

The experience of the Aboriginal Community Controlled Health Sector in the Barwon NDIS trial site 2015

Introduction

The National Disability Insurance Scheme (NDIS) prioritises participation of Aboriginal¹ people, who are under-represented as users of disability services despite experiencing double the rates of disability of non -Aboriginal Australians¹. The National Indigenous Access Framework outlines a range of measures to promote engagement of the NDIS with Aboriginal communities, and highlighted the role of community hubs and in facilitating equitable access to NDIS.

This paper outlines the experience of Wathaurong Aboriginal Cooperative and its preparation to deliver supports funded by the NDIS as the only community controlled service provider in the Barwon NDIS trial site, in order to identify:

- Factors influencing NDIS access by Aboriginal people
- Implications of Wathaurong's experience of transition for full roll out of the NDIS in Victoria

Background

- Wathaurong provides a range of health and community services to the local Aboriginal community, including those members of its community who have a disability, but it is not a specialist provider of disability services. Wathaurong and other Aboriginal community controlled health organisations evidence effective culturally competent practices in support of Aboriginal people and their communities. Their existing role and models of engagement and support enable them to act as community hubs for Aboriginal people and this is recognised both by Aboriginal people and the broader communities where they are located within the Barwon Region trial site and outside of this area.
- The NDIA, initially provided consultant support to Wathaurong, to assist their consideration of their potential role in delivering NDIS funded supports, and to facilitate change to business systems.
- Wathaurong now provides NDIS funded personal care, domestic services, and home maintenance to eight clients who previously received assistance through Wathaurong's Home and Community Care (HACC) program, and is working towards NDIS registration for the provision of case management and financial intermediary supports. The identification process for these clients took around 10 to 15 hours per client, for which Wathaurong is not funded.

1. In this submission the word "Aboriginal" refers to both Aboriginal and Torres Strait Islander People. Direct reference to Torres Strait Islander people and the word "Indigenous" have been used where these are part of a title or direct quote

- In addition, Wathaurong *In Home Support* staff have assisted eight families to provide diagnostic evidence which has enabled thirteen children to access NDIS-funded services. This task required between 10 and 15 hours of worker support per child and was not funded by NDIA.
- Although data is limited, there is some evidence to suggest high levels of unidentified need for disability supports amongst the 1500 clients who currently use Wathaurong's Health Services. Over 20% of these clients have been diagnosed with a mental health condition. Within Wathaurong Health Service's *Fresh Tracks* program, which currently serves clients with complex needs (e.g. Schizophrenia, acquired brain injury (ABI) posttraumatic stress disorder (PTSD) and disability relating to musculoskeletal problems) there are currently 17 clients in the process of applying for NDIA supports. Confirmation of disability has proven to be extremely difficult due to reluctance to engage assessment services and to gather patient histories from other agencies. Some of the conditions experienced by this group are compounded by chaotic service utilisation due to substance use. There is also more than 50 community members, currently attending the psychology and psychiatry clinics who are potentially eligible for NDIS but the identification process has not been undertaken for these clients as there are no resources to do so.
- In November 2014 Wathaurong was invited by NDIA staff to submit a proposal for *Community Inclusion and Capability Development Project* funds to resources small scale community engagement activities and to provide cultural safety training to a limited number of (45) NDIA staff.
- As a result of their ongoing involvement with the NDIS, Wathaurong staff involved in the provision of NDIs-funded supports have indicated that strong communication channels have developed between NDIA staff and Wathaurong at the service level.
- However, staff feedback suggests that NDIA does not understand the need to incorporate culture into the care plans or services provided to Aboriginal people.

Discussion

While there is a paucity of empirical data to quantify unmet need issues, the statistical data which is available evidences low access and participation rates in disability services by Aboriginal people.

