

Engaging Aboriginal and Torres Strait Islander peoples in the ‘Proper Way’



Rebecca Somerville is Communication Officer for the Queensland Alliance for Mental Health (QAMH)

Adjunct Associate Professor Jennifer Cullen is Chief Executive Officer of Synapse

Dr Michelle McIntyre is Research Fellow at the The Hopkins Centre, Menzies Health Institute Queensland, Griffith University and at Synapse

Associate Professor Clare Townsend is Manager, Research and Development at Synapse

Sue Pope is Manager, Engagement and Partnerships at QAMH

The National Disability Insurance Scheme (NDIS) provides Aboriginal and Torres Strait Islander peoples with a physical, intellectual, psychosocial and/or neurocognitive disability the opportunity, for the first time, to choose and access those supports and services which they feel are culturally appropriate and which meet their needs.

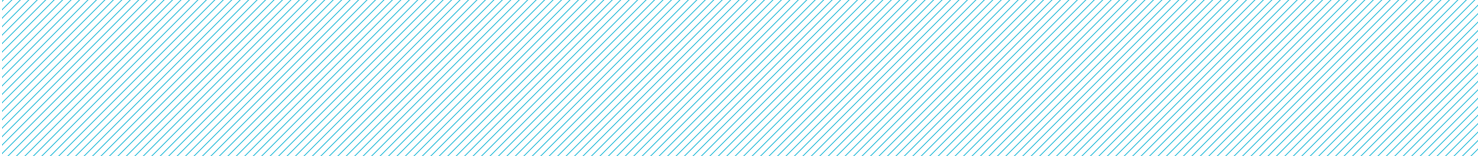
There are many barriers to Aboriginal and Torres Strait Islander peoples engaging with NDIS service providers and agencies, however. This article examines some of them and considers the cultural context in which they are experienced. It discusses Proper Way processes for engaging Aboriginal and Torres Strait Islander communities and outlines two examples of community engagement in rural and remote regions in Queensland.

Please note that in this article the term Indigenous is respectfully used to collectively refer to descendants of the original inhabitants of Australia, while acknowledging the heterogeneous nature of Aboriginal and Torres Strait Islander clans and communities.

NDIS inclusion issues for Indigenous people

In Australia, health disparities between Indigenous and non-Indigenous Australians are well documented, and Aboriginal and Torres Strait Islander peoples continue to be overly-represented in mental illness and disability populations (Australian Bureau of Statistics, 2016; Australian Institute of Health and Welfare, 2011). After taking into account age differences, the rate of disability among Aboriginal and Torres Strait Islander peoples is almost twice that of non-Indigenous people (Biddle N et al, 2012). Statistics relating to suicide, poor mental health, and substance use issues are similarly high (Department of Health and Ageing, 2013).

The reasons for these disparities are complex, but causative factors include social exclusion, racism, intergenerational trauma, and loss of land and culture (King, Smith & Gracey, 2009). Yet despite higher rates



of illness and disability, Aboriginal and Torres Strait Islander Australians are under-represented in mainstream health services (AIHW, 2011) and concerns have been raised about inequitable access to NDIS supports (Productivity Commission, 2011).

Issues relating to differing concepts of mental illness and disability, a mistrust of government services, the historical impacts of racism and intergenerational trauma, and a lack of culturally appropriate services have all been associated with a lack of access to and engagement by Indigenous Australians in mainstream health and social services (Biddle N, 2012; Gilroy J et al, 2016; Ypinazar V et al, 2007).

In contrast with the clinical focus of mainstream medical models, Aboriginal and Torres Strait Islander peoples' conceptualisations of health and wellbeing have been described as holistic, with mental, physical, cultural and spiritual health seen as indivisible (Commonwealth of Australia, 2013). Until mainstream services demonstrate an understanding of and respect for these understandings of health and disability, services will not meet the needs of Aboriginal and Torres Strait Islander peoples, and engagement levels may remain low (Wand, Eades & Corr, 2010).

Aboriginal and Torres Strait Islander peoples who are marginalised, such as through rural and remote living, homelessness, substance abuse, mental illness and/or cognitive disability, and those engaged with the criminal justice system are at an even higher risk of exclusion from the NDIS (Stephens A et al, 2014; Townsend C et al, 2017). The Department of Social Services has funded Participant Readiness activities to facilitate the inclusion of marginalised groups into the NDIS, and the Aboriginal and Torres Strait Islander Engagement Strategy outlines plans for Indigenous engagement (National Disability Insurance Agency, 2017). However, it remains unclear whether these initiatives are enough to engage Aboriginal and Torres Strait Islander peoples in the NDIS.

Engaging through Proper Way processes

The Aboriginal and Torres Strait Islander Engagement Strategy emphasises the need to engage Aboriginal and Torres Strait Islander peoples through Proper Way processes. These are named from 'proper way', a colloquial term for the carrying out of any business with Aboriginal and Torres Strait Islander peoples according to their wishes, values and customs.

Implicit in the concept of Proper Way is an understanding that Aboriginal and Torres Strait Islander peoples and communities are heterogeneous, and that protocols appropriate in one context may not be so in another.

Crucial to engaging Indigenous peoples in Proper Way is that procedures and processes must be determined by the Aboriginal and Torres Strait Islander peoples and communities involved. Indeed, any activities must be community driven and not "imposed, implied, intervened or developed with well-meaning intention from an external service system" (First Peoples Disability Network, 2010).

This can only be achieved through an approach which demonstrates cultural humility (Tervalon M & Murray-Garcia J, 1998), and builds relationships and trust over time. Establishing trust, building respectful relationships and fostering cultural understandings are crucial pre-cursors to any engagement initiatives.

