

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

IN REPLY: Thank you to Hill et al,¹ Bailie et al² and Malbon et al³ for their interest in our article.⁴ These letters raise further significant issues which must be addressed to ensure that the National Disability Insurance Scheme (NDIS) is equitable.

Hill and colleagues discuss the very significant issue of access to support under the NDIS for psychosocial disability and draw attention to suicide statistics for this group as a further indicator of inequity.¹ They comment that people with psychosocial disability receive fewer supports in areas that might bring about greater recovery, and address the broader health equity impacts of a failure to provide adequate, evidenced, psychosocial supports for this group (within the NDIS and beyond). This is an important point that underlines a key area for scheme reform. Currently, there is little information available to people with psychosocial disability, and those supporting their NDIS plan development, to understand which supports are available and which are more likely to promote recovery in the context of their own lives. In April 2023, the Minister for the NDIS, Bill Shorten, highlighted the need for evidence that links supports to outcomes,⁵ and in the 2023–24 budget, the Australian Government committed \$29.3 million to increasing the uptake of evidence-based supports in the NDIS and \$24.6 million for trialling a blended payment model, which in part aims to encourage NDIS providers to provide better evidence-based supports that will increase outcomes.⁶ These are important steps but will need significant research behind them.

Currently, the evidence for evidence-based supports is not there or is not easily brought together in a form useful to scheme participants. Evidence of outcomes from existing plan utilisation is either not mapped or has not been made available to researchers. Furthermore, our research completed for the National Disability Research Partnership, which mapped existing disability-related research in Australia,

showed that evidence for what works in many areas of Australian disability support is still lacking.⁷ Research is clearly needed, including qualitative research that provides evidence about the experiences of participants. This research must, as highlighted by Bailie and colleagues,² also bring together linked administrative and disability data. Bailie and colleagues suggest a “disability identifier” such as that discussed by Fortune and colleagues, which would allow disability to be more easily identified in administrative datasets.⁸ This would enable us to understand the impact of the NDIS on addressing inequity through social and economic participation more broadly, by tracking outcomes for people with disability in a broad range of administrative datasets. It would also help us to understand whether specific groups of participants, including rural and Aboriginal and Torres Strait Islander participants, are more or less likely to achieve the outcomes of other participants.

The points made by Malbon and colleagues focus on the involvement of people with disability in scheme reform. They rightly highlight that this knowledge is not only essential at all stages of NDIS development but also in scheme implementation and research.³ Our article included an authorship team with two people with disability, including an author with lived experience as an NDIS participant.⁴ This knowledge is invaluable because it situates our understanding of scheme design in the lived reality of the end users of the scheme. The increasing involvement of people with disability in the National Disability Insurance Agency, which runs the NDIS, is rightly viewed as an important step in the growth of this organisation and in improving scheme implementation and design.

Malbon and colleagues³ draw attention to key principles for including lived experience in scheme design.⁹ The second of these, to “make scheme design information accessible to people with disability”, supports the need for information on outcomes to be available to participants. Creating a scheme that enables participants to

make an informed choice about how plans are made and utilised, by drawing on accessible evidence, will enhance scheme equity because participants themselves, along with their family members and other supports, are best placed to understand which supports are able to meet their needs. Enabling informed decision making in health and social care is therefore both an important practical step, and an ethical duty that must be built into the reform of the NDIS.

Jennifer Smith-Merry 

Centre for Disability Research and Policy, University of Sydney, Sydney, NSW.

jennifer.smith-merry@sydney.edu.au

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