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

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Acronyms

ABS	Australian Bureau of Statistics
ACCHS	Aboriginal Community Controlled Health Services
ARF	Access Request Form
AT	Assistive technology
ECEI	Early Childhood Early Intervention
FPDN	First People Disability Network
LAC	Local Area Coordinator
MJD	Machado-Joseph Disease
MJDF	MJD Foundation
NAATI	National Accreditation Authority for Translators and Interpreters
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-governmental organisation
PRG	Project reference group

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Executive summary

The project

As a major change in the way 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 Torres Strait Islander people – challenges and opportunities*, was developed to examine the:

- Implementation of the NDIS Aboriginal and Torres Strait Islander Engagement Strategy (1);
- 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 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. These organisations have longstanding connections with Aboriginal and Torres Strait Islander communities in the Northern Territory and Queensland respectively. The project built on these strong relationships with Aboriginal and Torres Strait Islander communities, which enabled intimate access to participants, resource sharing and the expertise of highly experienced disability and community service professionals across design, planning and data gathering phases of the project.

The project was designed to enable Aboriginal and Torres Strait Islander leadership of the research in project development, implementation and dissemination. The project recognised a need to ensure this leadership reflects the views of Aboriginal and Torres Strait Islander researchers, people and families affected by disability and the community controlled health and disability sector across a spectrum of settings.

Methods

This project was approved by the Human Research Ethics Committee for the Northern Territory Department of Health and the Menzies School of Health Research (HREC 2018-3175).

The project involved four phases:

1. Establishment of a project reference group
2. Co-design
3. Data collection and analysis
4. Reporting and review

Phase 1: Establish project reference group

The project began with the establishment of a project reference group (PRG), which included key experts and representatives from agencies most likely to adopt project findings into policy. It included the research team, community members and staff from the Lowitja Institute and the NDIA.

Phase 2: Co-design

Co-design is a two-stage approach to health systems and service improvements that typically involves an information-gathering stage followed by a co-design stage (2). The co-design process for the development of the evaluation plan (see Figure 2) integrated the roundtable process developed by the Lowitja Institute (3), which is recognised as being both highly productive and culturally safe (2).

Phase 3: Data collection

Sites for the project included Cairns, Townsville and four East Arnhem communities. A total of 54 people were interviewed: 4 NDIA staff members, 24 NDIS participants, 16 disability support providers, 2 organisational partners and 8 Community Connectors. Participant interview schedules were designed to align with the different steps taken by participants to obtain access to the NDIS, develop a participant plan and access supports (Figure 4). Interviews with NDIA staff, providers and partner organisations covered various aspects of engaging with community, NDIS funding arrangements, the process of registering providers, developing participant plans and providing culturally appropriate support (Figures 5 and 6). Community Connector interviews focused on community and participant engagement, the training provided by the NDIS, developing participant plans and understanding of the NDIS (Figure 7). Interviews with NDIS participants were conducted by experienced fieldworkers familiar with local communities and language. Interviews were audio-recorded where consented to by participants. Where interviews were audio-recorded, they were then transcribed, otherwise notes of the interview were provided by the interviewer. To ensure data integrity and enhance analysis, all transcriptions were cross-checked by the research team. Both transcripts and notes were entered into NVivo and coded for thematic analysis.

There is very little statistical data available about the experiences of Aboriginal and Torres Strait Islander people living with disabilities compared to Aboriginal and Torres Strait Islander people without disabilities. In order to better understand the context of data collected in this study, data from the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) was analysed. The NATSISS is conducted by the Australian Bureau of Statistics (ABS). The survey instrument covers a range of subjects encompassing language and culture, health, employment and access to services. In this study the responses of people living with (n=2798) and without (n=3285) disabilities to questions about exposure to unfair treatment, avoiding situations because of unfair treatment, exposure to violence, exposure to threats and removal from natural family were considered. The situations where people reported that they were exposed to unfair treatment were also examined.

Phase 4: Reporting and review

A final co-design workshop was held to review the extent to which the findings of the project resonated with key stakeholders, to refine recommendations and to develop clear suggestions for action.

Recommendations

Overall, the NDIS is a scheme that has the potential to significantly benefit Aboriginal and Torres Strait Islander people living with disability. The NDIA has acknowledged that culturally appropriate engagement and delivery is a necessary component of the support required by Aboriginal and Torres Strait Islander people living with disabilities. However, there remain significant issues in the on-the-ground implementation of the NDIS, particularly in remote locations. The results of the study have informed recommendations for the implementation of the Aboriginal and Torres Strait Islander Engagement Strategy and development of the cultural competency framework, communication and engagement with Aboriginal and Torres Strait Islander

people and communities, improving participant plans and the provision of disability supports, and strengthening the capacity of organisations to provide appropriate disability support.

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 cultural competency framework developed. The specific recommendations below outline how the implementation of the Aboriginal and Torres Strait Islander Engagement Strategy could be strengthened. It is particularly important to ensure that NDIS participants' preferences around support and decision-making during planning are respected. In some cases, where a collective rather than individual approach is preferred, 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 results of NATSISS analysis suggest that across all ages groups, Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and Torres Strait Islander people to experience unfair treatment and avoid places where they have previously been treated unfairly. Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and Torres Strait Islander people to experience violence, threats and removal from their natural families. They also suggest 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

Community engagement is essential in ensuring community 'buy-in' for the NDIS and is recognised in the Aboriginal and Torres Strait Islander Engagement Strategy. It was clear in this study that in many communities the triple 'I' process outlined in the strategy (Introduction by a local community member, Initiate follow up contact to demonstrate commitment, and Invitation to return by the community) (1) was either not implemented or implemented in a manner that had little impact on 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. In this way, Community Connectors could facilitate 'place based' responses by providing information on community needs and contextual factors that may affect how the NDIS functions. Community Connectors should also be more strongly involved in the process of engaging community/traditional leaders. This would both ensure that Community Connectors are aware of the degree of support of community leaders and can provide an opportunity to open a channel of communication between these leaders and the NDIA.

Recommendation 4: Expanding, strengthening and supporting Community Connectors

The importance of enhanced involvement of Community Connectors in community engagement is outlined above. Community Connectors are also unique in their positioning 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. They are therefore in an ideal position to facilitate better communication

during planning meetings. In conjunction with Recommendation 7, 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. The development of explicit guidelines around the Community Connector role could facilitate a clearer understanding of how they could be best utilised.

However, in order for Community Connectors to operate effectively, they must be adequately supported and integrated into the community engagement process. Interviewed Community Connectors highlighted the need for enhanced and ongoing training from the NDIA to broaden their understanding of the NDIS and its components. Training could also be used as an opportunity to clarify the Community Connector roles. This training should be underpinned by a place-based approach, tailored to communities and incorporate Aboriginal and Torres Strait Islander ways of understanding and acting, in order to improve relevance to the local context. The interviewed Community Connectors were particularly supportive of activities such as role playing in training. Using a peer-to-peer approach where more experienced Community Connectors take on parts of the training may also increase relevance, understanding and acceptance.

Given the importance of the Community Connector position, Community Connectors should be employed and appropriately resourced within all remote communities. Having a stable workforce of locally based people will further develop local capacity. It is essential that adequate resources are allocated for the attraction, retention and supervision of appropriate personnel. Engaging and retaining Community Connectors necessitates honouring their connections to community, including their cultural obligations. A flexible approach that supports these obligations will involve allowing for adequate amounts of cultural leave.

Recommendation 5: Development of resources for participants and their families

Lack of understanding of the NDIS particularly leading into and during the planning process highlighted the need for the development of additional resources for participants and their families. It was reported that resources should be developed to support planning meetings. For example, Synapse developed 'Yarn Up' cards to help participants identify their needs during planning meetings (4). Specifically, it was felt that the planning process would be enhanced if resources 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. Such resources should include pictorial representation and a minimal amount of text, keeping language simple or translated. 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 and disseminated locally.

Recommendation 6: Improved communication with participants before initial face-to-face meetings

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 a sense that 'purple people were popping up' and a fear that the outcome of the meeting might be to cut funding or deprive participants of existing benefits. In many remote communities it is difficult to contact people directly (e.g. no mailing addresses and unreliable mobile phone connections) and communication can only be managed via facilitation through third parties. This again highlights the importance of Community Connectors and local support providers in engaging with participants to ensure that the process is clear and that their fears are allayed prior to the planning meeting. In order 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

Local support providers have existing relationships with participants and a good understanding of their needs. However, the role of local support providers in planning meetings has been limited and unfunded. Even if they are attending at the request of the participant, providers have been unable to speak on behalf of the participant because of concern that they will represent their own interests and not that of the participant--a situation characterised as shameful for both the provider and the participant. While it is critical that conflicts of interest are managed, it is also important that participants are able to access support that will enable meetings to be held in a culturally safe way. Provider involvement where appropriate will also enable the NDIA to capitalise on existing provider relationships to build trust with participants. Privileging participant preferences for the conduct of meetings is important for cultural safety particularly in initial engagement. 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

The requirement to use interpreters with NAATI certifiation is laudable in terms of ensuring the quality of interpretation. However, lack of certified interpreters made implementing this policy difficult and in some cases led to situations that were culturally confronting, for example where the interpreter was culturally inappropriate to be involved in the transmission of intimate information. 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 then other options (e.g. use of Community Connectors as language and cultural 'brokers') should be considered. This is particularly important if the only alternative is delays in implementation or the use of culturally inappropriate interpreters. Currently, use of interpreters is not funded beyond the planning meeting, as not having English as a first language is not regarded as related to a participant's disability. The ability to communicate and represent participant needs is, however, important to the development and implementation of an effective plan. The inclusion of funding for interpreting services is therefore 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

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. The Aboriginal and Torres Strait Islander Engagement Strategy recognises the centrality of culture, particularly connection to country, for Aboriginal and Torres Strait Islander people. It is therefore necessary to ensure that implementation of participant plans and associated funding reflect the importance of culture to Aboriginal and Torres Strait Islander participants.

Recommendation 10: Ensure participant plans are consistently funded according to needs discussed in planning meetings

In some cases there was a lack of continuity between what was discussed at the planning meeting and the funded plan from the perspective of providers. 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. 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. NDIA staff on the PRG 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 Torres Strait Islander support workforce

There is a clear need to build a local Aboriginal and 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

Many providers familiar with block funding mechanisms found it difficult to transition to a more individualised approach to funding. However, there was also a recognition that block funding alone did not meet the needs of Aboriginal and Torres Strait Islander people living with disabilities. In remote areas, an 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. Features of this model would include more flexibility around support coordination, respite (short term accommodation), and transport. In remote areas, better support provision by governments, and more collaboration with and between support providers is needed (5).