In the Barwon trial site, progress has been made in establishing communications at local service level between NDIA and Wathaurong, but there is little evidence of progress in establishing the system-wide changes that will make the NDIA genuinely accessible to Aboriginal people living with a disability and their families. One of the stated purposes of NDIS trial sites is to inform development of the scheme ahead of its roll out and full implementation. There is an excellent opportunity for Wathaurong and the NDIA to cooperate in identifying and resolving structural barriers to equitable access to the NDIS for Aboriginal people in readiness for the full implementation of the scheme. However, learnings generated by individual front line workers and small scale projects have not been translated into systemic changes which:

- ensure engagement between NDIS, Aboriginal communities and the community controlled organisations that serve them.,
- support development and delivery of culturally secure support services – including examination of service offerings with a cultural component,
- foster development of referral pathways to existing mainstream disability services and supports where appropriate,

Issues raised as a result of the interaction between Wathaurong and the NDIA include:

1. **Need to support Aboriginal people and their families in collecting evidence of eligibility for NDIS participation**

Unfunded assistance provided by Wathaurong staff to assist families in accessing the NDIS highlights two barriers facing Aboriginal people who seek NDIS participation:

- Lack of resources and/or designated responsibility for assisting families in collecting diagnostic and other evidence of NDIS eligibility
- Lack of assistance in navigating the process/accessing NDIS

There is no requirement NDIA support or resource people with a disability or their families to collect diagnostic and other evidence to support their

eligibility for NDIS participation. This remains a major barrier to NDIS access for Aboriginal people and is amplified by the multiple and aggravated disadvantage experienced by Aboriginal and Torres Strait Islanders with disability and their families.

There is currently no clear indication as to which jurisdiction, sector or organisation is responsible for supporting or resourcing:

- identification of Aboriginal people who have or may have a disability, and
- diagnostic assessment to determine the nature of the disability identification/ diagnosis of disability.

This issue precedes the instigation of the NDIS, but access to the NDIS is negatively affected by it as is provision of state-funded disability supports. For example, there are current Victorian Department of Health and Human Services (DHHS) protocols which relate to provision of disability supports to children with a known disability who are in out of home care (OOHC), but no protocols to enable diagnosis/ assessment of unidentified disability for children who are in, or entering OOHC. This has obvious implications for stability of placements and for long-term prospects for re-unification of families, as does the lack of assessment or diagnosis for parents with a disability, Aboriginal people are over-represented in the care and protection system, both as parents and children.²

Wathaurong's experience also demonstrates that families may have difficulties navigating NDIS processes and accessing the scheme. The issue of navigation/accessing NDIS clearly relates to the function of the Local Area Coordinator (LAC) which is tasked with responsibilities for providing information about NDIS. This will include providing advice on community members' potential eligibility for funded support and preplanning processes. There is the potential to address difficulties experienced by Aboriginal people in navigating the NDIS, by incorporating a cultural safety framework in provision of LAC services and a requirement that successful tenderers for LAC services demonstrate cultural expertise by partnering with the Aboriginal community controlled sector.

2. **Need for community engagement as an ongoing process**

Time limited community engagement projects have limited potential to achieve sound relationships between Aboriginal communities and the NDIA.

Factors which must be taken into account in the engagement process include but are not limited to, cultural non-recognition of disability by Aboriginal people and lack of trust which is the enduring legacy of Stolen Generation policies. Consequently, there is a need for engagement approaches based on ongoing dialogue between community and service providers, such as that which has been successfully employed by the *Balit Narum* Aboriginal disability network, which has conducted successive community Yarning Circles in the North West Metropolitan Region of Melbourne. This provides ongoing opportunities for Aboriginal people with a disability and their families to learn about services and supports available to them and is working to facilitate transition of Aboriginal children with a disability into the NDIS as it rolls out.

3. **Need for a systemic approach to embed cultural expertise in NDIA planning processes**

Cultural safety and cultural respect have a basis in human rights³. Ongoing provision of cultural safety training for all staff is necessary, but not sufficient to embed cultural safety in an organisation's operations. Factors which are integral to the development of cultural safety within mainstream organisations include:

- leadership at all levels of the organisation's operations
- capacity to thoughtfully and respectfully question cultural differences
- time to develop trusting and reciprocal relationships with Aboriginal community controlled organisations (ACCOs)
- a whole of agency approach that is embedded in governance, policies, programs, service delivery and practice approaches⁴.

