

The NDIS at ten years: designing an equitable scheme for the next decade

As the NDIS turns ten, we must make changes to improve scheme equity

The National Disability Insurance Scheme (NDIS) was created to provide reasonable and necessary supports for people with disability under the age of 65 years to live an included and meaningful life on an equal basis with other Australians. The mechanism for this is individualised support plans underpinned by personal budgets that are spent on services purchased from a social care market.

Former Prime Minister Julia Gillard announced the scheme in 2012 and the national roll-out, which began in 2013, was achieved in July 2020.¹ The NDIS is a very significant social policy innovation and its importance for people with disability in Australia cannot be underestimated. For many people with disability, the supports provided through the NDIS have been essential to living an included life.

The scheme was funded in part by an increase in the Medicare Levy, against which there was little initial protest.² However, providing these essential supports has been more costly than originally anticipated by the Productivity Commission.³ The NDIS is expected to cost \$50 billion annually by 2024–2025,⁴ which is higher than the annual budget for either Medicare or defence. Attention to the scheme costs has been mounting, along with attendant fears about cost-cutting to plans.⁵ This has caused mistrust, with fear over cost-cutting to and by the NDIS a factor in community rejection of the now cancelled “independent assessments”.⁶ Even with expanding costs there remains significant concerns about equity within the scheme, with some groups still failing to receive the services that they need in comparison with others. To address these and other concerns, such as access, market and workforce, the federal government has initiated an independent review into the NDIS.

Who is in? Who is out?

There are over 535 000 NDIS participants compared with almost 4.4 million people with disability in Australia, including 2.4 million aged under 65 years,⁷ which means the NDIS can only ever be part of the national disability support landscape. Yet in the early days of its implementation, it became the default disability system as other existing disability supports and approaches were defunded or removed. These supports included successful programs such as Partners in Recovery, which was defunded when most existing participants were not eligible for the NDIS.^{8,9} This has led to a situation where the NDIS is, as Bruce Bonyhady, the original Chair of the National Disability Insurance Agency, calls it, an “oasis in the desert”,¹⁰ with scheme participants receiving support to a much higher level than non-participants. This situation makes people currently eligible desperate to retain NDIS supports and others desperate to become eligible.¹¹ A Tier 2 scheme was originally envisioned



to provide referrals and community assistance so that people not eligible for individual NDIS plans could receive support. However, the Tier 2 scheme has not been effective in delivering this.¹⁰

Current NDIS participants are overwhelmingly young (under 18 years) and male, which is driven by the large number of participants with autism and developmental delay.^{12,13} Participants with a primary autism diagnosis comprise 30.9% of scheme participants, followed by intellectual disability (20.2%) and psychosocial disability (9.1%). Eighty-nine per cent of men aged over 18 years have applications for access approved compared with 80% of women.¹³ Just 37% of NDIS participants are women — substantially lower than the 49% of people with disability aged under 65 years who are women.^{14,13} This raises concerns that the intersectional influence of gender might drive disparities in access.¹⁵

Concerns about utilisation and support

Concerns have been raised about scheme access and utilisation of approved plans (ie, percentage of budgeted supports used), which are lower in some participant groups compared with others, resulting in inequity of access to necessary supports.¹⁶ Although utilisation is not a perfect measure because it relies on planning processes that may in themselves be inequitable, it is clear that utilisation differs by disability type; for example, people with psychosocial disability have an average plan utilisation of 53% compared with 70% for those with autism.¹⁷ A major factor in the disparity in plan utilisation is due to the failure of markets to function where participant needs necessitate more specialised supports, which come at higher costs to providers, and in areas where there are poor economies of scale.^{18,19} Plan utilisation is higher for people in metropolitan than regional and remote areas (eg, only 11% plan utilisation for people with psychosocial disability in the Far West region of New South Wales).²⁰ Interestingly, some populations that

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are traditionally underserved in health and social care receive good access to the NDIS, with culturally and linguistically diverse people with disability having higher than average plan spending and utilisation.¹⁷ This may be a function of rurality, with most of this population resident in metropolitan areas.¹⁷

