

Making every Australian count: challenges for the National Disability Insurance Scheme (NDIS) and the equal inclusion of homeless Aboriginal and Torres Strait Islander Peoples with neurocognitive disability

Clare Townsend^{1,2,3,5} PhD, National Manager (Research and Development);
Adjunct Associate Professor

Paul White⁴ MB, BS, FRANZCP, Clinical Director

Jennifer Cullen^{1,3} MHLthServMt/Ec., GradDip PH, BHSc (Geront), BA,
Chief Executive Officer; Adjunct Associate Professor

Courtney J. Wright^{1,2} BPsych (Hons), PhD, Post-doctoral Research Fellow

Heidi Zeeman² BBehSc (Hons), MClinPsych (Neuro), PhD, Professor

¹Synapse, 1/262 Montague Road, West End, Qld 4101, Australia.
Email: jcullen@synapse.org.au; cwright@synapse.org.au

²Menzies Health Institute Queensland, Griffith University, Logan Campus, University Drive,
Meadowbrook, Qld 4131, Australia. Email: h.zeeman@griffith.edu.au

³James Cook University, James Cook Drive, Townsville City, Qld 4811, Australia.

⁴Queensland Government Department of Communities, Child Safety and Disability Services,
Specialist Disability Services Assessment and Outreach Team, Russell Street, South Brisbane,
Qld 4101, Australia. Email: paul.white@communities.qld.gov.au

⁵Corresponding author. Email: ctownsend@synapse.org.au

Abstract. This article highlights the dearth of accurate evidence available to inform the National Disability Insurance Scheme (NDIS) regarding the extent and nature of neurocognitive disability amongst homeless Aboriginal and Torres Strait Islander people. Without accurate prevalence rates of neurocognitive disability, homeless Aboriginal and Torres Strait Islander people are in danger of not being counted by the NDIS and not receiving supports to which they are entitled. Addressing this knowledge gap is challenged by a range of factors, including: (1) the long-term effect of profound intergenerational disenfranchisement of Aboriginal and Torres Strait Islander people; (2) Aboriginal and Torres Strait Islander cultural perspectives around disability; (3) the generally unrecognised and poorly understood nature of neurocognitive disability; (4) the use of research methods that are not culturally safe; (5) research logistics; and (6) the absence of culturally appropriate assessment tools to identify prevalence. It is argued that an accurate evidence base that is informed by culturally safe research methods and assessment tools is needed to accurately guide the Commonwealth government and the National Disability Insurance Agency about the expected level of need for the NDIS. Research within this framework will contribute to the realisation of a truly inclusive NDIS.

Additional keywords: consumers, drug and alcohol, epidemiology, health policy, Indigenous health.

Received 12 October 2016, accepted 12 January 2017, published online 30 March 2017

Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)¹ establishes the rights of all people who have a disability to accessible, appropriate, evidence-based services that enable them to achieve personal goals and to enjoy a quality of life equal to that of people who do not have a disability. Australian Commonwealth and state governments

have undertaken significant disability policy reform over the past decade to recognise and promote the rights of people living with a disability.² Central to this reform agenda is the National Disability Insurance Scheme (NDIS), which is to be fully implemented by the end of 2019.³ The NDIS reflects a systemic move away from traditional models of service delivery by repositioning people with disability within a consumer market. Individual ‘choice and

control' are fundamental principles, with eligible individuals allocated individualised funding to purchase care and support services. It is to be an all-inclusive scheme in which 'every Australian counts'.⁴

Although the NDIS represents the most significant disability policy reform in Australian history, there are concerns that Australia's First Peoples will face greater barriers to accessing disability supports than non-Indigenous Australians.^{5,6} Homeless Aboriginal and Torres Strait Islander people with neurocognitive disability are especially at risk of missing out on the NDIS.

Disability and homelessness among Aboriginal and Torres Strait Islander people

Disability research among Australia's First Peoples has received limited attention.^{7,8} Current estimates suggest that Aboriginal and Torres Strait Islander people experience approximately twice the rate of disability as non-Indigenous Australians.⁹ The proportion of Australia's First Peoples aged 15 years and over reporting a disability or long-term health condition has been estimated at 37% (roughly 102 900 people).¹⁰ However, current estimates of disability prevalence appear to be undercounts.^{11,12} The incidence of neurocognitive disability in particular has not been accurately established, but is thought to be high.^{11,13}

