



the
Lowitja
Institute

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

POLICY BRIEF: OCTOBER 2019

Understanding disability through the lens of Aboriginal and/or Torres Strait Islander people – challenges and opportunities

Representing a major change in the way supports for people living with disability are funded, the National Disability Insurance Scheme (NDIS) presents both opportunities and significant challenges. This project, Understanding disability through the lens of Aboriginal and/or Torres Strait Islander people – challenges and opportunities, was developed to examine the:

- Implementation of the NDIS Aboriginal and Torres Strait Islander Engagement Strategy¹
- Interaction between National Disability Insurance Agency (NDIA) staff, local area co-ordinators (LACs) and Aboriginal Community Controlled Health Services (ACCHSs) and non-governmental organisations (NGOs)
- Experiences of Aboriginal and/or Torres Strait Islander people in accessing the NDIS, planning, and receiving disability supports through the scheme

The research was conducted in collaboration with the MJD Foundation (MJDF) and Synapse, organisations which have longstanding connections with Aboriginal and/or Torres

Strait Islander communities in the Northern Territory and Queensland respectively. The project was designed to enable Aboriginal and/or Torres Strait Islander leadership of the research and to reflect the views of Aboriginal and/or Torres Strait Islander researchers, people and families affected by disability and the community controlled health and disability sector across a spectrum of settings.

Data sources for the project included:

- Analysis of exposure to unfair treatment, avoiding situations because of unfair treatment, exposure to violence, exposure to threats and removal from natural family among Aboriginal and/or Torres Strait Islander people with disabilities from the National Aboriginal and Torres Strait Islander Social Survey (NATSISS)²
- Semi-structured interviews with NDIA staff (n=4), disability support providers (n=16) partner organisations (n=2), Community Connectors (n=8) and participants in the NDIS (n=24)



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



SYNAPSE
AUSTRALIA'S BRAIN INJURY ORGANISATION



Findings

For an in-depth presentation of the research findings, please refer to the full project report.³

Overall, the 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.

Analysis of the NATSISS suggests that across all ages groups, Aboriginal and/or Torres Strait Islander people living with disabilities were more likely than other Aboriginal and/or Torres Strait Islander people to experience unfair treatment, avoid places where they have previously been treated unfairly and more likely to experience violence, threats and removal from their natural families. This suggests the importance of considering safety issues for people living with disabilities particularly in relation to engagement with the NDIS.

Community engagement is essential in ensuring community 'buy-in' for the NDIS and is recognised in the Aboriginal and Torres Strait Islander Engagement Strategy. However, in many communities the process outlined in the strategy¹ was either not implemented or implemented in a manner that had little impact on community engagement. Insufficient community engagement resulted in inadequate direct engagement with participants and meant they were often surprised by the initial contact with NDIA staff and/or unclear about purpose of meeting. This contributed to confusion and a fear that the outcome of the meeting might be to cut funding or deprive participants of existing benefits.

One way of strengthening community engagement is through expanding the use of Community Connectors. Community Connectors are unique as individuals who have direct access to information about the way the NDIS functions, speak in the first language of the NDIS participants, and know the local communities and families. Effective Community Connectors can create a cultural bridge between the NDIA and the community as well as supporting NDIS participants.

Local support providers have existing relationships with participants and a good understanding of their needs and can therefore also help to facilitate effective engagement between the NDIA and participants. However, even if they are attending planning meetings at the request of the participant, providers have been unable to speak on behalf of the participant because of perceived concern that they will represent their own interests and not that of the participant. While it is critical that conflicts of interest are managed, it is also important that meetings are held in a culturally safe way and information exchange is effective. Optimal plan development is compromised by unnecessary exclusion.

The need to improve understanding of the planning process for participants and their families was a key theme. It was felt that the planning process would be enhanced if resources were provided that identified who individuals involved in the NDIS are (such as NDIA staff), gave information about their role and explained what will be asked of participants during the planning process. For example, Synapse developed 'Yarn Up' cards to help participants identify their needs during planning meetings.⁴

The requirement to use interpreters with NAATI certification is laudable in terms of ensuring quality interpretation. However, lack of local certified interpreters made implementing this policy difficult and in some cases led to situations that were culturally confronting. Moreover, use of interpreters is not funded beyond the planning meeting. The ability to communicate and represent participant needs is, however, important to the effective development and ongoing implementation of participant plans.

Interviewees raised concerns regarding the quality of participant plans resulting from planning meetings. While most NDIS plans did include cultural elements, it was reported that connection to culture was seen as discretionary and not valued in the same way as other aspects of life. In some cases providers reported a lack of continuity between what was discussed at the planning meeting and the funded plan. Additionally, for some participants funding was reduced after the yearly plan review due to underutilisation of funding and supports in the previous year. This was seen as particularly unjust as underutilisation was frequently tied to a lack of access to supports in remote areas.

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.

An increase in appropriate providers is necessary to address the issue of thin markets in remote areas. However, the need for organisational change and associated administrative burden can be a disincentive to provider participation in the NDIS, including for ACCHSs. Currently, there is no seed funding to ensure that providers are able to implement the administrative and financial changes necessary to become registered providers, such as the installation of new IT systems that are compatible with NDIS payment systems.