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 need for organisational change and the associated administrative burden can be a disincentive to participating in the NDIS for current and potential providers, including for providers whose core business is not disability services but who might be well equipped to provide such supports, such as ACCHSs. The NDIS therefore requires a different approach to funding models to support the organisational changes and capacity building for support providers. 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. Support for organisational change around participation in the NDIS may be important to expanding markets and strengthening the participation of ACCHSs.

Background

Introduction

Described as the largest reform of the Australian disability services sector (6-8), the National Disability Insurance Scheme (NDIS) was introduced in 2013 by the Federal Government of Australia. Managed by the National Disability Insurance Agency (NDIA), the NDIS was initially trialed in selected communities in 2013, with a gradual national roll-out to all communities in Australia beginning in 2016 (7). The purpose of the reform was to provide tailored, personalised funding packages for disability supports to Australians living with permanent and significant disability. One of the key overarching aims of the NDIS is to help empower Australians living with disability by providing them with the choice of 'reasonable and necessary' supports to enhance independence, participation and quality of life (7). There is no set definition of what constitutes 'reasonable and necessary' but the NDIA considers whether the support will:

1. Assist the participant to pursue the goals, objectives and aspirations agreed to in their plan
2. Assist the participant's social and economic participation
3. Represent value for money
4. Be, or likely to be, effective and beneficial for the participant
5. Take into account what is reasonable to expect families, carers, informal networks and the community to provide
6. Be appropriate for the NDIS to fund or provide

Part of the significance of the NDIS is that it has enacted a shift from block funding of disability organisations to market-based support provision through individualised funding packages (9, 10).

People are eligible for the NDIS if they are an Australian citizen, permanent resident or permanent visa holder, are under 65 years of age when they enter the scheme and have a permanent (lifelong) and significant disability. An annual cycle of plan development and review is undertaken once people have been assessed as eligible and their first plan developed. Participants have three options to manage their participant plans. If participants choose to have their plans managed by the NDIA (i.e. agency managed), then their choice of providers is restricted to NDIS registered providers. If they choose self-managed plans then they have their choice of providers but must provide an upfront payment which will then reimbursed by the NDIA at a later time. If participants choose to have their plans managed by another organisation (i.e. plan managed), then that organisation must be registered with the NDIS but the providers engaged by the participants do not have to be registered. The vast majority of NDIS participants choose to have their plans managed by the NDIA.

Aboriginal and Torres Strait Islander people are disproportionately affected by disability and often not well served by mainstream services. The 2011 Census indicated that Aboriginal and Torres Strait Islander people experience profound or severe disability at higher rates than non-Indigenous Australians at all ages, with 6.1% of Indigenous males and 5.4% of Indigenous females reporting a profound or severe disability (11). The Australian Bureau of Statistics found in 2015 that Aboriginal and Torres Strait Islander people were 1.8 times more likely than non-Indigenous people to be living with a disability (12). The First People Disability Network (FPDN) estimates that the current number of Aboriginal and Torres Strait Islander people nationally eligible for participation in the NDIS is around 60,000, although the NDIA disagree with this assessment (13).

The high prevalence of disability in Aboriginal and Torres Strait Islander communities has led to strong advocacy and the development of culturally competent service models by the community controlled and NGO sectors to meet these needs. Whilst the NDIS presents an opportunity to improve the provision of disability supports for Aboriginal and Torres Strait Islander people living with disabilities, the successful implementation of the scheme faces significant challenges. The NDIA publishes Quarterly Reports, which details the number of Aboriginal and Torres Strait Islander people enrolled in the scheme. However, data regarding participant outcomes and participant experiences are not disaggregated, which makes it difficult to identify the specific impacts on Aboriginal and Torres Strait Islander people (14).

Due in part to the high prevalence and level of need amongst Aboriginal and Torres Strait Islanders living with disabilities, the NDIA developed the 2017 Aboriginal and Torres Strait Islander Engagement Strategy (1) in consultation with Aboriginal and Torres Strait Islander people and people who are not Aboriginal or Torres Strait Islander. The NDIA outlines the following principles as underpinning the Aboriginal and Torres Strait Islander Engagement Strategy:

- Centrality of Country, Culture and Community
- Human rights
- Inclusion in mainstream services is as important as specialist disability services
- Universal consideration of disability
- Meaningful engagement with Aboriginal and Torres Strait Islander peoples with disability
- Improving the evidence base on Aboriginal and Torres Strait Islander peoples with disability

In the strategy, the NDIA also identified ten key priority areas for working with and supporting Aboriginal and Torres Strait Islander people living with disability:

- Communication and sharing of information
- Cultural competency
- Sharing best practice
- Local solutions—participant-centric design
- Market enablement
- Leveraging and linking
- Cultural leadership
- Supporting internal infrastructure, and
- Tracking progress

The strategy is largely principles-based and does not outline specific competencies, training and support required for implementation of the NDIS for Aboriginal and Torres Strait Islander communities. This is partly because the development of a cultural competency framework based on the strategy is foreshadowed but has not been developed. However, the strategy does outline a 'triple I' consultation process designed to take place with communities before working with individuals. This involves the *Introduction* to the community by a trusted community member, *Initiation* of follow-up contacts and *Invitations* back to the community (1). The evaluation framework for the pilot of the NDIS also recognises the importance of assessing the extent to which the NDIS is meeting the needs of Aboriginal and Torres Strait Islander people (15). This is difficult to determine, however, as no data on Aboriginal and Torres Strait Islander people were included in the interim evaluation report (16).

The NDIA also released the 2016 Rural and Remote Strategy (17) which outlines the key challenges and planned strategies to address issues which are faced by those living with disability in rural and remote

communities. The NDIA concluded from feedback from other agencies and trial sites that the key challenges faced by rural and remote communities were:

- Limited service choice and availability
- The need for travel and transportation
- Difficulties with recruiting, training and retaining professionals
- Issues relating to support quality
- Lack of alternative accommodation options

Unlike the Aboriginal and Torres Strait Islander Engagement Strategy, the Rural and Remote Strategy provides clear outlines of the challenges, trial roll-out results, success indicators, proposed improvement areas and indicators of progress. Outcomes since the publication of this report on the progress of key areas have not been published but both the Aboriginal and Torres Strait Engagement Strategy and Rural and Remote Strategy have reviews planned for 2019.

In order to facilitate community engagement and roll-out of the NDIS, Aboriginal and Torres Strait Islander Community Connectors operate in some remote communities. Community Connectors are employed through partner organisations and are provided training by the NDIA. Their primary role is to provide a link between the NDIA and participants, help guide NDIS participants through the planning and assessment process and support community awareness of the scheme.

Key challenges and themes

Challenges facing Aboriginal and Torres Strait Islander participants

The Aboriginal and Torres Strait Islander understanding of disability and health can be markedly different than that of non-Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander people often view health in a holistic or broad sense, encompassing not only their own physical health, but also cultural, communal and spiritual elements (18-20). In many Aboriginal and Torres Strait Islander language groups, there is no equivalent word for 'disability' or for specific disabilities (18, 20-23), and many Aboriginal and Torres Strait Islander people living with disabilities do not self-identify as having a disability (18, 19). Culturally, disability may be seen as an integrated part of the human experience, or unique to the individual living with the disability (21). The language of disability and under-identification of disability can therefore serve as a barrier (19) by contributing to under-reporting and under-utilisation of disability services (6, 21). In addition, it is likely that the number of Aboriginal and Torres Strait Islander peoples living with a disability is significantly under-represented, and they are therefore not receiving the support services that they need. This is demonstrated in the contrast between the FPDN estimate that 13% of the total Aboriginal and Torres Strait Islander population is living with a disability (13) and the NDIA estimate that this proportion is 7% of the population (24).

As kinship is an important element of Aboriginal and Torres Strait Islander family structures and way of life, caring for family members with a disability is often considered to be a responsibility of family members, rather than external support workers or support providers (23, 25). These carer obligations might be a burden on family members, particularly when the disability is complex and when other family members require support as well (22). Recognising and building family and community support into NDIS plans is a key challenge for participants as well as the NDIA.

Geographical and logistical access to services is a significant issue for Aboriginal and Torres Strait Islander people living with disabilities living in regional, remote and very remote areas. Limited or non-existent

accessible transport options, inadequate housing and over-crowding may also serve as barriers to NDIS utilisation and support provision (20, 21, 23). Due to the remoteness and lack of public transport in some communities, many people are forced to use private resources or taxis for transport, which can easily become extremely expensive; therefore, many Aboriginal and Torres Strait Islander people in remote communities (as well as their carers and families) can become socially isolated and cut off from important cultural and communal activities, as well as needed health services (26). In addition, many Aboriginal and Torres Strait Islander peoples live in the often harsh physical environment of remote Australia, and housing, assistive technology (AT) and equipment is often ill-adapted for such environments (26, 27).

In many rural and remote communities, whilst funding has been approved and allocated to the individual, there is a general dearth of NDIS registered disability support providers (22). Poor and seasonal weather conditions, limited accessibility and lack of infrastructure may also lead to support providers being regularly unable to access remote Aboriginal and Torres Strait Islander communities (23). These issues can lead to Aboriginal and Torres Strait Islander people living with disabilities either travelling frequently or needing to move themselves and their families away from their community in order to access needed supports (22). Under current implementation, the rigidity of the NDIS funding approval process does not allow for Aboriginal and Torres Strait Islander participants to use their plan's core budget for travel in relation to return to country, which is an important aspect of Aboriginal and Torres Strait Islander culture and spirituality (28). Given the importance of kinship, connection to the land and to family and community, dislocation can have a significant impact to the wellbeing of Aboriginal and Torres Strait Islander people living with disabilities, their carers and families (23).

Linguistic and cultural accessibility to NDIS funded supports is also an issue for Aboriginal and Torres Strait Islander people living with disabilities, who often face language barriers when trying to communicate their needs and access supports (22). There is a lack of awareness of what the NDIS is and how it works in both urban and rural Aboriginal and Torres Strait Islander communities (19, 20), as well as about the disability support system in general (18), though this may change with continued roll-out of the NDIS.

Challenges facing support providers

One of the underlying assumptions of the NDIS is that the new consumer-led funding model will increase the demand for disability supports and result in new market opportunities for support providers. However, as many Aboriginal and Torres Strait Islander people live in remote and rural communities with sparse, widely spread populations, there are relatively fewer providers operating, resulting in a 'thin' market. There is also limited lived experience of disability and other supports by participants. It is difficult for participants to envision things they have never experienced (29), consequently they may not seek supports that may be beneficial, hindering market growth.