According to the American Psychological Association (APA),¹⁴ neurocognitive disability is caused by acquired (rather than developmental) damage to the brain where the 'primary clinical deficit is in cognitive function'.¹⁴ A neurocognitive disability may result from a traumatic brain injury, infection, dementia, or substance abuse, for example.¹⁴ Although the APA's¹⁴ definition may characterise Fetal Alcohol Syndrome Disorder (FASD) as a developmental disability, several scholars in the field have argued that prenatal exposure to alcohol represents an acquired (rather than developmental) impairment that is difficult to identify and manage.^{15–18} In Aboriginal and Torres Strait Islander homeless populations, the prevalence of neurocognitive disability is likely to be particularly high given: (1) people with a disability are at greater risk of homelessness compared with the general population;¹⁹ and (2) the proportion of homeless Aboriginal and Torres Strait Islander people is 14-fold higher than for non-Indigenous Australians.²⁰ Given the dearth of accurate evidence available to inform the NDIS regarding the extent and nature of neurocognitive disability among homeless Aboriginal and Torres Strait Islander people, it can be assumed that the level of need for disability assistance by this group has not been properly estimated.

Challenges for the NDIS

Without accurate prevalence rates of neurocognitive disability, homeless Aboriginal and Torres Strait Islander people are in danger of not being counted by the NDIS and not receiving supports to which they are entitled. Addressing this knowledge gap is challenged by a range of factors, including:

- the long-term effect of profound intergenerational disenfranchisement resulting in limited self-determination and/or fear by Aboriginal and Torres Strait Islander people to seek help²¹
- Aboriginal and Torres Strait Islander cultural perspectives around disability (e.g. there is no word for 'disability' in traditional languages; the label of 'disability' may be

stigmatising and result in a disinclination to identify people in need of support)²²

- neurocognitive disability is often generally unrecognised and poorly understood⁵
- historically, research methods have not been culturally safe⁹ and have been negatively experienced by Aboriginal and Torres Strait Islander people²³
- research logistics (i.e. difficulties in locating people, particularly those who are rough sleepers and/or are living in rural or remote areas of Australia)²⁴
- the absence of culturally appropriate assessment tools to identify prevalence.¹¹

An accurate evidence base that is informed by culturally safe research methods and assessment tools is needed to accurately guide the Commonwealth government and the National Disability Insurance Agency about the expected level of need for the NDIS and to be 'NDIS ready'.

Directions for future research

The development of a strong evidence base to inform the successful inclusion of homeless Aboriginal and Torres Strait Islanders with neurocognitive disability in the NDIS will only be achieved through ongoing, culturally safe partnerships with Aboriginal and Torres Strait Islander people and the use of culturally safe research methodologies and tools. To accurately identify the prevalence of neurocognitive disability within the Aboriginal and Torres Strait Islander homeless population, a culturally appropriate assessment tool must be developed and tested for reliability and validity. The authors are currently undertaking a comprehensive study to achieve this objective. Future research must also investigate the viability of the NDIS model for non-urban communities and, in particular, the practical challenges inherent in living in regional and remote areas of Australia. Evidence collection must be conducted in community by people who have credibility and respect, taking into account cultural learning, the importance of family and community, the history of disadvantage and mistrust, and heterogeneous ways of knowing, thinking and doing. Respect for Aboriginal and Torres Strait Islander ways and spirituality will be paramount. Research within this framework can inform effective, culturally appropriate and safe evidence-based policy reform and development inherent within the NDIS initiative and will contribute to the realisation of a truly inclusive NDIS.

Competing interests

The authors report no actual or potential conflict of interest that could inappropriately influence, or be perceived to influence, this work.

Acknowledgements

This work was funded by an anonymous philanthropic Trust which has had no involvement in the conceptualisation or writing of this article, or in the decision to submit this article for publication.

References

- 1 United Nations. Convention on the rights of persons with disabilities. 2006. Available at: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> [verified 19 September 2016].

