of disabled people who have gotten together to campaign for the NDIS. It is also grammatically boring to always have to use the politically correct phraseology.

12. Again, this phrase references the collective power of the campaign for the NDIS.


17. For a detailed discussion, see Amos Yong, *The Bible, Disability, and the Church: A New Vision of the People of God*, Grand Rapids, Eerdmans, 2011.


29. MacIntyre, *Dependent Rational Animals*, p. 130.
33. Ibid, ch. 8.

45. Ibid.

46. Thill, ‘Listening for Policy Change,’ p. 16.