Support providers also face financial risk setting up and running as a registered NDIS support provider and there is currently no seed funding available to assist with technical or other developments necessary to develop NDIS capacity (18). It is therefore very unlikely that market mechanisms alone will cater for adequate support provision for Aboriginal and Torres Strait Islander people living in very small remote communities across Australia (18). Other mechanisms will be necessary to stimulate growth in support providers and counter the thin market.

The change from block funding to individualised funding models has led to support providers spending extra time and money on complex NDIS procedures in order to receive payment. This reduces the resources available for direct support provision (28). Many support providers have found the change in funding models

so disruptive that they have been forced to make staff redundant or consider closing the organisation (9). The NDIA and State and Territory governments recognise these issues in principle and have made attempts to redress them by implementing some initiatives designed to support a stronger disability services market in remote locations. For example, in 2017 the Northern Territory government introduced a $2 million Innovation Grant Project designed to support local providers, increase local jobs, promote local-decision making and help to reshape the disability market in the Northern Territory (30) while in 2017 the NDIA began to offer Information, Linkages and Capacity Building (ILC) Grants in order to build organisational capacity to provide support to people living with disabilities (31).

Transportation costs have emerged as a significant issue. Support providers tend to cluster in larger regional centres as there is limited accommodation and infrastructure capacity to sustain permanent business models in rural and remote communities. Rural and remote providers frequently need to travel extensive distances to participants to deliver supports (28). However, the NDIS support provider transport allowance only allows the provider to charge up to 45 minutes of travel time, which forces providers to absorb travel costs in excess of this or choose not to provide supports to participants in remote areas (28). In an attempt to address this issue in some cases, the NDIA is approving the use of therapy hours (or Support Coordination hours) across multiple participants' NDIS plans to fund provider travel; however, the approval process for this remains inconsistent and unclear.

Maintaining cultural competence and accessibility is problematic as very few ACCHSs are registered as NDIS providers (19). The reasons for this are varied with NACCHO having cited three main barriers: pricing of services below cost to the provider, lack of available disability workers and the need for upfront investment (32). Additionally, in remote communities where food, housing and safety are primary concerns, many supports regarded as valuable by participants may not fit within the NDIA's current definition of 'reasonable and necessary', and therefore may not be eligible for funding (29). To address the issues of having a thin market and assist potential support providers in registering and transitioning to the NDIS, additional business resources, capacity building, localised flexibility and NDIA support is required (24).

Challenges facing the NDIA and NDIS

Insufficient statistical data regarding the prevalence and needs of Aboriginal and Torres Strait Islander people living with disabilities, as well as a lack of culturally appropriate assessment instruments and processes, present as significant challenges to successful implementation of the NDIS (22, 33-35). Assessment and planning for NDIS eligibility need to be undertaken in a culturally-appropriate and holistic manner, so that it incorporates Aboriginal and Torres Strait Islander perspectives of health and disability, cultural practices (such as yarning and storytelling) and familial and communal roles of caring (19, 24, 35). The Guddi Protocol, developed by Synapse, has been assessed by Aboriginal and Torres Strait Islander peoples as a culturally safe and appropriate method of engagement and has been utilised in rural and remote communities in supporting Aboriginal and Torres Strait Islander people to access the NDIS (35).

Cultural competence and maintaining the cultural diversity of the NDIS workforce is a major challenge facing the NDIA (7, 20). Holistic understanding and respect for Aboriginal and Torres Strait Islander sociocultural practices, protocols, perspectives and sensitivities is needed when working with Aboriginal and Torres Strait Islander individuals, communities and community-controlled health services (19). A distinct lack of community input, control and ownership of the NDIS is currently apparent, and is amplified by the inflexibility of the scheme in relation to application with Aboriginal and Torres Strait Islander peoples and communities (29). Service co-design may be a solution to challenges surrounding cultural competence of the NDIS roll-out and assist to ensure cultural appropriateness in providing disability supports within remote communities (19).

This would enable the NDIS to incorporate a place-based response, accounting for different communities, linguistic and cultural groups, and geographical specificities (24). Effectively engaging with Aboriginal and Torres Strait Islander peak bodies, such as FPDN and the National Aboriginal Community Controlled Health Organisation (NACCHO), is also imperative to ensuring the cultural relevance of the NDIS (19) and this should be mirrored at a local level with community leaders. Establishing and sustaining an Aboriginal and Torres Strait Islander disability workforce (including training and mentoring, career development opportunities and dedicated Aboriginal and Torres Strait Islander roles and/or teams), will additionally be required to support culturally safe practice (7, 20).

English is not the first language for many Aboriginal and Torres Strait Islander people (36), so it is imperative that culturally and linguistically accessible information about the NDIS, how it works and how to access it is being provided in an effective and comprehensible manner (20, 22). Appropriate resource development should involve local co-design to ensure applicability.

Another challenge facing the NDIA, though not specific to the NDIS, is Aboriginal and Torres Strait Islander people's fear, mistrust and/or hesitance to engage with government agencies or support providers, consequent to intergenerational and historical racist treatment, social exclusion and discrimination experienced by Aboriginal and Torres Strait Islander communities (18, 20, 22). Therefore, it needs to be acknowledged that changing the patterns of mistrust within these contexts will necessitate a broad systemic and ecological change that incorporates trauma-informed approaches at individual, family, community and policy levels.

Central to the success of the NDIS roll-out in rural and remote communities is capacity to address longstanding issues related to inadequate infrastructure, housing and health service provision (20, 23). Far from being a panacea for such long established issues, however, it has been noted that the NDIS will be unable to provide funding to adequately address shortfalls in the provision of safe, appropriate housing for Aboriginal and Torres Strait Islander people living with disabilities. For example, while the NDIS does include funding for modifications to housing to improve independence of people living with a disability, due to dilapidated housing conditions and numerous pre-existing health and safety issues, making modifications to existing housing can be a redundant and ineffective process (21).

As a way of addressing issues related to infrastructure, housing, health service provision and accessibility, start-up funding to assist support providers with meeting the NDIA's Registered Support Provider requirements has been suggested (23). The NDIA provides funding based on what it considers 'reasonable and necessary' needs. However, as discussed, the understanding of 'reasonable and necessary' needs may differ significantly for Aboriginal and Torres Strait Islander people, particularly in disadvantaged remote communities where disability-specific needs may be a lower order priority compared with food housing and safety concerns (29).

Historically inadequate service provision has resulted in the carer role traditionally having been provided by family in many Aboriginal and Torres Strait Islander communities. Legitimising and formalising these support arrangements by facilitating payments and training to family carers, capacity building programs, cultural brokerage and broadening the range of supports included in NDIS packages may be a mechanism for the NDIA to better help enable Aboriginal and Torres Strait Islander people living with disabilities to receive the support they need, especially in rural and remote areas (18, 24, 34, 35) . As previously noted, it is also critical for funding to adequately compensate for access and transport needs, particularly in regional and remote communities, where access to specialist supports can be limited (18).

These key challenges and structural responses to them are reflected in Figure 1 which was generated by the Inside Policy workshop (titled: *Economic development opportunities for Aboriginal and Torres Strait Islander Australians & the National Disability Insurance Scheme*), which was organised for the Prime Minister's Aboriginal and Torres Strait Islander Advisory Council in 2017 (24).

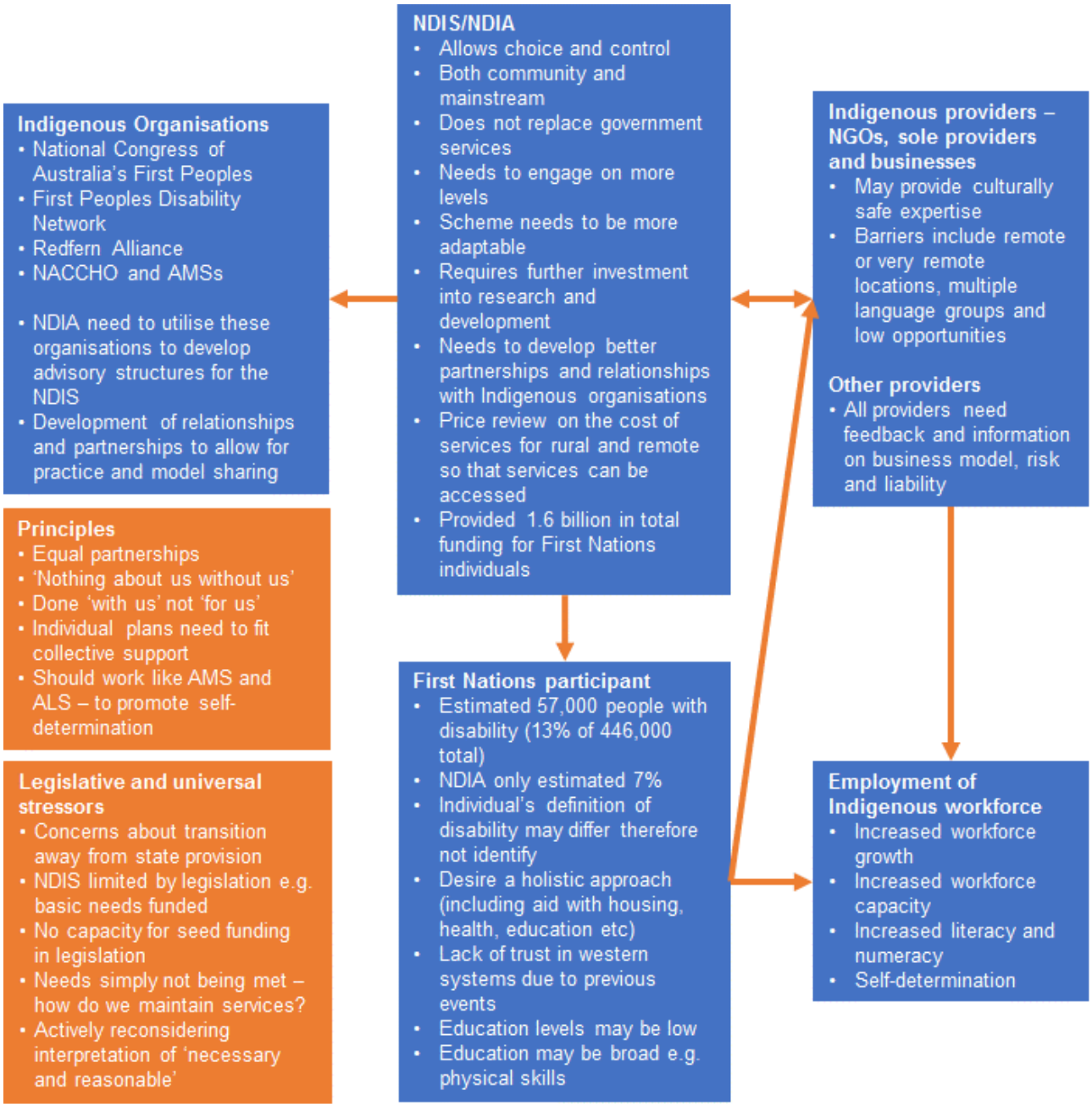

Figure 1. Mind map of key challenges facing the NDIA, providers and Aboriginal and Torres Strait Islander adapted from the Inside Policy workshop (24)

The project: Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities

As a major change in the way supports for people living with disability are funded, the NDIS presents both opportunities and significant challenges. The current project was developed to examine the following dimensions of NDIS implementation in the Northern Territory and Queensland:

- Implementation of the NDIS Aboriginal and Torres Strait Islander Engagement Strategy (1);
- Interaction between NDIA staff, local area coordinators (LACs) and ACCHSs and NGOs;
- Experiences of Aboriginal and Torres Strait Islander people in accessing the NDIS, planning, and receiving supports.

