



Australia's National Institute for Aboriginal
and Torres Strait Islander Health Research

Independent Review of the National Disability Insurance Scheme submission

Submission to the Independent Review Panel

The Lowitja Institute, January 2022

Independent Review of the National Disability Insurance Scheme
Independent Review Panel

Dear Independent Review Panel,

Re: Independent Review of the National Disability Insurance Scheme submission

The Lowitja Institute is Australia's national institute for Aboriginal and Torres Strait Islander health research, named in honour of our Patron, Dr Lowitja O'Donoghue AC CBE DSG. We welcome the opportunity to provide a submission to the Independent Review Panel's NDIS Review.

The Lowitja Institute has long advocated for national awareness and action on the social and cultural determinants of health and wellbeing. Significant to implementing cultural determinant driven health policy is the recognition that policy making must be anchored in Aboriginal and Torres Strait Islander ways of knowing, being and doing, and that self-determination is essential for a holistic approach to bettering the health and wellbeing of our communities.

Such an approach is vital in the context of disability; our peoples have significantly higher rates of disability compared with the non-Indigenous population. Our peoples also experience multiple barriers to accessing services, including disability services. The reduced quality of life that our people experience as a result is attributable to policy failures; this includes a failure to recognise the importance of cultural safety and the profound health impacts of racism and discrimination. We hope that this Independent Review is a foundational step to rectifying this.

Please find our submission attached. We would welcome the opportunity to further discuss any of the issues contained therein.

Warm regards



Dr Janine Mohamed
CEO, Lowitja Institute



About the Lowitja Institute

The Lowitja Institute is a national Aboriginal and Torres Strait Islander Community Controlled Organisation working for the health and wellbeing of Australia's First Peoples through high impact quality research, knowledge translation, and by supporting Aboriginal and Torres Strait Islander health researchers.

Established in January 2010, we operate on the key principles of Aboriginal and Torres Strait Islander leadership, a broader understanding of health that incorporates wellbeing, and the need for the work to have a clear and positive impact.


The Lowitja Institute has a longstanding commitment to the National Agreement on Closing the Gap, as members of the Coalition of Peaks, National Health Leadership Forum and the Close the Gap Steering Committee, including authoring the Close the Gap Report over the past 4 years.

Based on this experience we offer the following general comments and note some specific issues for consideration.

General preamble

As Aboriginal and Torres Strait Islander peoples, we have maintained sophisticated and diverse cultures and knowledge systems for millennia. We also established and adhered to sophisticated systems of law and lore, which maintained our nations and the health and wellbeing of our peoples.

Over millennia we have cared for Country and for our communities in this place now called Australia. We have maintained our health and wellbeing with holistic approaches aimed simultaneously at community and individual health and wellbeing. Despite the traumatic and ongoing consequences of colonisation and institutional racism, we continue to revitalise, maintain and develop our cultures and knowledge systems, strive towards improved health and wellbeing, and we continue to rebuild our nations.



From the early days of European settlement in Australia in 1788, racism against our peoples has taken many forms, including murder, exploitation and dispossession from our traditional lands and cultures. Our peoples were forced onto missions and reserves, breaking apart our communities and nations, and the systems that were in place to self-govern. Discriminatory and racist policies stopped our peoples from being able to practice our holistic approaches, eroding our health and wellbeing. Modern dominant cultural policy approaches were built on this legacy and policymaking is often inappropriate and excludes our peoples and communities.

In 2019, the Lowitja Institute funded a comprehensive evaluation of the NDIS, which was conducted by the Centre for Health Policy, Melbourne School of Population and Global Health, University of Melbourne. This review, *Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities* (Ferdinand, 2019) found that

[T]he NDIS has the potential to significantly benefit Aboriginal and/or Torres Strait Islander people living with disability. However, there remain significant issues in the on-the-ground implementation of the NDIS, particularly in remote locations.¹

The upshot of the review was that the following are vital to ensuring that the NDIS works effectively and is accessible for Aboriginal and Torres Strait Islander peoples:²

- ⦿ Cultural safety. Our peoples are more likely to experience unfair treatment, and avoid the places where they have experienced such treatment. We are more likely to experience violence, threats and removal from our natural families.
- ⦿ Community engagement. Aboriginal and Torres Strait Islander peoples have been surprised by initial NDIA staff contact and experience confusion and fear about meeting outcomes. Community buy-in is also vital to the proper functioning of the NDIS in our communities.