Following are two models of culturally appropriate engagement with rural and remote Aboriginal and Torres Strait Islander communities that aim to enhance their understanding of and participation in the NDIS.

Peer-led NDIS Engagement Activity on Palm Island

In 2016, the QAMH worked in partnership with the Townsville-based mental health service provider Supported Options in Lifestyle and Access Services (SOLAS) to deliver a peer-led NDIS Activity on Palm Island, funded by Mental Health Australia from funding provided by the Department of Social Services.

The project sought to understand why engagement with the NDIS on Palm Island had been low, and to bring together key learnings from peer-led community consultation activities. These consultations sought to identify the opportunities, facilitators and barriers to building the capacity of the community to actively engage with the NDIS.

SOLAS has worked closely with the community of Palm Island since 2009 to support people with severe mental illness to access support services through the Federal Government-funded Personal Helpers and Mentors program (PHaMs). Services provided by SOLAS on Palm Island are delivered by local residents to ensure that support is culturally appropriate.

The project confirmed that, in communities where there may be issues of violence, substance abuse, family conflicts, unemployment and a high incidence of suicide and self-harm, many Aboriginal and Torres Strait Islander peoples are focused on addressing day-to-day aspects of their lives, not on the NDIS. It also found that there have been few resources provided to communities like Palm Island to enable the community to engage with the NDIS in a way that is meaningful to them. Moreover, where positive outcomes have been reported, resources have only supported one-off and time-limited engagement.

The Guddi Protocol has been assessed by Aboriginal and Torres Strait Islander peoples for its cultural safety and appropriateness, and could potentially be used as a basis for an NDIS assessment.

The project identified three key areas of importance for Aboriginal and Torres Strait Islander peoples on Palm Island, namely to:

- work more holistically with the whole family rather than individual participants, and provide reasonable support to empower families and build capacity to engage
- focus on NDIS engagement activities that are de-stigmatising, such as one-on-one sessions
- utilise culturally appropriate engagement methods, such as yarning and storytelling opportunities with people from the community.

Yarning and storytelling build on the Indigenous oral tradition of handing down information. Often, conversations might take the form of a story as a way of exploring a topic or responding to a question. Telling and sharing stories can be a powerful experience, yielding important information and knowledge.

A key recommendation from the project stipulated that when funding is provided for the delivery of activities on Palm Island and other Aboriginal and Torres Strait Islander communities, funding bodies must consider the context of the Aboriginal and Torres Strait Islander culture when looking at research processes and measuring outcomes. General outcome measures and research processes taken from a non-Indigenous context are not appropriate. Finally, it is important that measures of success and outcomes are developed from within the community.

The Guddi Protocol

Synapse is a non-government organisation dedicated to reconnecting the lives of people who are affected by acquired brain disorders and to building partnerships with Aboriginal and Torres Strait Islander peoples in order to build on their ideas, strengths and leadership.

The Guddi Protocol arose out of research undertaken by Synapse in far north Queensland in relation to marginalised Aboriginal and Torres Strait Islander peoples with neurocognitive disability (NCD). NCD relates to any disorder of the brain such as through acquired brain injury, dementia, alcohol and drug use, infections, and Foetal

Alcohol Syndrome Disorder (FASD). NCD can affect multiple domains including cognitive processes, psychological and physical function, as well as impacting personality and behaviour.

Discussions with services indicated a lack of culturally appropriate methods for screening for NCD and highlighted concerns about the engagement of Indigenous service users in NDIS inclusion processes.

The Guddi Protocol consists of a culturally appropriate interview which includes questions relating to thinking skills, psychosocial functioning, depression, psychosis, and post-traumatic stress disorder. The Guddi Protocol is underpinned by a 'yarning' method, which has been described as an Indigenous cultural form of conversation (Bessarab D & Ng'andu B, 2010). Yarning facilitates trust and relationship building, and represents a culturally safe method of engagement.

The Guddi Protocol has been approved by Aboriginal and Torres Strait Islander people for its cultural safety and appropriateness, and could be used as a basis for an NDIS assessment.

Proper Way protocols guided the research process during its development. Ongoing discussions with relevant Traditional Owners, Elders, and an Indigenous Research Manager/Cultural Advisor (RMCA) ensured that the research processes and materials were culturally safe and appropriate. The RMCA was embedded in the service for a three-month period in order to build relationships and liaise with relevant Elders and respected others, to ascertain research and engagement processes appropriate to this context.

At all sites where Synapse is introducing the Guddi Protocol, similar Proper Way processes are being applied. The opinions and advice of Aboriginal and Torres Strait Islander services, Elders, and respected community members inform the process. Synapse is also assisting Indigenous services to support Aboriginal and Torres Strait Islander peoples with neurocognitive disability to prepare for and access the NDIS through pre-planning activities using the Synapse Proper Way resources, and any relevant programs available in the site area.

In summary

The Guddi Protocol, and the recommendations resulting from the Peer-Led NDIS Activity Project on Palm Island, highlight the importance of undertaking engagement with Aboriginal and Torres Strait Islander communities in culturally appropriate ways. The two models demonstrate that by conducting business in the Proper Way, it is possible to increase participation of Aboriginal and Torres Strait Islander peoples in the NDIS.

The NDIS has potential to enable Aboriginal and Torres Strait Islander peoples to access supports and services to which they are entitled, providing the aforementioned engagement barriers are addressed. NDIS engagement activities must be designed with consideration of Aboriginal and Torres Strait Islander concepts of health and disability, and cultural heterogeneity, and be delivered in the Proper Way, according to community advice.

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