The research was conducted in collaboration with the MJD Foundation (MJDF) and Synapse. These organisations have longstanding connections with Aboriginal and Torres Strait Islander communities in the Northern Territory and Queensland respectively. The project built on these strong relationships with Aboriginal and Torres Strait Islander communities, which enabled intimate access to participants, resource sharing and the expertise of highly experienced disability and community service professionals across design, planning and data gathering phases of the project.

Synapse is a national organisation which has undertaken targeted research activities for 34 years. Synapse are committed to reducing the disadvantage that Aboriginal and Torres Strait Islanders living with disability face and are working to connect more Aboriginal and Torres Strait Islander people with the NDIS.

The MJD Foundation is a charity that was founded in 2008 which works in partnership with Aboriginal Australians, their families and communities to support those living with Machado-Joseph disease (MJD). They provide comprehensive supports to clients living with MJD, provide education and training around the genetics of MJD to families/community/health professionals, work with communities to help them better understand MJD, and provide practical training for care workers and family carers to support them in caring for those living with MJD.

The project was designed to involve Aboriginal and Torres Strait Islander people in leading the research at all stages of project development, implementation and dissemination. The project aimed to ensure the leadership reflects the views of Aboriginal and Torres Strait Islander researchers, people and families affected by disability and the community-controlled health sector. This was achieved by recruiting a research team that included several Aboriginal researchers. Jennifer Cullen, CEO of Synapse, has extensive experience in the provision of a range of community-based services which provide benefits for people living with a disability and in leading research projects focused on supporting Aboriginal and Torres Strait Islander people living with neurocognitive disabilities. Yin Paradies, a Professor at Deakin University, provided his expertise on anti-racism and cultural competence theory, policy and practice to the team. Scott Avery from FPDN brought the leadership team a wealth of experience regarding advocacy and policy directions for Aboriginal and Torres Strait Islander people affected by disability. The team also included junior Aboriginal researchers and health workers who were mentored through the leadership team to build their capacity for future Aboriginal leadership in this important field. In addition to the research team, Aboriginal leadership was also an important aspect of the Project Reference Group (PRG). This was achieved by including numerous Aboriginal and Torres Strait Islander individuals and representatives from the Lowitja Institute in the PRG. The PRG also included representatives from the Aboriginal Community Controlled Health sector and Federal Government. Aboriginal and Torres Strait Islander people living with disabilities participated in all stages of the project, including the PRG, co-design process, data collection and analysis.

Methods

Co-design, or experience-based co-design, is an approach to not only actively involve consumers in the design, delivery and/or evaluation of services but also to enable the design of systems where consumer and carer experiences are central (37). The approach to the project brought expertise from Aboriginal and Torres Strait Islander organisations working to provide supports to people living with disabilities together with researchers and policy makers. The approach to design and data collection supported Aboriginal and Torres Strait Islander leadership, optimised existing data and knowledge, and developed local research capacity among Aboriginal and Torres Strait Islander people.

This project was approved by the Human Research Ethics Committee for the Northern Territory Department of Health and the Menzies School of Health Research (HREC 2018-3175).

The project involved four phases:

1. Establishment of a project reference group:
2. Co-design
3. Data collection and analysis
4. Reporting and review

Phase 1: Establish project reference group

The project began with the establishment of a project reference group (PRG), the members of which included key experts and representatives from agencies most likely to adopt project findings into policy. It included the research team, community and staff from the Lowitja Institute and the NDIA.

Phase 2: Co-design

Co-design is a two-stage approach to health systems and service improvements that typically involves an information-gathering stage followed by a co-design stage (2). The process used in this evaluation is outlined in Figure 2. The information-gathering stage included consultation with key stakeholders and brought together all information currently collected by support providers and NDIA on the roll-out of the NDIS to Aboriginal and Torres Strait Islander people.

The co-design process for the development of the evaluation plan (see Figure 2) integrated the roundtable process developed by the Lowitja Institute (3), which is recognised as being both highly productive and culturally safe, with the co-design process (2). This modification of the co-design process enabled it to occur in a single workshop. This process was used to finalise the approach to data collection.

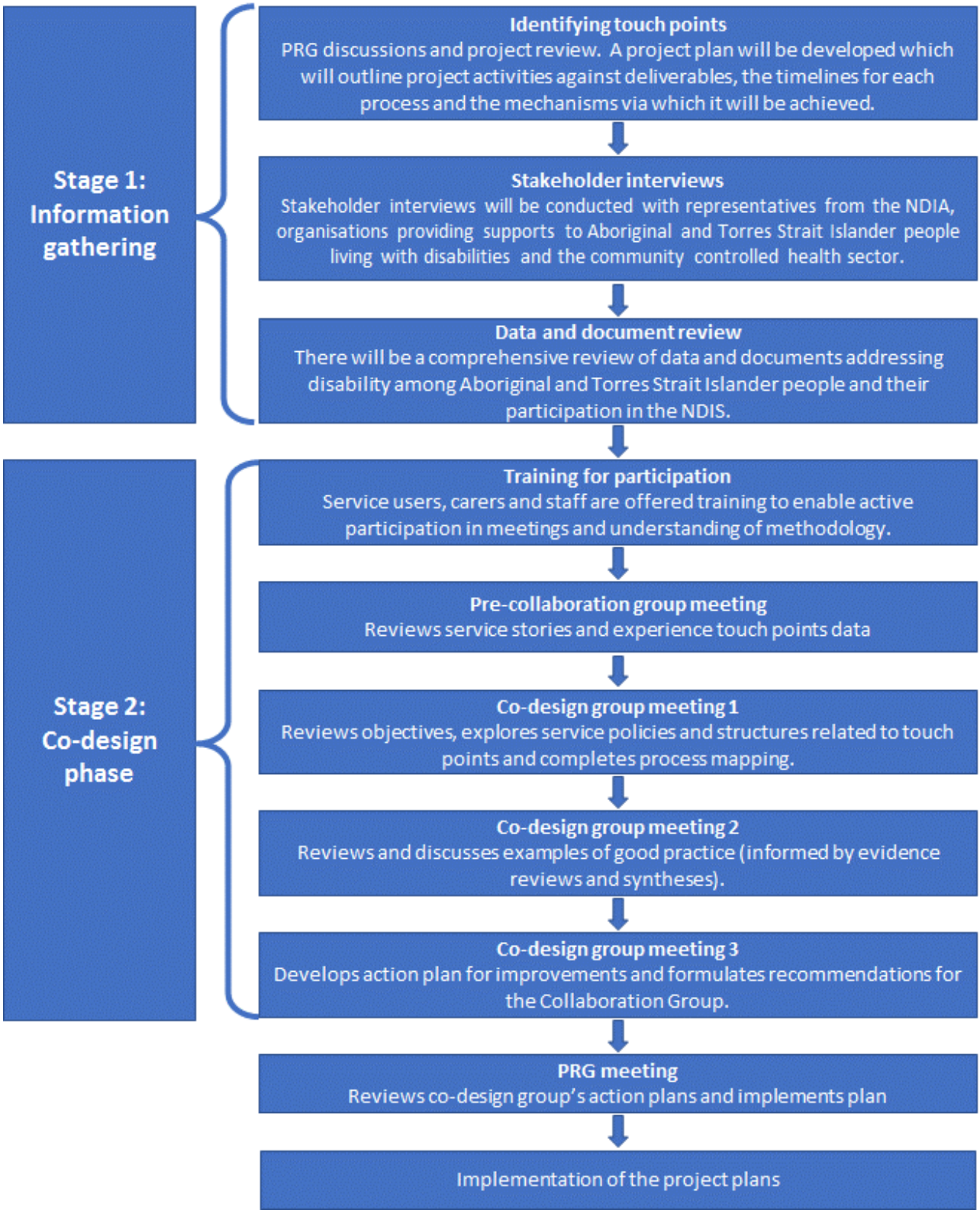

Figure 2. Two-stage co-design evaluation approach

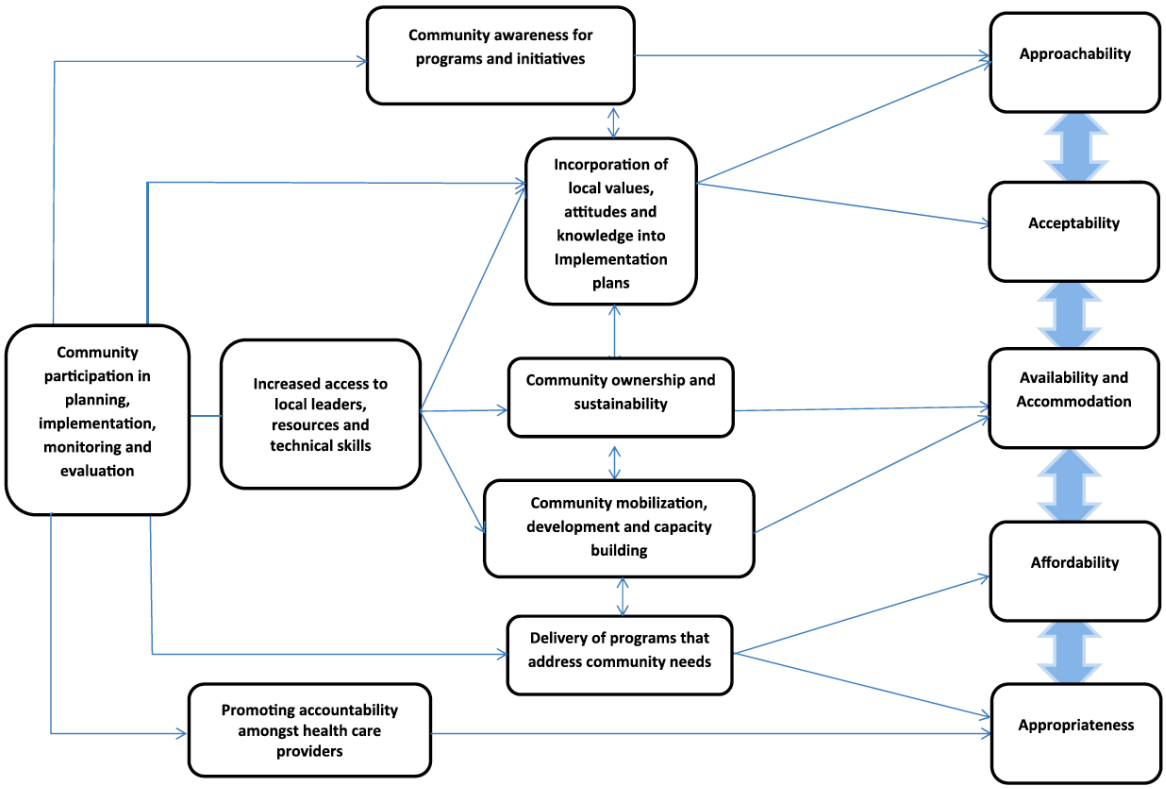

Figure 3. Link between Aboriginal and Torres Strait Islander engagement in services and improvement in equity of access

Phase 3: Data collection

Interviews

Sites for the project included Cairns, Townsville and four East Arnhem communities.