Differences in use of plans, for some groups of people with disability compared with others, underline the fact that the scheme functions better for people with support needs that are relatively straightforward and can receive support from less specialised, more generic services and support workers. In an exploration of plan utilisation by people with psychosocial disability, a 2022 study found that utilisation of plans is affected by both individual and broader systemic conditions, including available workforce.²¹ Workforce planning to ensure more equitable access for people with more complex needs is therefore one part of the strategy for addressing this deficit.²² Much of the NDIS workforce do not have specialised qualifications in disability, which makes them an easier workforce to come by and a workforce that is therefore cheaper for services to employ compared with experienced or qualified workers (and with wage costs reduced, enables easier profits). This can mean that the quality of support is lower even for those with lower support needs because the workforce may have limited knowledge of disability and have low expectations of what people with disability want and need to do, for example, beyond assisted showers, walks around the neighbourhood, and some social conversation. Participants prefer experience specific to their needs.²³ Relevant experience does not necessarily come from training but may come from lived experience of disability and disability support, with many people prioritising interpersonal skills over qualifications in disability.²⁴ Without an experienced workforce, people with complex language and communication disability (including one of the authors of this article with deaf-blindness), for instance, will not have their needs understood and so remain marginalised. There is a fear that ill-informed service providers sometimes act as gatekeepers denying supports that people with disability, the true experts, know they need: “They need to be able to have walked in our shoes”.²⁵ These workforce deficiencies are structural problems enabled by deficiencies in the market structure that accompanies the NDIS and must be addressed to provide equity for people with disability.²⁶

Aboriginal and Torres Strait Islander people with disability

There are also cultural barriers to equity in the operation of the NDIS, with lower levels of plan utilisation in Indigenous people with disability.¹⁷ There are a number of reasons for this, including the number of Indigenous people living outside of major cities (56.8% v 31.6% non-Indigenous) and in remote areas (9.8% v 0.8%).¹⁷ NDIS planning processes are fraught with challenges for Indigenous people living in regional and remote areas. The process of providing evidence of disability often causes significant stress and trauma.^{27,28} The principle and process of providing evidence is

situated in a deficit model, requiring people to prove the experience of disability as a burden. This model of disability is the antithesis of Indigenous cultural ways of experiencing disability where disability is interpreted as part of the diverse human experience as opposed to a limitation or impediment.^{27,28} The NDIS is also designed on Western-centric assumptions that all people with disability exist at the same starting line: house, shelter, food, family support. Many Indigenous people with disability are homeless, living in poverty or in overcrowded houses.²⁹⁻³¹ To address equity for this group there needs to be Indigenous-controlled service providers who generate whole-of-life case management to help Indigenous people with disability who are living in disadvantage understand and access the scheme.³²

What next?

Inherent in these tensions is a concern that a scheme that should be agnostic to diagnosis and provide support based on individual needs does not work well for those with more complex needs or whose experiences do not fit mainstream ways of understanding or experiencing disability. The NDIS is one mechanism through which Australia fulfils its obligations under the United Nations Convention on the Rights of Persons with Disabilities.³³ Under the UN Convention, rights should be equitable, so should not be better enjoyed by people with some types of disability or needs over others.

Equity decisions should not be outsourced to a market where decisions of profit compete with decisions about equitable service access. In order to ensure equitable disability support, we need to consciously build a disability support system (including the NDIS) that i) ensures that decisions with equity consequences do not rely on the goodwill of service providers but are a product of market design, and ii) that provides a cohesive system structure that enables access to necessary services for people with disability sitting outside the NDIS (including people aged over 65 years). The National Disability Insurance Agency has significant existing powers to make decisions affecting scheme equity through scheme redesign to address underutilisation and, at a micro-level, through decisions relating to individual participants. Key to realising equity is an adaptive approach to the design of social care markets where all parts of the market are not treated in the same way.²⁶ This approach means that the areas of disability support that work best within a traditional market environment may continue to function in that way but with government directing markets in a proactive way to provide supports for people with complex or unique needs. This could include increased pricing for services for particular groups or locations or appointing providers to deliver services where markets do not emerge to provide services. We urgently need evidence for how this can be done successfully.³⁴

It is critical that issues of equity for people with disability, both within and outside the NDIS, are brought to the fore in the current NDIS review. A failure to address inequity within the operation and

design of disability support means that the NDIS will continue to perpetuate the disabling and ableist structures that marginalise people with disability in the Australian society.

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