¹ Ferdinand et al. 2019, *Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities*, Melbourne University, Melbourne, p. 7. Accessed on 19 January 2023 at:

https://www.lowitja.org.au/content/Document/20190905_NDIS%20Report_final.pdf

² Lowitja Institute 2019, *Understanding Disability Through the Lends of Aboriginal and Torres Strait Islander peoples*, Lowitja Institute, Melbourne, p. 2. Accessed on 19 January 2023 at: [Lowitja UnderstandingDisability 291019 D4 WEB.pdf](#)

- ⦿ Greater understanding and resources to support participants and their families.
- ⦿ Clear communication and representation of participant needs when participants speak languages other than English.
- ⦿ Good quality participant plans that include cultural elements.
- ⦿ Uptake of funding and supports available to participants and no reduction in funding and supports available in new plans due to underutilisation in the previous year. Underutilisation is often tied to lack of access to supports in remote locations.
- ⦿ Increase in appropriate providers in remote areas with seed funding available for the required organisation change and administrative burden.

The review notes,

In remote areas, a funding approach able to accommodate the realities of remote Aboriginal community life, taking into account issues such as thin markets, support provider needs, and issues related to employment and training opportunities for local people, is necessary. Better support provision by governments, and more collaboration with and between support providers is needed. Features of this model would include more flexibility around support coordination, respite (short term accommodation), and transport.³

We encourage the Independent Review Panel to read the review in full because many of the issues presented and findings will still be relevant today.⁴

Issues of note


Cultural Safety

Aboriginal and Torres Strait Islander peoples' approach to health and wellbeing is holistic, placing equal emphasis on physical, social, emotional and cultural wellbeing, which are interconnected.⁵ Disability also needs to be

³ Ibid.

⁴ Ferdinand et al. op cit.

⁵ Salmon et al., 2019, Defining the indefinable: descriptors of Aboriginal and Torres Strait Islander Peoples' cultures and their links to health and wellbeing, Aboriginal and Torres Strait Islander Health Team, Research School of Population Health, The Australian National University, Canberra, p. 1.



understood through this holistic lens, which centres culture, community and Country.

It is widely acknowledged by Aboriginal and Torres Strait Islander experts and peak health organisations that 'social and cultural determinants' impact significantly on the health and wellbeing of our peoples and communities. These factors are key to closing the gap on our peoples' health and wellbeing outcomes, which has been acknowledged by the National Agreement on Closing the Gap 2021.⁶

Our culture comes from our lore, a very deep and sacred place. The cultural determinants of our health provide many of the remedies for Aboriginal and Torres Strait Islander health equity and these determinants should be respected, understood and embraced by all.

June Oscar, Aboriginal and Torres Strait Islander Social Justice Commissioner 2020

Further, the Mayi Kuwayu study is an Aboriginal and Torres Strait Islander led research project that is building a stronger evidence base for the importance of cultural determinants of health and wellbeing.⁷ The study is based on Indigenous Data Sovereignty principles and Participatory Action Research methods. This study is generating strong evidence that the cultural determinants are key to social and emotional wellbeing.

The cultural determinants of health constitute a conceptual framework based on Indigenous knowledge, spanning multiple portfolios beyond health and include these six domains:⁸

- ⊗ connection to Country
- ⊗ family, kinship and community
- ⊗ Indigenous beliefs and knowledge
- ⊗ cultural expression and continuity
- ⊗ Indigenous language

⁶ It is worth noting that there is no specific target for disability in the National Agreement on Closing the Gap 2021. Some Aboriginal and Torres Strait Islander Stakeholders –the First Peoples' Disability Network is a leading voice – are calling for a disability-specific target.

⁷ [About Mayi Kuwayu - Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing - ANU \(mkstudy.com.au\)](https://www.mkstudy.com.au)

⁸ Lowitja Institute 2020, Culture is Key: Towards cultural determinants-driven health policy – Final Report, Lowitja Institute, Melbourne. Viewed on 22 June 2022 at [Lowitja CultDefReport 210421 D14 WEB.pdf](#)

- ⦿ self-determination and leadership.

