

Committee Secretary
Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6021
Parliament House
Canberra ACT 2600

26 September 2020

RE: Inquiry into General issues around the implementation and performance of the NDIS

Dear Committee Secretary,

The Australian National University Law Reform and Social Justice Research Hub ('**ANU LRSJ Research Hub**') welcomes the opportunity to provide this submission to the Joint Standing Committee on the National Disability Insurance Scheme ('NDIS') regarding general issues around the implementation and performance of the NDIS.

The ANU LRSJ Research Hub falls within the ANU College of Law's Law Reform and Social Justice program, which supports the integration of law reform and principles of social justice into teaching, research and study across the College. Members of the group are students of the ANU College of Law, who are engaged with a range of projects with the aim of exploring the law's complex role in society, and the part that lawyers play in using and improving law to promote both social justice and social stability.

Summary of Recommendations:

1. The NDIS should increase reporting of cultural and community engagement with Aboriginal and Torres Strait Islander communities.
2. The NDIS should increase research into rates of NDIS uptake amongst Aboriginal and Torres Strait Islander people, and gather data on barriers to enter the NDIS scheme for minority groups.
3. The NDIS should update guidelines with respect to cultural competency and implement a process by which NDIA staff and contractors can have their cultural competency reviewed.
4. The NDIS should be expanded to include all New Zealanders resident in Australia paying the Australian Medicare Levy and their dependents such as children.

If further information is required, please contact us at

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I INTRODUCTION

The National Disability Insurance Scheme ('NDIS') presents the opportunity for the Australian community to access disability information, connections and services from one centralised body. The NDIS has been instrumental in the reform of Australia's disability services.

Noting that Indigenous and Culturally Diverse Australians will face many challenges to accessing the NDIS and disability support services in general,¹ this submission condenses its focus to these specific aspects of the scheme: service delivery, data collection, eligibility for the scheme and cultural competency. Our submission focuses on Indigenous Australians, Culturally and Linguistically Diverse ('CALD') Australians and the expansion of the scheme to New Zealanders living in Australia.

The NDIS deserves praise for its attempts to engage with Aboriginal and Torres Strait Islander People, and CALD Australians.² Nonetheless, various issues with the scheme persist for Indigenous and Culturally Diverse Australians. Policy-makers ought to ensure that the NDIS works in a manner that continues to promote the best interests of those who have historically struggled to access disability support.

II BACKGROUND

It is well documented that Indigenous and CALD communities face disproportionate challenges when accessing disability support services.³ Ensuring effective engagement with these communities so that services can be delivered in an efficient and culturally sensitive way is therefore vital to dismantling barriers to access, and promoting policy success surrounding disability support services.

2.1 *Challenges Facing Disabled Indigenous Australians*

The rate of disability amongst Indigenous people is approximately 1.5 to 2 times that of non-Indigenous people.⁴ Despite this, Indigenous Australians remain under-represented in the disability service participation rate. As of 30 June 2019, there were 16,417 Indigenous participants in the NDIS, making up 5.7% of all active participants in the NDIS.⁵ This comes despite the fact disability prevalence rates for Indigenous Australians is relatively higher than

¹ See, eg, Angeline Ferdinand et al, *Understanding Disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities* (Report, Melbourne School of Population and Global Health, May 2019).

² National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Engagement Strategy* (Report, 2017)

³ Angeline Ferdinand et al, *Understanding Disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities* (Report, Melbourne School of Population and Global Health, May 2019).

⁴ National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Participants* (Report, 30 June 2019); Australian Bureau of Statistics, 'Australian and Torres Strait Islander People with Disability' (Web Page, 8 May 2020)

<<https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features802015?OpenDocument>>.