Interviews with NDIA staff and organisational partners were undertaken by University of Melbourne research team members. Support provider interviews were undertaken by University of Melbourne staff in the Northern Territory and a combination of University of Melbourne and Synapse staff in Queensland.

The interviews addressed the dimensions of access outlined in Figure 3 and the engagement process to support them (38). Participant interview schedules were designed to align with the different steps taken by participants to obtain access to the NDIS, develop a participant plan and access supports. Interviews with NDIA staff, providers and partner organisations covered various aspects of engaging with community, NDIS funding arrangements, the process of registering providers, developing participant plans and providing culturally appropriate supports. Partner organisations are organisations that do not provide direct disability

supports, but may provide support coordination, employ Community Connectors or collaborate with the NDIA in other ways. Community Connector interviews focused on community and participant engagement, the training provided by the NDIS, developing participant plans and understanding the NDIS (see Appendices 1, 2, 3 and 4). In the Northern Territory sites for this project, Community Connectors were employed through Miwatj Health Aboriginal Corporation.

Interviews were audio-recorded where consented to by participants. Where interviews were audio-recorded, they were then transcribed, otherwise notes of the interview were provided by the interviewer. To ensure data integrity and enhance analysis, all transcriptions were cross-checked by the research team. Both transcripts and notes were entered into NVivo and coded for thematic analysis.

Table 1. Number of NDIA staff, participants, disability support providers, organisational partners and Community Connectors who completed interviews per state

	Northern Territory	Queensland
NDIA	3	1
Participants	19	5
Disability support providers	2	14
Partner organisations	1	1
Community Connectors	8	

Figure 4. Structure of participant interviews

Figure 5. Structure of NDIA staff interviews

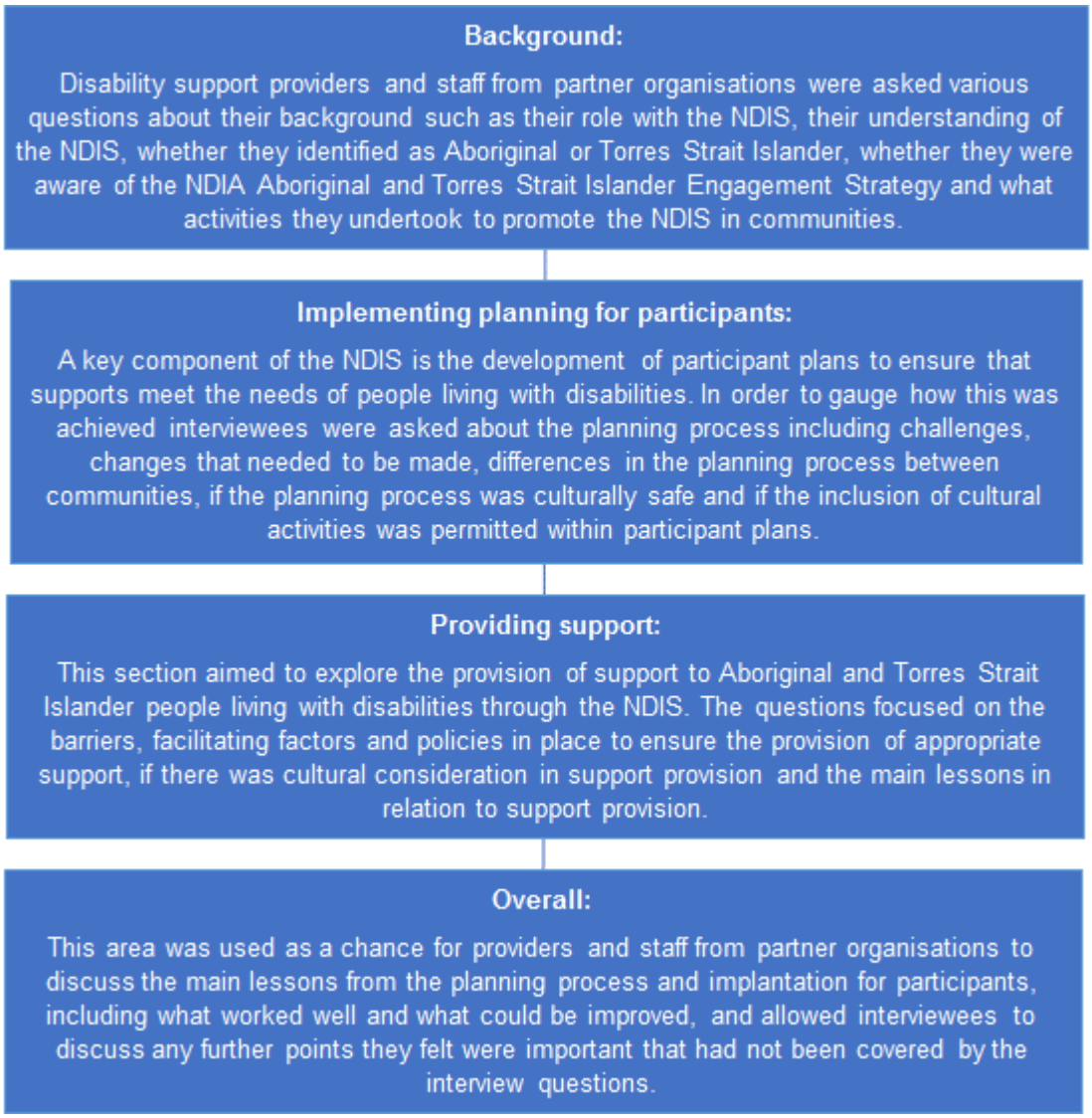

Figure 6. Structure of provider and organisational partner interviews

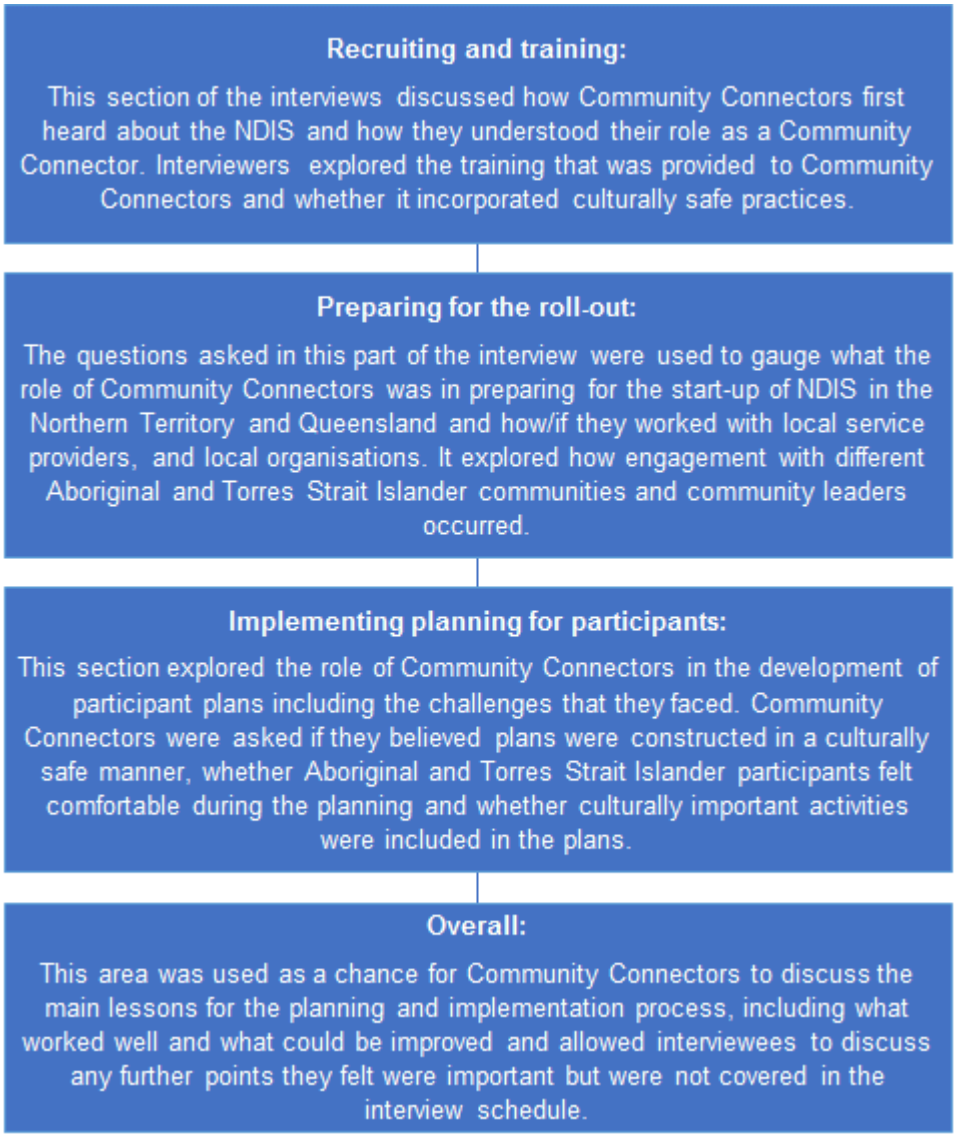

Figure 7. Structure of Community Connector interviews

Analysis of the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) data

There is very little statistical data available on the experiences of Aboriginal and Torres Strait Islander people living with disabilities compared to other Aboriginal and Torres Strait Islander people. In order to better understand the context of data collected in this study, data from the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) was analysed. The NATSISS survey is conducted by the Australian Bureau of Statistics (ABS). Data were collected using a computer-assisted interviewing questionnaire in a personal interview between September 2014 and June 2015 (39). The NATSISS is of multi-stage design, including Aboriginal and Torres Strait Islanders living in private dwellings in remote and non-remote areas, including discrete communities, across all Australian States and Territories. Discrete communities include 'regions inhabited or intended to be inhabited predominately by Aboriginal and Torres Strait Islander people,

with housing or infrastructure that is either owned or managed on a community basis' (40). Persons living in non-private dwellings such as hospitals or nursing homes were not included in this survey.