These determinants can be influenced, and any adverse impacts ameliorated through sound policy changes⁹ and system reform. Further, the right to practice culture, traditions and customs is outlined across a number of Articles included in the United Nations Declaration of the Rights of Indigenous Peoples and should be affirmed in developing and implementing health policy; this includes disability policy.

Cultural safety centres the cultural determinants of health and as such, improving cultural safety leads to improved health and wellbeing outcomes. Cultural safety also reduces barriers to service access and increases service uptake for our peoples.

Recently, cultural safety has started to gain traction in mainstream health organisations at a national level, as well as with Government. For example, cultural safety has been incorporated into the following:

- ⦿ National Aboriginal and Torres Strait Islander Health Plan (NATSIHP) 2013-2023
- ⦿ The Implementation Plan for the NATSIHP
- ⦿ The National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework 2016-2023
- ⦿ The Australian Health Practitioners Regulation Agency has a cultural safety strategy (AHPRA 2020).

While cultural safety supports positive health outcomes, it must also be recognised that a lack of cultural safety has significant detrimental health and wellbeing impacts, both directly and indirectly. For example, the *Mayi Kuwayu* study has been looking at our peoples' experiences of, and the health impacts, of racism. Their 2021 study comprehensively explored and provided evidence for the strong links between racial discrimination and our peoples' health and wellbeing outcomes.¹⁰

⁹ Ibid, p. x.

¹⁰ Thurber et al. 2021, Prevalence of Everyday Discrimination and Relation with Wellbeing among Aboriginal and Torres Strait Islander Adults in Australia, *International Journal of Environmental Research and Public Health*, vol. 18, issue 6577, pp. 12 & 16. Accessed 19 January 2023 at: <https://mkstudy.com.au/wp-content/uploads/2021/06/Prevalence-of-Discrimination.pdf>, p. 13.

In terms of the health and wellbeing impacts of racial discrimination, the study found that there are links to:¹¹


- ⊗ Social and Emotional Wellbeing
 - General mental health
 - Anxiety
 - Depression
 - Psychological distress
- ⊗ Physical health (general health)
- ⊗ Health behaviours
 - Smoking
 - Alcohol use
 - Gambling
- ⊗ Key health conditions
 - Heart disease
 - High cholesterol
 - High blood pressure
 - Diabetes
- ⊗ Cultural and spiritual wellbeing
 - Feeling torn between cultures
 - Feeling disconnection from culture
 - Choosing not to identify as Aboriginal or Torres Strait Islander.¹²

A recent article published in *The Lancet*, *Population-level contribution of interpersonal discrimination to psychological distress among Australian Aboriginal and Torres Strait Islander adults, and to Indigenous–non-Indigenous inequities: cross-sectional analysis of a community-controlled First Nations cohort study* (Thurber, 2022), found that everyday racial discrimination could explain up to half (47.4%) of the overall gap in psychological distress between Indigenous and non-Indigenous people.¹³ This demonstrates that interpersonal discrimination, which is a manifestation of structural racism, might contribute substantially to psychological distress among Aboriginal and Torres Strait Islander adults.

¹¹ Ibid, p. 14.

¹² Note that the strength of these associations varied between the above outcomes, with particularly high links found to alcohol use, smoking, and social and emotional wellbeing outcomes.

¹³ Thurber et al. 2022, *Population-level contribution of interpersonal discrimination to psychological distress among Australian Aboriginal and Torres Strait Islander adults, and to Indigenous–non-Indigenous inequities: cross-sectional analysis of a community-controlled First Nations cohort study*, *The Lancet*, vol 400, issue 10368, DOI:[https://doi.org/10.1016/S0140-6736\(22\)01639-7](https://doi.org/10.1016/S0140-6736(22)01639-7)



The authors of the 2021 study concluded that there is potential for improving our peoples' health and wellbeing by reducing exposure to racism; this is clearly needed.¹⁴ Embedding cultural safety and anti-racism in policy and imbedding it in our systems and institutions is key to this.

For this reason, The Lowitja Institute advocates for the inclusion of cultural safety and the cultural determinants of health in health and health-related policy. Cultural safety must be at the heart of the NDIS system to ensure that our peoples with disabilities benefit from equitable access and support.

