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Published in:
Australian and New Zealand Journal of Public Health

DOI:
[10.1111/1753-6405.12120](https://doi.org/10.1111/1753-6405.12120)

Published: 01/12/2013

Document Version
Publisher's PDF, also known as Version of record

[Link to publication](#)

Citation for published version (APA):
Bohanna, I., Catherall, J., & Dingwall, K. (2013). Ensuring Indigenous Australians with acquired brain injuries have equitable access to the National Disability Insurance Scheme. *Australian and New Zealand Journal of Public Health*, 37(6), 587-587. <https://doi.org/10.1111/1753-6405.12120>

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Ensuring Indigenous Australians with acquired brain injuries have equitable access to the National Disability Insurance Scheme

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The National Disability Insurance Scheme (NDIS) has the potential to change the lives of Indigenous Australians living with an acquired brain injury (ABI) by providing much needed services and support. We believe it is imperative that greater effort and resources be focused on ensuring that Indigenous Australians with an ABI can access accurate and culturally acceptable cognitive assessment of a similar standard to that available for non-Indigenous Australians.

While there is little data on incidence of ABI in Indigenous Australians, the prevalence of risk factors for ABI is high. For example, head trauma accounts for 30% of injuries requiring hospitalisation in Indigenous Australians,¹ compared to 18% in non-Indigenous Australians.² Between 2005 and 2008, Indigenous Australians were 21 times more likely to suffer a head injury due to assault.³ Indigenous Australians are 1.5 times more likely to drink alcohol at risky levels,⁴ although rates of risky drinking and alcohol-related head trauma appear to be much higher in regions such as the Northern Territory.⁵ Data suggest the burden of ABI is high in this population.

The NDIS could significantly improve outcomes for Indigenous people with an ABI. For those eligible, the NDIS could provide financial support to access services including early intervention, community reintegration support, allied health therapy, equipment, home modification, care and employment support. These services could significantly improve the capacity of individuals with an ABI to enhance their economic and social participation, which are stated goals of the NDIS.⁶

Importantly, for Indigenous Australians with an ABI, gaining access to the NDIS will likely rely on demonstration of cognitive impairment, which typically requires a cognitive assessment. While relatively straightforward in the non-Indigenous population, this is problematic for Indigenous Australians, due to the lack of scientifically validated instruments for assessing cognition in adult Indigenous Australians.⁷

We consulted with 56 psychologists, allied health practitioners, disability services staff, cultural advisors and community members across New South Wales, Queensland, the Northern Territory and Torres Strait Islands. All were concerned about high rates of often unrecognised ABI, and those involved in assessment expressed frustration at the lack of valid and culturally acceptable cognitive assessment tools available. A recent study by Dingwall and colleagues⁸ echoes these concerns. Clinicians assessing cognition in Indigenous clients in the Northern Territory relied heavily on informal and modified assessments, observations and clinical judgement, and there was little consistency in approach.⁸

These informal approaches are susceptible to bias and are inconsistent with best practice in cross-cultural assessment.⁹ Compounding the issue, the small number of neuropsychologists who have the specialist skills to assess cognition in this population

are concentrated in metropolitan areas. This lack of an accessible, transparent, valid and accurate assessment process may prevent Indigenous Australians with an ABI from obtaining NDIS support. Given the range of existing barriers that already prevent Indigenous Australians from accessing services, this is concerning.

What can be done? Financial and political support needs to be directed toward development of cognitive assessment instruments specifically for Indigenous Australians that can establish the presence of cognitive impairment. Mainstream cognitive assessment instruments may also prove culturally acceptable for use with Indigenous Australians; however, careful evaluation and formal validation studies are essential, as is the collection of normative data. Those with expertise in Indigenous cognitive assessment should be brought together to develop reliable, valid and culturally acceptable instruments. While not a simple task, it is possible, with efforts already being made to remedy this problem. The Kimberley Indigenous Cognitive Assessment has been developed to assess dementia in Aboriginal Australians; however, it is only valid for people aged 45 years or older and does not comprehensively assess the range of deficits associated with ABI.¹⁰

A crucial policy consideration should be to ensure that access to assessment meets the identified need. It is essential that concerted effort and funding be directed toward developing valid methods for assessing cognitive function in Indigenous Australians, to ensure that those who need it most can access the National Disability Insurance Scheme.

Acknowledgements

This research was managed by Brain Injury Australia, in partnership with James Cook University and Synapse Inc., funded by a Department of Families, Housing, Community Services and Indigenous Affairs grant. The opinions, comments and analysis expressed are those of the authors and do not necessarily represent the views of the Minister for Disability Reform and cannot be taken in any way as expressions of government policy.

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