The ABS sought input for NATSISS from Aboriginal and Torres Strait Islander peak bodies, government departments with Aboriginal and Torres Strait Islander responsibilities and from the ABS Advisory Group for Aboriginal and Torres Strait Islander Statistics (39). ABS interviewers received extensive training in cultural awareness and the collection methods used by interviewers varied across geographies. For example, some items on the questionnaire were reworded or concepts changed to take account of language and cultural differences. In community areas, Aboriginal and Torres Strait Islander facilitators accompanied ABS interviewers to assist with the data collection (39).

Following screening for the presence of an Aboriginal or Torres Strait Islander person living in the household, a response rate of 83.8% was achieved in remote Australia and 78.1% in non-remote Australia. The confidentialised survey data file contains records on 11,178 persons who self-identify as being an Aboriginal and/or Torres Strait Islander (39).

The NATSISS survey instrument covers a range of subjects encompassing language and culture, health, employment and access to services (39). In this study we compare the responses of people living with (n=2798) and without (n=3285) disabilities to questions about exposure to unfair treatment, avoiding situations because of unfair treatment, exposure to violence, exposure to threats and removal from natural family. The places where people reported being exposed to unfair treatment were also examined.

Phase 4: Reporting and review

A final co-design workshop was held to review the extent to which the findings of the project resonated with key stakeholders, to refine recommendations and to develop clear suggestions for action.

Findings

The findings integrate perspectives from NDIA staff, disability support providers, NDIS participants and Community Connectors. In the first instance, NATSISS data is used to contexualise the study findings. Subsequently, study findings relating to participant needs and experiences of disability are presented. From there, the critical themes of engagement with community and participants are explored. This leads in to examination of the role of Community Connectors. Following this, support providers' experiences with the NDIS are presented, as well as perspectives on developing participant plans and participants' access to and provision of disability supports.

Participant needs and experiences of disability

The NATSISS and discrimination experienced by Aboriginal and Torres Strait Islander people living with disabilities

There is very little data that specifically focuses on the experiences and needs of Aboriginal and Torres Strait Islander people living with disabilities. Much of the work leading up to the NDIS was based on the insight of support providers and learnings from working with Aboriginal and Torres Strait Islander people more generally. The NATSISS analysis was conducted to provide insight into the experiences of Aboriginal and Torres Strait Islander people living with disabilities compared to other Aboriginal and Torres Strait Islander people at a population level. This analysis serves to better understand issues of specific concern to Aboriginal and Torres Strait Islander people living with disabilities in order to inform future iterations of the NDIS.

The results of NATSISS analysis suggest that across all ages groups Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and Torres Strait Islander people to experience unfair treatment and avoid places where they have previously been treated unfairly (Table 2). These differences were particularly marked for avoidance.

Table 3 shows that the situations where people were treated unfairly were reasonably consistent for people living with and without disabilities. Unfair treatment applying for work or at work and in educational settings was more common among people without disabilities. This may possibly reflect the fact that exposure to these settings is more common among people without disabilities. In contrast, people living with disabilities were more likely to experience unfair treatment at home by neighbours and in others' houses as well as in legal settings. The results suggest that people living with disabilities may be less safe in their own homes and in the homes of others than people without disabilities. This suggests the importance of considering safety issues for people living with disabilities particularly in relation to engagement with the NDIS.

Table 2. NATSISS participants: Unfair treatment and avoidance

	Age	15-29	30-44	45-54	55-64	Unweighted	Total n=
Prevalence of unfair treatment	Without disability	32.5	34.7	30.3	26.7	32.5	3285
	With disability	41.5	45.8	43.4	34.3	42.1	2798
Prevalence of avoidance	Without disability	10.0	11.8	14.1	9.6	11.0	3285
	With disability	19.2	22.4	18.8	17.7	19.8	2798

Notes: From a sample of n=6424. Omits n=341 cases where the respondent answered 'don't know' if they experienced unfair treatment.
Missing cell counts include violence (n=7), removal (n=156), threat (n=6).

Table 3. NATSISS participants: Most recent situation treated unfairly by disability

	Disability Status		
	No	Yes	Total
Most recent situation treated unfairly	**%**	**%**	**%**
Applying for work, or at work	18.9	16.8	17.9
At home, by neighbours or at somebody else's house	8.9	12.7	10.8
At school, university, training course or other educational setting	14.5	9.6	12.1
While doing any sporting, recreational or leisure activities	5.4	6.1	5.7
By the police, security people, lawyers or in a court of law	5.5	8.6	7.0
By doctors, nurses or other staff at hospitals or doctor's surgeries	1.2	2.5	1.8
When accessing government services	2.1	2.4	2.2
When seeking any other services	4.0	5.7	4.8
On the internet or telephone	2.4	2.0	2.2
By members of the public	26.8	25.5	26.2
Any other situation	10.4	8.1	9.3

Safety issues were further explored in the NATSISS by examining exposure to violence and threat (see Table 4). Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and Torres Strait Islander people to experience violence and threats. This was true for all age groups, but the differences were particularly marked for people aged 30-54 years. The results highlight the need to further explore safety issues for Aboriginal and Torres Strait Islander people living with disabilities and to consider these issues in the roll-out of the NDIS and the development of plans.

The NATSISS analysis also showed that Aboriginal and Torres Strait Islander people living with disabilities were more likely than people without disabilities to be removed from their families (Table 4). Generally, it would be expected that rates of removal from natural families would be higher among older Aboriginal and Torres Strait Islander people due to the policies that contributed to the stolen generation. This is reflected in the trends for Aboriginal and Torres Strait Islander people without disabilities. In contrast, there is very little difference in rates of removal from natural families due to age for Aboriginal and Torres Strait Islander people living with disabilities. Although the reasons for these differences are not clear from the NATSISS, it does suggest that the concerns about removal from families is a salient threat for Aboriginal and Torres Strait people living with disabilities and does not appear to have decreased over time. This in turn may affect the willingness of people to engage with the NDIS and suggests that there is a need to address the trauma and psychological sequalae of separation from family.

Overall, the results of the NATSISS analysis suggest that the safety of Aboriginal and Torres Strait Islander people living with disabilities is an important consideration in the roll-out of the NDIS and plan development. It also suggests that there needs to be further analysis of why Aboriginal and Torres Strait Islander people

living with disabilities are removed from their families, the support they receive once removed and the implications of this for ongoing support and engagement with the NDIS. It should be noted that NATSISS data is cross-sectional, so it is plausible that both exposure to violence and removal from families may have contributed to the development of disabilities. Overall, the NATSISS data highlight important issues for Aboriginal and Torres Strait Islander people with disabilities that should be addressed in further development of the NDIS strategies around engagement and cultural competency.

Table 4. NATSISS participants: Violence, threat and removal by disability

	Age	15-29	30-44	45-54	55-64	Unweighted	Total n=
Prevalence of violence	Without disability	14.6	10.4	6.9	5.5	11.9	3281
	With disability	20.4	19.3	14.4	7.7	17.0	2795
Prevalence of Threats	Without disability	15.8	13.2	12.8	7.4	14.2	3281
	With disability	29.9	28.1	19.9	12.5	24.7	2796
Prevalence of Removal from Natural Family	Without disability	4.2	7.0	9.5	13.6	6.3	3191
	With disability	12.0	11.7	15.0	15.8	13.1	2736

Experiences of disability in the current study

While exploring NDIS participant experiences of disability was not a main focus of the study, participants were asked some background questions as a way of understanding their needs and their positioning within the community. Participants tended to report few experiences of isolation or discrimination within their community. Rather, the majority of participants indicated that people in their community respected them, with some attributing this to people knowing them or their family.

> *I don't really find obstacles that block me. I like to do things, not just stay at home. I haven't ever experienced other people being mean to me because of my disability. Everyone knows who I am and my family and clan, so that hasn't happened.* (Participant)

> ***Interviewer:*** *Do you feel like you have been treated fair by other people, or unfair by other people in the…community? Are they treating you in the right way?*
> ***Participant:*** *Yeah they treat me alright*
> ***Interviewer:*** *Anyone ever been nasty to you because of this problem?*
> ***Participant:*** *Nah – cos they respect me there.*

However, there were some reported incidents of discrimination.

> ***Participant:*** *No – um my cousin Yes? she mocked me and everything, in the house*
> ***Interviewer:*** *Mocked you -is that like teasing you?*
> ***Participant:*** *Yeah… (she said) 'You're MJD person – you're going to die'*
> ***Interviewer:*** *Really!? How did that make you feel?*
> ***Participant:*** *Yeah I don't wanna go back there now….. yeah I crawled outside, I'm leaving right now*

The participant below indicates that they understand that others in the community view them differently because of their disability and accept that this is the case, although it does cause them worry.

> ***Interviewer:*** *Other people in the community – do you think that they notice that disability?*
> ***Participant:*** *Yes… cos they know… but they see… it's not their fault*
> ***Interviewer:*** *Do you think that they see you as a different person because of that disability?*
> ***Participant:*** *Yeah*
> ***Interviewer:*** *And how does that make you feel?*
> ***Participant:*** *I feel worry for myself you know…*

Some participants spoke about the things that they wanted or needed help with. The quotes below demonstrate a range of the needs and desires of participants. Some people spoke about their own responsibilities as parents—such as in the first quote below, where the participant wants to write down their story in order to be able to pass it on to their children, and the quote following, where the participant talks about the impact of his disability on the activities that make him feel like a Dad. Others speak about needing help with basic tasks of living, such as washing or using the toilet and cleaning.