⁵ Ibid.

non-Indigenous Australians (approximately 23.9% as opposed to 17.5%).⁶ Part of this difficulty is due to physical barriers of access such as geographic location, but also because of other social and economic factors that are linked to Indigenous persons' historic experience of dispossession and colonisation.⁷ The social distrust of government services that has occurred as a result of this experience means that the NDIA's engagement with Indigenous communities will need to overcome unique cultural challenges.⁸ Ensuring this cultural engagement is conducted appropriately and monitoring consistently will therefore be critical to its effectiveness.⁹

2.2 Challenges Facing Other CALD Communities

Other CALD communities confront similar challenges to those faced by the Indigenous community. There are gaps in terms of cultural competency, language barriers and awareness of the scheme.¹⁰ Often, people have recently migrated to Australia and are unfamiliar with the available government schemes, many coming from societies where there is widespread mistrust towards government. Furthermore, people within CALD communities may be hesitant to identify as having a disability,¹¹ preventing them from accessing a scheme like the NDIS. This submission will highlight how the NDIS can be doing better for such communities.

III MEASUREMENT, RESEARCH, REPORTING AND TRACKING PROGRESS FOR INDIGENOUS COMMUNITIES

One of the hallmarks of good policy is transparency. Effectively monitoring and measuring the effectiveness of the NDIS is crucial to its success. As various NDIS reports themselves have acknowledged, 'effective communication and information sharing directly educates and informs participants, the community and stakeholders' about various policy measures'.¹² For Indigenous people, who have historically suffered disproportionately worse outcomes with respect to disability policy,¹³ this monitoring is especially important.

⁶ Australian Bureau of Statistics, 'Australian and Torres Strait Islander People with Disability' (Web Page, 8 May 2020) <<https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features802015?OpenDocument>>.

⁷ John Gilroy et al, 'Need for an Australian Indigenous Disability Workforce Strategy: Review of the Literature' (2017) 39(16) *Disability and Rehabilitation* 1664 – 1673.

⁸ Ibid.

⁹ Ibid.

¹⁰ Refugee Council, *Barriers and Exclusions: The support needs of newly arrived refugees with a disability* (Report, 15 March 2019) <<https://www.refugeecouncil.org.au/disability-report/12/>>.

¹¹ See, eg, Keah Brown, 'Disabled People of Colour Struggle to be Heard,' *The Establishment* (14 October, 2016) <<https://theestablishment.co/disabled-people-of-color-struggle-to-be-heard-b6c7ea5af4b4/index.html>>.

¹² National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Engagement Strategy* (Report, 2017) 17.

¹³ See, eg, Michelle DiGiacomo et al, 'Childhood disability in Aboriginal and Torres Strait Islander peoples: a literature review' (2013) 12(7) *International Journal for Equity in Health* 1.

The NDIS should be praised for the various steps it has taken to promote transparency in its policy implementation for various minority groups. The June 2019 report on *Aboriginal and Torres Strait Islander Participants* in the NDIS is particularly commendable.¹⁴

However, this measurement scheme suffers from several defects. Rectifying these issues, and promoting more culturally specific research metrics, would enhance the effectiveness of the NDIS.

3.1 Greater Reporting of Cultural and Community Engagement with Aboriginal and Torres Strait Islander Communities

The NDIS has established its commitment to engaging with various Aboriginal and Torres Strait Islander communities when implementing its policy scheme. For instance, the NDIS' 2017 *Aboriginal and Torres Strait Islander Engagement Strategy*, emphasised that the NDIS intends to 'engage with Aboriginal and Torres Strait Islander peoples in a way that supports their involvement' in the policy scheme.¹⁵ Goals listed in the report include:

- The introduction of various NDIS programs into the community 'by a trusted community member', by ensuring that 'community leaders' connect and interact with the 'NDIA and staff';¹⁶
- Creating the 'participant-centric design' of the program, ensuring that the 'experience of Aboriginal and Torres Strait Islander participants, their carer and communities can inform the implementation of the NDIS';¹⁷
- Promoting 'local solutions' through a 'listen, learn, build and deliver' approach to the implementation of the NDIS;¹⁸
- Developing rural and remote strategies to better target the unique needs of isolated Indigenous communities.¹⁹

These are important and worthwhile goals. Prior research demonstrated that appropriate community consultation is important to ensuring the success of policy implementation in Indigenous communities.²⁰ Evidence also indicates that Indigenous Australians are less likely to seek-out assistance on their own accord.²¹ Therefore, effective engagement with community leaders, and the creation of 'local solutions', will likely enhance the NDIS.