Recommendations

RECOMMENDATION 1:

Implement the Aboriginal and Torres Strait Islander Engagement Strategy and develop a cultural competency framework

An overarching recommendation is to ensure the principles and processes outlined in the Aboriginal and Torres Strait Islander Engagement Strategy are implemented and the necessary cultural competency framework developed. The specific recommendations below outline how the implementation of the Aboriginal and Torres Strait Islander Engagement Strategy could be strengthened. In some cases, it may be necessary to provide support to enable family members and organisations important to the participant to meaningfully contribute to the decision-making process.

RECOMMENDATION 2:

Expand the Aboriginal and Torres Strait Islander Engagement Strategy

The NATSISS analysis suggests that the strategy should be expanded to consider the needs of parents, safety issues and the implementation of the NDIS for people who have been removed from their family, particularly younger people.

PEOPLE: ENGAGEMENT AND COMMUNICATION

RECOMMENDATION 3:

Strengthen community engagement

One way of strengthening community engagement is through expanding the use of Community Connectors. Effective Community Connectors can create a cultural bridge between the NDIA and the community as well as supporting NDIS participants. Redefining the Community Connector role to explicitly include the facilitation of community engagement could represent opportunities for two-way learning between the NDIA and communities. Community Connectors should also be more strongly involved in the process of engaging community/traditional leaders.

RECOMMENDATION 4:

Expanding, strengthening and supporting Community Connectors

The use of Community Connectors as interpreters/language and cultural brokers could enhance better support and understanding of the planning process for participants and introduce improved options for providing culturally

appropriate interpreting services. However, in order for Community Connectors to operate effectively, they must be adequately supported and integrated into the community engagement process. Community Connectors should be employed and appropriately resourced within all remote communities.

RECOMMENDATION 5:

Development of resources for participants and their families

A range of resources may be needed in order to address the diversity of Aboriginal and Torres Strait Islander communities and needs and the diversity of disabilities. It should be noted that the NDIA has developed a number of resources which could be evaluated, modified where necessary, and disseminated locally.

RECOMMENDATION 6:

Improved communication with participants before initial face-to-face meetings

Community Connectors and local support providers have important roles to play in engaging with participants to ensure that the process is clear and that their fears are allayed prior to the planning meeting. To facilitate this engagement, local providers should be adequately compensated for providing such support.

RECOMMENDATION 7:

Utilise existing participant-provider relationships in engagement and planning process

Provider involvement where appropriate will enable the NDIA to capitalise on existing provider relationships to build trust with participants. Clear policies and processes around provider engagement and discussions prior to meetings can assist in both managing potential conflicts of interest and ensuring cultural safety.

RECOMMENDATION 8:

Increasing and expanding use of interpreters

While using a certified interpreter should be the first choice in meeting with participants who do not have English as a first language, where this cannot accommodate important social/cultural mores other options (e.g. use of Community Connectors as language and cultural 'brokers') should be considered. The inclusion of funding for interpreting services is essential for ensuring equitable and appropriate support and therefore should be part of the participant plans.

SCHEME: IMPROVING PLANNING AND PROVISION

RECOMMENDATION 9:

Value cultural elements of participant plans, including return to country

It is necessary to ensure that implementation of participant plans and associated funding reflect the importance of culture to Aboriginal and/or Torres Strait Islander participants.

RECOMMENDATION 10:

Ensure participant plans are consistently funded according to needs discussed in planning meetings

Providing an explicit rationale linking the planning meeting discussion and participant plan would help to ensure that the plans reflect the discussion as understood by all involved parties. NDIA staff confirmed that there is no 'use it or lose it' policy and highlighted the need to address this issue.

RECOMMENDATION 11:

Strengthen the local Aboriginal and/or Torres Strait Islander support workforce

There is a clear need to build a local Aboriginal and/or Torres Strait Islander workforce to support the implementation of the NDIS. This could increase community and participant understanding of the NDIS, improve cultural safety, strengthen links with the community and improve continuity. However, further engagement with communities may be required to improve the profile of the NDIA and ensure that it is seen as an employer that people are comfortable working with.

PROVIDERS: STRENGTHENING SYSTEMS

RECOMMENDATION 12:

Develop hybrid models for support provision for remote areas

Providers suggested hybrid approaches which privilege individual preferences but also support aggregation or pooling of resources and provide time-limited certainty of funding (secure block-based funding). Such an approach should provide access to support to build technical capacity that tapers gradually as capacity is built. This might also support funding across other programs and/or sectors.

RECOMMENDATION 13:

Better support for organisations under current approach

The NDIS requires a different approach to support the organisational changes and capacity building for support providers. Support for organisational change around participation in the NDIS may be important to expanding markets and strengthening the participation of ACCHSs.

References

1. National Disability Insurance Agency. Aboriginal and Torres Strait Islander Engagement Strategy. 2017.
2. Australian Bureau of Statistics. 4720.0 - National Aboriginal and Torres Strait Islander Social Survey: User Guide, 2014-15 2016 [Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/0/880A750EFFDE2611CA2570BF007B1CD4>].
3. Ferdinand A, Massey L, Cullen J, Temple J, Chamravi D, Meiselbach K, et al. Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities. Melbourne, Australia: Centre for Health Policy, University of Melbourne; 2019.
4. Synapse. Connecting Aboriginal and/or Torres Strait Islander Peoples with the NDIS [Available from: <https://synapse.org.au/support-services/indigenous-services/connecting-aboriginal-and-or-torres-strait-islander-peoples-with-the-ndis.aspx>].

The Lowitja Institute

PO Box 650, Carlton South

Victoria 3053 Australia

t +61 3 8341 5555

e admin@lowitja.org.au

w www.lowitja.org.au

© The Lowitja Institute, 2019