> *I have a wheelchair, but I am looking after it and stopping kids from using it wrong way, so I'm still using my walking stick and walker to help me move around the house. Talking is getting harder for me. We are looking for new ways to make it easier when people's voice is fading away. My daughter cares for me, cleaning up, preparing meals and also other family. Aged Care, they help me with cleaning my room, mopping, windows clean and washing blankets.* (Participant)

> ***Participant:*** *It makes it hard for me to be a Dad, to be in my day…things like cooking, hunting, fishing, cleaning*
> ***Interviewer:*** *…What about doing things with your family – you said it is hard to go hunting and fishing, is anything hard for you because of this disease?*
> ***Participant:*** *It's a bit hard for me because, because I don't … walk a long distance*

> *My sister, she helps me get up go toilet make me have a shower, even L helps me too. They make my tea and when we go shopping I go and look – 'I want that that, that' and they are my arms and legs. My nieces help push me in the chair.* (Participant)

> *The other important thing is respite, staying away from family to give them a break. Hospital and NDIS working together to help me with transport to Darwin and they are also supporting with respite the same way they help me here at [community] to give my family a rest because they get tired.* (Participant)

In some cases where the disease is degenerative, like Machado-Joseph Disease, capturing personal and family stories was also critically important to participants:

> *I want to write my (MJD) story for my kids. I need to write it down now, before I lose my memory and before my voice fades away.* (Participant)

Overall, the family was a strong theme in terms of the aspirations of people with the disabilities, their current care and the supports that they felt were necessary.

While a few participants spoke about wanting to work, this was not a strong theme across interviews.

> *The main thing for me is finding a job. I want a real job, that's why I want to work at the school because it's interesting and I can use computers and internet and learn new things. And I want to talk with students and listen to them and help them with learning new things. That's what I really want to do….The other thing I really like is playing wheelchair basketball. I would like to play regularly in a competition and travel to Darwin and maybe even play interstate.* (Participant)

> ***Interviewer:*** *Let's see if I remember what you said – you wanted help with the gardening and keeping the house clean and having people come and help you in your bedroom and going on country and we talked about the gardening...was there anything else?*
> ***Participant:*** *Bush medicine*

> ***Interviewer:*** *What other good things do you want to come from your plan…?*
> ***Participant:*** *…My house needs a wheelchair…*
> ***Interviewer:*** *Ah ramp – so you want some modifications to your house?*
> ***Participant:*** *Yeah – ramp – it's going to be renovated soon*

NDIS engagement with community

Several NDIA staff members spoke in some detail about the process of engaging Aboriginal and Torres Strait Islander communities. In line with the Aboriginal and Torres Strait Islander Engagement Strategy, emphasis was placed on having initial meetings with key stakeholders in order to give information about the NDIS, including how it would work in the community. Following this, NDIA staff would then meet with participants, families and support workers.

> *We've worked with our community mainstream engagement team to visit the community, talk to the stakeholders, the council, the people, and engage to let them know what the agency's about, what the scheme can do, and then the service delivery team will follow. And then meet with those participants, the families, the advocates, the support people, and then, you know, start talking about how to build a plan, what you want in the plan, and we do that with interpreters, and we do that with remote Community Connectors.* (NDIA staff)

The quote from the NDIA staff member below also speaks about this process. This staff member indicates that while the basic approach may be similar, the way it is implemented can vary between communities, especially depending on the strength of existing relationships.

> *So, it looks different for each community, and I can say specifically in Darwin that process has been probably a lot smoother mainly because the people that we've employed here have long trusted relationships in the Northern Territory, remote and very remote region. So it's probably been a little bit easier for us. …So basically, the process, the collaboration starts with contact to some key stakeholders in community, conversation, allowing time for the community to digest the information and coming back to us with questions, then slowly working through to support the community identify people with disabilities that would benefit from the scheme.* (NDIA staff)

While the first quote above indicates that Community Connectors were involved in the engagement process with participants, the Community Connectors interviewed had little information about the extent to which community leaders had been consulted or engaged.

> ***Interviewer**: …when NDIA came for a visit, to tell you more story about NDIS and get ready for visits to houses. Did they meet with community leaders here at [remote community 1].....?*
> ***Community Connector:** We don't really know. We didn't see where they went to.*
> ***Interviewer**: They didn't meet separately with each set of clan leaders?*
> ***Community Connector:** No*
> ***Interviewer**: Just arrived and came straight to you [Aboriginal Corporation] workers?*
> ***Community Connector:** They did go to Aged Care who prepare the food for people. No, they just met with us School Attendance Officers and [Aboriginal Corporation] staff and also Aged Care, (not with community or clan leaders).*
>
> ***Interviewer:** So when NDIA first visited here to [remote community 1], did they have any meeting with community leaders or clan leaders, like [remote community 2]?*
> ***Community Connector:** No, we went straight to disabled person's houses*
> ***Interviewer:** You didn't meet with the leaders or elders from any clans?*
> ***Community Connector:** No, nothing.*

Organisational partners and disability support providers also indicated that they had seen little evidence of the engagement process in the communities that they worked in.

> *But we went to lots of communities where they had allegedly been to. And some of the trial sites in … Arnhem Land, and they said 'Oh, we've been there three times.…We've engaged with that community,' we went out there and pretty much nobody has been there ... And then they move on to the next community. They haven't been trying to engage with the community at all.* (Provider)

> *…they came in and had the story what the scheme is about have a couple workshops to inform communities of what the scheme is about and they have to transition and move on to another region. So, it's sort of left on your own to develop. But they don't spend enough time in the region nor are there resources from the engagement teams to do that. I think they should be engaged more.* (Organisational partner)

The following provider working with an ACCHS indicates that they have seen the NDIA attempting to engage with the community, but in an ineffective and inappropriate way which did not take into account the community structure.

> ***Provider:** NDIA keep approaching [us] as if we control community. We make no decisions for community. We're a community controlled health organisation and I've explained that numerous times. They do not understand what that means….People look at me like I'm talking mad. I said, if at any time that council doesn't want us there, we're out. That's who they need to be engaging with.*
> ***Interviewer:** And have you seen that at all? Have you seen them engaging local councils?*
> ***Provider:** No.*
> ***Interviewer:** None of those, the LACs, no one?*

> ***Provider:*** *I think they probably had some meetings, but I could tell you that from my experience of doing my presentation to staff, they know nothing.*

The disconnect between NDIA perceptions of engagement and those of Community Connectors, providers and organisational partners indicates that while engaging community leaders may be happening to some extent, it has not been sufficient. This suggests that there may be a need for more intensive and extensive engagement and/or to sustain engagement for longer periods of time. Moreover, stronger involvement of Community Connectors throughout this process may be necessary. As will be discussed in more detail below, Community Connectors have been identified as essential to ensuring community buy-in for the NDIS. Ensuring that Community Connectors are aware of the engagement of community/traditional leaders will enhance the legitimacy of the role within the community and may help support uptake of the scheme. Additionally, as Community Connectors are positioned as the main links between the NDIA and the community as a whole, ensuring that they are involved with the initial steps of engaging with community leaders may increase the effectiveness of the community engagement process.

NDIS engagement with participants

Approaching participants

Engagement with participants and potential participants occurred after contact had been made with community leaders and other stakeholders. The importance of appropriate face-to-face contact with participants and potential participants was stressed by both disability support providers and the NDIA. This was important both to make sure that participants received appropriate information about the scheme and to build relationships between participants, NDIA representatives and support providers. The quote below speaks about the process the NDIA went through in changing their approach to focus on face-to-face contact.

> *I remember back in 2016 …nationally, the approach to participants was outbound calls, sending out letters …That approach didn't necessarily work. There's two parts to it. One, sort of being an insurance agency, that we were asking for people to sign up to buy. That they weren't sure of. But, the other part of that is, in the Northern Territory…we know that face-to-face servicing is the model that we have to use. Yes, we have those channels of over the phone conversations, and things like that, but, when you've got a transient population. We've got a high percentage of Aboriginal, Torres Strait Islander people, who are in dwellings that have overcrowding through housing. So we have quite a vast range of challenges.* (NDIA staff)

NDIA staff stressed that while working within a complex environment that presented significant challenges, the wellbeing of the participant was a central concern.

> *But what I can assure you is that we put the participant at the heart of everything that we do. So, if we're out in the field and we can't find them…we'll come back the next time. Even though we're driven by KPIs here, we always put the participant first.* (NDIA staff)

Interviews with participants and support providers stressed the need for the interactions to be pre-planned or advertised and advocated for cultural sensitivity and the importance of clear communication in the initial stages of participant engagement. Sensitivity in approaching Aboriginal and Torres Strait Islander people

living with disabilities is especially necessary in light of the considerations around safety, prevalence of violence, threats and removal from natural family highlighted in the NATISS analysis. A number of participants indicated that they felt apprehensive, confused or scared when people from the NDIS showed up unexpectedly.

> *…that time I didn't know they were coming. I wasn't expecting them.* (Participant)

> *I was confused that time. They just popped up out of nowhere. I didn't know they were coming. I was surprised and a little bit frightened…When they come I want a straight story from them that I can understand…They missed me with their words they were using. I rang up J..... and asked her who they were. We didn't know.* (Participant)

> *I don't know who told me first about NDIS. It's very hard to think clearly about all those people when they came to see me at my house…They didn't tell me they were coming and I wasn't sure what they wanted.* (Participant)

The quote below indicates that some participants had undergone a planning meeting with NDIA staff without understanding what was taking place, and also highlights the intimate and sensitive nature of some of the conversations undertaken without appropriate prior notice.

> *Our participants, not even knowing that they'd had a planning session like or someone came to see me today, and they wanted to know the ins and outs of everything about my life, and I don't really know what it was…* (Provider)

The confusion provoked by these unexpected visits was tied to a lack of utilisation of existing relationships. As expounded below, some support providers were diligent in attempting to prepare their participants for the transition to the NDIS. This included explaining the nature of the NDIS and what would be covered in the planning meeting so the participant would be able to properly express their needs and what should be included in their participant plans.

> *So to start with, we put together some key messages for our staff to be able to talk to participants about just trying to really simplify and clarify those concepts of what it was. And then with each of our participants, we went through what we called a pre-planning meeting…. So we spend time with our participants documenting those things so that they are kind of ready to be able to talk about that when they actually had the plan.* (Provider)

However, in the first stages of the roll-out, these relationships between participants and providers were not accounted for, leading to NDIA staff approaching participants without the involvement of existing providers. The same provider goes on to say:

> *So we also did a lot of work to collaborate with the NDIA on the ground leading up to the roll-out to say that our participants want us to be involved, we've done this pre-planning, we're happy to share the information with you…the NDIA kind of ignored all of that and …started doing plans with participants without us involved. Those participants were confused, they didn't really understand what was happening or what they were really being asked....* (Provider)

The same provider also explained that this situation has improved, and collaboration between the NDIA and existing providers has been strengthened, in part through advocacy on the part of providers.