¹⁴ National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Participants* (Report, 30 June 2019).

¹⁵ National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Engagement Strategy* (Report, 2017) 6.

¹⁶ Ibid 15.

¹⁷ Ibid 18.

¹⁸ Ibid.

¹⁹ National Disability Insurance Agency, *Rural and Remote Strategy: 2016-2019* (Report, February 2016).

²⁰ Michelle Dunbar et al, 'Clear not simple: An approach to community consultation for a maternal pneumococcal vaccine trial among Indigenous women in the Northern Territory of Australia' (2007) 25(13) *Vaccine* 2385; Andrew Guilfoyle et al, 'Culturally Strong Childcare Programs for Indigenous Children, Families and Communities' (2010) 35(3) *Australasian Journal of Early Childhood* 68; Northern Territory Government, *Northern Territory Aboriginal Justice Agreement 2019-2025* (Report, Department of the Attorney-General and Justice, 2019).

²¹ See, eg, Megan Price and John Dalglish, 'Help-seeking among Indigenous Australian adolescents: Exploring attitudes, behaviours and barriers' *Youth Studies Australia* (2013) 32(1) *Youth Studies Australia* 10.

Despite the importance of this community engagement, there has been little reporting on the uptake of these goals. Existing reports primarily examine the rate of Indigenous uptake of the NDIS,²² and the nature of any payments made.²³ However, no formal NDIS reporting has detailed the rate or effectiveness of community consultation. Nor have any NDIS reports mentioned the participant-centric nature of the scheme, or any attempted local solutions.

A lack of available evidence is particularly problematic in the context of remote Indigenous communities. Anecdotes of wheelchairs being provided in rural communities without footpaths,²⁴ and evidence of a significant number of disabled Aboriginal and Torres Islander people relying on unpaid, non-expert advice and assistance to assist with their disability,²⁵ are worrying. A lack of available evidence on the NDIS' interactions with rural communities therefore seems highly problematic. A more rigorous assessment of the NDIS roll-out to remote Aboriginal and Torres Strait Islander communities is needed.

Without this information, it is impossible to measure and evaluate the effectiveness of NDIS community consultation. The prevalence and appropriateness of community implementation of programs cannot be discerned without further information. Given that one of the stated goals of the NDIS is to promote better 'communication and information sharing' about the program,²⁶ we would encourage greater reporting of how the NDIS engages with various Aboriginal and Torres Strait Islander Communities. With greater information, more rigorous assessment of these strategies can be made.

Recommendation 1: Increase reporting of cultural and community engagement with Aboriginal and Torres Strait Islander communities.

3.2 Increase research into rates of NDIS uptake amongst Aboriginal and Torres Strait Islander People

A related, but separate, recommendation stems from the metrics of effectiveness used by the NDIS.

Currently, the primary measurement of the effectiveness of the NDIS for Aboriginal and Torres Strait Islander people involves an assessment of 'how outcomes have changed for participants between their point of entry into the NDIS, and after their first year in the scheme'.²⁷ This metric

²² National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Participants* (Report, 30 June 2019) 24.

²³ Ibid 37.

²⁴ Scott Avery, 'Indigenous people with disability have a double disadvantage and the NDIS can't handle that' *The Conversation* (online, 8 October 2018) <<https://theconversation.com/indigenous-people-with-disability-have-a-double-disadvantage-and-the-ndis-cant-handle-that-102648>>.

²⁵ Nicholas Biddle et al, *Indigenous Australians and the National Disability Insurance Scheme* (Australian University Press, 2014); John Gilroy, 'Understanding the NDIS: The Scheme Does not Yet Address all the needs of Indigenous People with Disabilities' *The Conversation* (online, 8 July, 2016) <<https://theconversation.com/understanding-the-ndis-the-scheme-does-not-yet-address-all-the-needs-of-indigenous-people-with-disabilities-57572>>.