In the 2019 Lowitja Institute funded NDIS review, the first recommendation was: **Implement the Aboriginal and Torres Strait Islander Engagement Strategy and develop a cultural competency framework.** This recommendation goes to improving cultural safety in the NDIS system. We urge the Independent Review to take up this recommendation and urgently develop an Aboriginal and Torres Strait Islander cultural competency framework.

It also important that this review takes an intersectional approach.

*No person has a singular or unitary identity; intersectionality and anti-essentialism mean that “everyone has potentially conflicting, overlapping identities, loyalties and allegiances”.*¹⁵

As June Oscar AM highlights, current systems fail our people because they lack holistic integration.¹⁶ The key to ensuring best alignment between policy areas is in meaningful engagement with Aboriginal and Torres Strait Islander peoples, communities, experts and Peaks; and in facilitating their leadership in these spaces.


Engagement with Aboriginal and Torres Strait Islander peoples

The Independent Review has asked stakeholders how best to engage with those they represent to ensure that all voices are heard. When engaging with

¹⁴ Ibid, pp. 12 & 16.

¹⁵ Watego, C., Singh, D. & Macoun, A. 2021, Partnership for Justice in Health: Scoping Paper on Race, Racism and the Australian Health System, Discussion Paper, The Lowitja Institute, Melbourne, p. 8

¹⁶ Australian Human Rights Commission 2020, Wiyi Yani U Thangani (Women's Voices): Securing Our Rights, Securing Our Future Report, AHRC, Sydney, p. 147. Accessed 27 January 2022 at: Wiyi Yani U Thangani Report (2020) | Australian Human Rights Commission.



Aboriginal and Torres Strait Islander peoples, the historical context of colonisation and unethical research and engagement practices must be considered.

Aboriginal and Torres Strait Islander peoples have been subjected to huge amounts of research since 1788. Research was used as a tool of colonial violence and data has been weaponised against our peoples. We were locked out of the research process and othered by it. Historical truth-telling reminds us that medical experimentation and many other harms were carried out on our peoples in the name of “research”.

Other forms of engagement with our peoples and policy development followed a similar pattern; non-Indigenous peoples or organisations have often come into our communities and services seeking to engage with our peoples in a way that was not culturally respectful nor safe; such practices are disempowering. Even the recent shift to co-design is not sufficient because in practice, it does not facilitate Aboriginal and Torres Strait Islander leadership.¹⁷ As a result, there is a large degree of justified mistrust.


The Lowitja Institute’s discussion paper, *Aboriginal Participatory Action Research: An Indigenous Research Methodology Strengthening Decolonisation and Social and Emotional Wellbeing* speaks to the above and outlines engagement approaches and methodology that are culturally safe and empowering.¹⁸ The Independent Review may find this document a helpful resource.

What this means for the Independent Review is that visiting Aboriginal communities to speak with our peoples directly won’t work. Without trust and a culturally safe approach, our peoples will not be willing to share their experiences. Our peoples trust our Aboriginal Community Controlled Organisations (ACCOs). We recommend that the Independent Review works in partnership with and resources ACCOs to engage with our peoples.

It is also important to ensure that the principles of Indigenous Data Sovereignty are adhered to during this review. Partnering with ACCOs would assist with this.

¹⁷ See Dudgeon, et al. 2020, *Aboriginal Participatory Action Research: An Indigenous Research Methodology Strengthening Decolonisation and Social and Emotional Wellbeing*, Discussion Paper, Lowitja Institute, Melbourne.

¹⁸ Ibid.



The Independent Review should also ensure that culturally safe, trauma-informed support is available for any Aboriginal or Torres Strait Islander person who shares their story and experiences.

Future research

Through engagement with our Aboriginal and Torres Strait Islander stakeholders, the Lowitja Institute has been made aware that there are significant barriers to access to NDIS (PBS and MBS) and other disability supports in prisons for Aboriginal and Torres Strait Islander peoples. We have also been made aware of the lack of continuity in service access when transitioning out of prisons. We were not able to have input into this topic for the purposes of this submission as this has been identified as an area of investigation for our policy team in 2023, but we encourage the NDIS Independent Review to investigate this issue.