4. **Need for systematic processes for engagement with Aboriginal community hubs such as ACCHOs**

The National Indigenous Access Framework expresses a commitment to:

“reducing those barriers and building accessibility needed to improve the experience of Indigenous Australians. It seeks to foster approaches that are inclusive, and actively engage Indigenous Australians with a disability and their families in designing, planning and delivering culturally competent and accessible services and supports”⁵

The framework highlights the role of community hubs and the need for services which ‘complement people’s every-day and cultural life’⁶ as a means of acting on that commitment. Wathaurong and VACCHO acknowledge that not all Aboriginal people with a disability are connected to an ACCHO and that some people may not wish to be. Nonetheless, Wathaurong and VACCHO are committed to working with all Aboriginal people, sharing their learnings and resources developed from the projects to ensure that a model of response is relevant in all circumstances for the benefit of Aboriginal people with a disability and their families.

The trialling of the NDIS in Barwon offers an opportunity, as yet unrealised, for collaborative development of culturally safe access and planning protocols for Aboriginal people and their families. At the systems level, the trial period could be used to develop, implement and evaluate a scalable model of service provision which is culturally safe and applicable to Aboriginal community controlled organisations across Australia. A model of this type also provides service options for use by mainstream providers working with small, dispersed populations or in ‘thin markets’ in socially disadvantaged areas.

There is a disparity between the potential role of Aboriginal peak bodies and community controlled organisations and the current capacity of Aboriginal organisation to positively influence access to disability supports for their communities. This raises questions about the roles that Aboriginal organisations are expected to have, given the relatively small range of funded disability specialist services they are able to provide and the fact that the financial resources provided to these groups for the purpose of developing specialist disability services is extremely limited. In summary: how does the NDIA intend to achieve the objectives of the National Indigenous Access Framework, and to what extent is this achievement possible without significant input from Aboriginal community controlled organisations?

Recommendations

That Aboriginal communities and the community controlled organisations that represent them advocate for:

1. NDIA to take responsibility for assisting Aboriginal people to connect with the NDIS prior to the planning process by allocating resources to support Aboriginal people and their families in obtaining diagnostic and other evidence which will contribute to NDIS eligibility assessment.
2. NDIA development and implementation of a cultural safety strategy which incorporates:
 - a. a whole of agency approach to embedding cultural safety in governance, policies, programs, service delivery and practice approaches – including service delivery provided by contracted services such as LACs
 - b. ongoing community engagement processes
 - c. structured processes to engage/facilitate Aboriginal community controlled sector in the development of:
 - i. culturally safe processes for access, planning and service delivery
 - ii. culturally appropriate service offerings

(Endnotes)

1. Disability Policy and Research Working Group (2012) National Indigenous Access Framework
2. Biddle, Al-Yaman, Gourley , Gray , Bray, Brady, Pham, Williams, Montaigne (2012) Indigenous Australians and the National Disability Insurance Scheme: The extent and nature of disability, measurement issues and service delivery models Centre for Aboriginal Economic Policy Research (CAEPR) at the Australian National University (ANU) and the Australian Institute of Health and Welfare (AIHW) p80
3. National Community Controlled Health Organisation (May 2011) Creating the NACCHO Cultural Safety Training Standards and Assessment Process A background paper http://www.naccho.org.au/download/cultural_safety/CSTStandardsBackgroundPaper.pdf p 17 downloaded 11/11/15
4. Victorian Aboriginal Child Care Agency (October 2008) Aboriginal Cultural Competence Framework Victorian Government Department of Human Services, Melbourne, Victoria
5. Disability Policy and Research Working Group (2012) National Indigenous Access Framework, p5
6. Ibid p8