²⁶ National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Engagement Strategy* (Report, 2017) 17.

²⁷ Ibid 50.

is appropriate and effective in measuring the effectiveness of the NDIS for those who have joined the program.

However, there is comparatively less data on the broader uptake of the scheme amongst Aboriginal and Torres Strait Islander people. Little research has been conducted into those who *could be* eligible for the scheme but are not accessing available services and programs.

Measurement of the uptake of available programs is particularly important in the context of Indigenous communities. Research demonstrates that Aboriginal and Torres Strait Islander people are less likely to take-up policy opportunities.²⁸ In the context of Aboriginal and Torres Strait Islander people, preliminary research indicates that a lack of uptake in the NDIS may be problematic. Almost 45% of Aboriginal and Torres Strait Islander aged 15 years or over live with a disability or restrictive long-term health condition (approximately 225,000 people).²⁹ A further 8% aged 15 or above live with a 'profound or severe disability' (approximately 42,240 people).³⁰ Yet, as of 30 June 2019, only 16,417 participants in the NDIS were Indigenous participants.³¹

This low rate of uptake is concerning and deserves closer scrutiny. Further research into rates of uptake amongst Aboriginal and Torres Strait Islander people, and analysis of any barriers to accessing the NDIS scheme, seems warranted.

Recommendation 2: Increase research into rates of NDIS uptake amongst Aboriginal and Torres Strait Islander people, and gather data on barriers to enter the NDIS scheme for minority groups.

Recommendations 1 and 2 work to strengthen our knowledge and understanding of the unique challenges facing disabled Aboriginal and Torres Strait Islander people. The NDIS should be commended for its previous attempts to engage Indigenous communities with this policy scheme, particularly in remote parts of Australia. However, in order to be most effective, accurate monitoring and reporting on these strategies must occur.

²⁸ See, eg, Margaret Kelaher et al, 'Comparison of the Uptake of Health Assessment Items for Aboriginal and Torres Strait Islander people and other Australians: Implications for Policy' (2005) 2(1) *Australia and New Zealand Health Policy* 1; Karen L Gardner et al, 'Understanding Uptake of Continuing Quality Improvement in Indigenous Primary Health Care: Lessons from a Multi-Site Case Study of the Audit'.

²⁹ Australian Bureau of Statistics, *Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People Living with Disability* (Report, 4714.0: National Aboriginal and Torres Strait Islander Social Survey, 2014-15) <

³⁰ Ibid.

³¹ National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Participants* (Report, 30 June 2019) 7.

IV ENSURING AND ENHANCING CULTURAL COMPETENCY

One of the key objectives of the NDIS has been to deliver services in a culturally competent manner. There are numerous reasons why we might think that cultural competency is important when delivering the NDIS.

First, cultural competency can ensure appropriate engagement with customary practices that are not easily understood by non-Indigenous Australians.³² Where culturally competent practices are in place community engagement tends to be more effective.³³ Aboriginal and Torres Strait Islander people are more likely to engage with programs where they know they will be treated respectfully, fairly and appropriately.³⁴ Moreover, cultural competency can improve policy outcomes within the NDIS. By improving health workers awareness, knowledge and skills, we can better prepare workers to interact in complex, cross-cultural environments.³⁵ Given the unique experience of Indigenous Australians with government services, the consequences of failing to deliver services in a culturally competent manner could be severe. Cultural competency is thus a key part of 'closing the gap'.³⁶

The NDIS should be commended for acknowledging the risks facing Indigenous Australians and for its commitment to being a culturally competent organisation. One of the key pillars of its *Aboriginal and Torres Strait Islander Engagement Strategy* remains the development of culturally competent practices.³⁷ The report specifically states that 'all NDIA staff, NDIA partners (including LACs), suppliers, providers and contractors' should have some form of cultural competency training.³⁸

However, various anecdotal reports indicate that this objective has not yet been uniformly achieved by the NDIS. Advocate organisations have detailed instances where incorrect interpreters have been used or incorrect cultural assumptions have been made by NDIA staff.³⁹ This is particularly concerning with respect to contractors under the scheme, since participants are often exposed to contractors at particularly vulnerable points in their engagement with the NDIS, such as internal reviews. Anecdotal reports from several law students who have been contracted under the scheme to conduct internal reviews of claims have suggested that their training was insufficient with respect to cultural competency. In some cases, students received only a brief reference to cultural competency as part of their initial training procedures.