- 2 Barton R, Robinson T, Llewellyn G, Thorncraft K, Smidt A. Rural and remote perspectives on disability and mental health research in Australia: 2000–2013. *Adv Ment Health* 2015; 13: 30–42. doi:10.1080/18374905.2015.1023417
- 3 Wiesel I, Habibis D. NDIS, housing assistance and choice and control for people with disability. AHURI Final Report No. 258. Melbourne: Australian Housing and Urban Research Institute; 2015.
- 4 Nicholls R. 'Every Australian counts': The campaign for the National Disability Insurance Scheme 2011. Available at: <http://www.ethos.org.au/online-resources/engage-mail/every-australian-counts> [verified 21 September 2016].
- 5 Productivity Commission. Disability care and support: draft report. Volumes 1 and 2. Canberra: Productivity Commission; 2011. Available at: <http://www.pc.gov.au/inquiries/completed/disability-support/report> [verified 21 September 2016].
- 6 Russell LM. Closing the gap on Indigenous disadvantage: an analysis of provisions in the 2013–14 Budget and implementation of the Indigenous Chronic Disease Package. Sydney: Menzies Centre for Health Policy, University of Sydney; 2013. Available at: <https://web.archive.org/web/20140302114745/http://www.naccho.org.au/download/aboriginal-health/2013-14IndigenousBudgetandICDP.pdf> [verified 19 September 2016].
- 7 Biddle N, Yap M, Gray M. CAEPR Indigenous Population Project: 2011 census papers. Paper 6: disability. Acton: Centre for Aboriginal Economic Policy Research, The Australian National University; 2013. Available at: http://caepr.anu.edu.au/sites/default/files/cck_indigenous_outcomes/2013/02/2011_CensusPaper_06_Disability.pdf [verified 20 September 2016].
- 8 Glasson EJ, Sullivan SG, Hussain R, Bittles AH. An assessment of intellectual disability among Aboriginal Australians. *J Intellect Disabil Res* 2005; 49: 626–34. doi:10.1111/j.1365-2788.2005.00722.x
- 9 Biddle N. Improving Indigenous health: are mainstream determinants sufficient? In B. Hunter, N. Biddle, editors. Survey analysis for Indigenous policy in Australia: Social science perspectives. Canberra: ANU ePress; 2012. pp. 65–78.
- 10 Steering Committee for the Review of Government Service Provision. Overcoming Indigenous disadvantage: key indicators 2011. Canberra: Productivity Commission; 2011.
- 11 Stephens A, Cullen J, Massey L, Bohanna I. Will the National Disability Insurance Scheme improve the lives of those most in need? Effective service delivery for people with acquired brain injury and other disabilities in remote Aboriginal and Torres Strait Islander communities. *Aust J Public Admin* 2014; 73: 260–70. doi:10.1111/1467-8500.12073
- 12 Thrift AG, Cadilhac DA, Eades S. Excess risk of stroke in Australia's Aboriginal and Torres Strait Islander populations. *Stroke* 2011; 42: 1501–2. doi:10.1161/STROKEAHA.111.617746
- 13 Henderson S. Dementia in Aboriginal Australians. *Aust N Z J Psychiatry* 2010; 44: 869–71. doi:10.3109/00048674.2010.514858
- 14 American Psychological Association (APA). Neurocognitive disorders. In: Diagnostic and statistical manual of mental disorders. 5th edn. 2013. Available at: <http://dsm.psychiatryonline.org/doi/abs/10.1176/appi.books.9780890425596.dsm17> [verified 23 September 2016].
- 15 Green CR, Mihic AM, Nikkel SM, Stade BC, Rasmussen C, Munoz DP, Reynolds JN. Executive function deficits in children with fetal alcohol spectrum disorders (FASD) measured using the Cambridge Neuropsychological Tests Automated Battery (CANTAB). *J Child Psychol Psychiatry* 2009; 50: 688–97. doi:10.1111/j.1469-7610.2008.01990.x
- 16 Kodituwakku PW. Neurocognitive profile in children with fetal alcohol spectrum disorders. *Dev Disabil Res Rev* 2009; 15: 218–24. doi:10.1002/ddev.73
- 17 Lafler J. Expanding a *Drosophila* model of fetal alcohol spectrum disorder: a forward genetic screen for developmental ethanol exposure phenotypes. Master's thesis, San Jose State University, San Jose, California; 2015.
- 18 Leonard J. Aboriginal justice: the challenges of FASD & implications for the legal system. *Bulletin* 2016; (*Law Society of South Australia*) 2016; 38: 38–9.
- 19 Beer A, Baker E, Mallett S, Batterham D, Pate A, Lester L. Addressing homelessness amongst persons with a disability: identifying and enacting best practice. Canberra: Department of Families, Housing, Community Services and Indigenous Affairs; 2012. Available at: www.melbourneinstitute.com/downloads/hilda/Bibliography/Other_Publications/2012/Beer_etal_Homelessness-and-Disability-FINAL-REPORT-2-2.pdf [verified 24 September 2016].
- 20 Australian Institute of Health and Welfare (AIHW). Australia's health 2014. Australia's health series no. 14. Catalogue no. AUS 178. Canberra: AIHW; 2014.
- 21 Purdie N, Dudgeon P, Walker R, editors. Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice. Barton: Commonwealth of Australia; 2010.
- 22 First People's Disability Network. Ten-point plan for the implementation of the NDIS in Aboriginal communities; 2013. Available at: <http://fpdn.org.au/ten-point-plan-for-the-implementation-of-the-ndis-in-aboriginal-communities/> [verified 19 September 2016].
- 23 Smith L. Decolonising methodologies research and Indigenous Peoples. London: Zed Books; 1999.
- 24 Memmott P, Chambers C. Indigenous homelessness in Australia: an introduction. *Parity* 2010; 23: 8–11.