³² National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Engagement Strategy* (Report, 2017) 10.

³³ John Gilroy et al, 'Need for an Australian Indigenous Disability Workforce Strategy: Review of the Literature' (2017) 39(16) *Disability and Rehabilitation* 1665.

³⁴ Ibid.

³⁵ Ibid.

³⁶ Lisa Hindman, 'Disability Continues to be a Forgotten Target as Closing the Gap Report Released in Canberra' (Report, First Peoples Disability Network Australia, 2019) <<https://fpdn.org.au/disability-continues-to-be-forgotten-as-a-target-area-under-closing-the-gap/#:~:text=For%20a%20policy%20that%20aspires,headed%20down%20the%20same%20path.>>.

³⁷ National Disability Insurance Scheme, *Aboriginal and Torres Strait Islander Engagement Strategy* (Report, 2017).

³⁸ Ibid 17.

³⁹ Ethnic Disability Advocacy Centre, *Submission to Joint Standing Committee on National Disability Insurance Scheme* (Submission to the Joint Select Committee on General Issues Around the Implementation and Performance of the NDIS, 2020).

The lack of any empirical metrics to measure cultural competency is concerning. There is a risk that, without further reporting and detailing, breaches of cultural competency standards will continue. It is therefore important that cultural competency within the NDIA is continually updated and monitored.

Recommendation 3: The NDIS should update guidelines with respect to cultural competency and implement a process by which NDIA staff and contractors can have their cultural competency reviewed.

V NEW ZEALANDERS LIVING IN AUSTRALIA

The NDIS is partially funded through the Australian Medicare Levy. Currently, New Zealand citizens that lawfully reside in Australia are entitled to Medicare, and they pay the Medicare Levy and the Medicare Levy surcharge if their income is above the requisite tax threshold.⁴⁰ However, in order to access the NDIS, a person must be an Australian citizen, hold a permanent visa or hold a protected Special Category Visa card.⁴¹ This means that many New Zealanders who help to fund the NDIS are unable to access this scheme. Changes made in 2001 mean that New Zealanders on a Special Category Visa after 2001 are locked out of Australian social security and welfare payments.

OzKiwi, a lobby group for New Zealanders living in Australia, estimates that approximately 250 000 to 350 000 New Zealanders in Australia are unable to access the NDIS even though they have to pay the Medicare Levy.⁴² This also disproportionately impacts children as children born in Australia to non-protected New Zealand citizens are not eligible for the NDIS until they are able to become citizens at the age of 10. Many (otherwise eligible) children who are born in Australia miss out on the scheme, due to their parents' residence status.

Ultimately, it seems somewhat perverse that individuals who help pay for the scheme, and would otherwise be eligible to receive its benefits, are currently prevented from accessing the NDIS by virtue of their citizenship requirements. The scheme should be expanded in order to provide services for all individuals who pay the Medicare Levy and thus contribute to the funding of the scheme.

Recommendation 4: The NDIS should be expanded to include all New Zealanders resident in Australia paying the Australian Medicare Levy and their dependents such as children.

⁴⁰ Parliament of Australia 'New Zealanders in Australia: a quick guide', *APH* (Web Page, 29 August 2016) <
https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/NZAust>.

⁴¹ OzKiwi 'The National Disability Insurance Scheme (NDIS)', *OzKiwi* (Web Page, 12 June 2017), <
<http://www.ozkiwi2001.org/2017/06/the-national-disability-insurance-scheme/?>>.

⁴² OzKiwi 'The National Disability Insurance Scheme (NDIS)', *OzKiwi* (Web Page, 12 June 2017), <
<http://www.ozkiwi2001.org/2017/06/the-national-disability-insurance-scheme/?>>.