> *Then, I guess we're pretty strong with our voice back to the NDIA about that's not going to get the best outcome for our participants. The NDIA then started to work more collaboratively with us and you can really see that in those first year plans where we were involved and they're much more reflective of our participants' needs.* (Provider)

However, while progress in this area has been made in the Northern Territory, it was also evident that some disjuncture existed between the jurisdictions, with the learnings not carrying across to more recent implementation in Queensland.

> *So we're quite disheartened because it just did not, it doesn't feel like a national scheme. It feels like [here it's] a completely new scheme, a completely new set of rules, and again, we're getting the quite poor quality plans coming out of Far North Queensland at the moment.* (Provider)

Participant understanding of the NDIS

In speaking to participants, it was apparent there was a wide range regarding the level of understanding about the NDIS. While there were some participants who had some understanding about the new scheme and why it had been put in place, there were no participants interviewed who fully understood the structure of the NDIS or how it functioned. The quote below is from a participant who demonstrated one of the strongest understandings of the NDIS, but also illustrates the limits of this.

> *When I first heard about NDIS I was thinking about organisation like MJD Foundation, because they have a helping law and those Balanda people working for them always help Yolŋu. So I'm thinking NDIS is like that, everyone wants to help and support for people in their everyday life. But I don't know what each of those letters N D I S really means.* (Participant)

This level of understanding stands in contrast to the vast majority of participants who had very little understanding of the NDIS at all.

> ***Participant:*** *Ummm… some ahh… one… some guys they were here -they wearing NDIS shirts*
> ***Interviewer:*** *Ahh yeah –what colour are their shirts?*
> ***Participant:*** *Umm – I don't remember*
> *…*
> ***Interviewer:*** *Do you remember where they came from?*
> ***Participant:*** *Ummm… Yeah they came asking us for… I don't remember*
> *…*
> ***Interviewer:*** *Do you think that they… did they use Anindilyakwa or English when they were explaining that story to you.*
> ***Participant:*** *English*
> *…*
> ***Interviewer:*** *Did they give you a clear picture about that NDIS? Did you understand that?*
> ***Participant:*** *No*
> ***Interviewer:*** *Not really?*

Some participants illustrated better levels of understanding when local providers had previously spoken to them about the scheme. The quote below illustrates stronger participant understanding of the NDIS facilitated by MJDF staff, with the participant linking the NDIS and some outcomes from their participant plan.

> ***Participant:*** *N told me.*
> ***Interviewer:*** *So N is that MCS with the MJD Foundation. Do you remember when he talked to you about that?*
> ***Participant:*** *Maybe last year*
> ***Interviewer:*** *Did they explain about the NDIS to you in your own language or did they use English?*
> ***Participant:*** *In English*
> ***Interviewer:*** *Did they give you a clear picture about the NDIS?*
> ***Participant:*** *Yeah and the NDIS helping me, they put a garden bed in my...*
> ***Interviewer:*** *That was one of the things in your plan? Oh that's good.*

However, even with some level of intervention on the part of providers, this did not always ensure a good understanding for participants.

> ***Participant:*** *Nah I can't remember – it's a lady called ahhh… lives at [remote area]*
> ***Interviewer:*** *So she came from the NDIS. Did anybody from anywhere else talk to you about NDIS, anybody from MJD Foundation or anywhere? So N or C or K or J?*
> ***Participant:*** *Yes, K*
> ***Interviewer:*** *So K talked to you about the NDIS, she explained that new thing was coming and then that lady came over from [remote area].*
> ***Participant:*** *Yes*
> ***Interviewer:*** *And did they explain in English or in Anindilyakwa*
> ***Participant:*** *In English*
> ***Interviewer:*** *Do you think you got a clear picture? Do you understand what it is all about?*
> ***Participant:*** *No – not really*

In addition to limited understanding regarding how the scheme worked generally, both participants themselves and providers spoke of the ongoing uncertainty participants had regarding the impact of the NDIS on existing payments. It is likely that this confusion would have negative implications for engagement with and uptake of the NDIS.

> *Yes, now I'm remembering when they came to see me. But I didn't get much help that time. And they take $85 for food, and they also take another $280 from my pay, but I don't know what that's for, why they take that money. That's my money they are taking, but what for?* (Participant)

> *There's still a misunderstanding that the NDIS is going to affect their carers pension, or their disability pension, or all sorts of things.... It's still not widely understood that the NDIS can be separate. And also they won't get the money…And it has to be known out there that the NDIA is an additional service from your carers pension, or that child's pension, that disability support. It won't affect your other payments, but that's a real fear that... My parents pension, my carers pension, or you know my disability pension can disappear.* (Organisational partner)

Community Connectors

There was broad agreement from support providers, organisational partners and NDIA staff that when effectively implemented, Community Connectors were vital for the success of the scheme in remote areas. However, it was noted that Community Connectors have not been installed in all remote communities.

> *I can say it wouldn't happen, it couldn't happen, if we didn't have Community Connectors. So for all the other remote communities in Australia, it's imperative that Community Connectors are onside, otherwise the scheme just will not exist in those communities. You won't have the buy-in from community.* (Organisational partner)

> *Starting from our most place-based activities we have, where we can have Community Connectors based at community. And a Community Connector is, for want of a better way to describe it, a local person who provides that link between our local area coordination services, so our LAC and the local community. So it's someone who brings strong cultural credentials to the work we do and are able to assist us in that regard and assist with those very important connections with individual and people to the scheme. So we have Community Connectors where we can. And in Queensland we have Community Connectors for each of the Indigenous communities, discrete Indigenous communities across Queensland, bar one.* (NDIA staff)

Community Connectors strengthened communication between the NDIA and communities, facilitated understanding between the NDIA and participants, and acted as interpreters and supporters for participants and their families.

> *…that's where our Community Connectors are really important is that they know the families, because they've lived in the community all their life. And they're able to bring them to the planning meetings rather than an interpreter, and in most of our places English is a third or fourth language. And they have three or four dialects that they speak before even engaging English. So it's really important that these Connectors engage with the families and get into the meetings where practical.* (Organisational partner)

Providers and organisational partners stressed the need to allocate sufficient resources towards employing, training and retaining Community Connectors. This was met with agreement from the PRG. However, interviewees indicated that this was not currently the case, with partner organisations supporting Community Connectors through other sources.

> *…Community Connectors full time employment, not part time employment. It needs to be full time employment. More local Aboriginal people need to occur for the scheme to be successful. You can't just leave out your coordination support services and no people on the ground working as connectors…. I think there's the biggest learning that I've got.* (Organisational partner)

> *So we support them and employ them, and employ outreach workers to support Community Connectors. And that's not funded, we generate that business through our coordination support dollars, yeah?* (Organisational partner)

The PRG also agreed that there needs to be more attractive, consistent and stable employment conditions provided for Community Connectors. Interviews indicated that this retention necessitated a flexible and

supportive approach that recognised Community Connectors' positions in and obligations to their communities.

> *…we in the NDIA program have a more flexible approach. So, for example, we have a Community Connector that has some cultural obligations…this week and he has taken leave…we work with him to be able to take that leave. He knows that he won't be receiving any pay because he's used all of his annual leave, et cetera. But he doesn't lose his job. Where a lot of the time in other organisations they will dismiss him or say, 'You've used all your cultural leave….' And they'll lose their jobs.* (Organisational partner)

Beyond training, this provider indicates that Community Connectors needed to be incorporated and supported as part of the roll-out more broadly, recognising that the NDIS represents a substantial change.

> *[We] would make the ideal host for Community Connectors. We have our health worker led model there on the ground. You could educate them and get them to think. I said, but for me, such a huge change and a new way of doing ... You're asking communities who fundamentally live on welfare to actually take responsibility in a process when they live in these isolated communities and they only have to take responsibility for each other and how they live culturally, right? But we're asking them to be responsible in a process that sits outside of their normal way of living. And we're doing it without any education or consultation with what will work for those communities.* (Provider)

The same provider also believed that the way Community Connectors were utilised needed to be more strongly situated within a broader approach to rolling out the NDIS that included community education and workforce development.

> *…to me, the Community Connector is step three, but we can't do step three until you've done step one and two, and that is to educate the community, educate workforce and identify numbers that are likely to be eligible. And you'll continue to do that with your Community Connector, but you would need to educate these health workers and support them so that they can support community and just keep reinforcing those messages.* (Provider)

Without this more holistic approach, this provider believes that placing responsibility for community education and engagement on Community Connectors is unfair and inappropriate.

> *The thing is with that you did the community engagement stuff and education, and if you developed a model that would make it financially viable, this is when you build your Community Connectors and then they carry on. You can't give them the responsibility of doing that. It's not fair to them.* (Provider)

PRG members noted that Community Connectors represented opportunities that extended beyond their current positioning. In particular, members valued the possibility of utilising the Community Connectors to enhance two-way learning between the community and the NDIA. In their role, Community Connectors can facilitate place-based approaches by providing information to the NDIA from community regarding what's happening in the community and what works for participants and communities. This could enable the NDIA to better accommodate the needs and expectations of communities and take into account unique community contexts. During the PRG meeting, NDIA representatives confirmed that there is a commitment to expanding the Community Connector role, including beyond Aboriginal and Torres Strait Islander communities. Given that there are currently no program guidelines for Community Connectors, providing

more clarity regarding this could also help strengthen understanding of the Community Connector role and responsibilities for providers, organisational partners and Community Connectors themselves.

Community Connector training

Generally, interviewed Community Connectors indicated a good understanding of the intention of the NDIS and knowledge about the actions required in order to facilitate participant access and the process of developing participant plans. However, there was little knowledge about the NDIA and a general confusion about the 'NDIS story' or the rationale for the implementation of the scheme.

> *Help people with disabilities, to help them with their needs in their houses and in their lifestyle. Help them to live a better life. And to give them more options/choice about the kind of help they receive, and for NDIS to assist them in those choices. Not to have only one option available to choose from.* (Community Connector)

> ***Community Connector**: If the person is approved for* molu-rrupiya*, they ring us up. We do visiting this and that. We're doing this .... OK. NDIS is just to support. But that ND.... what's the other name?*
> ***Interviewer:** (clarifying) NDIA*
> ***Community Connector:** The first one (NDIS) is just to spread the story, and the second (NDIA) I don't know..*

> *The two of us went from here, but we were very surprised about all that NDIS story, because we didn't know what we were going to learn about. But it was interesting and we learnt some things, but lots of story was also very confusing.* (Community Connector)

A key theme in the interviews with Community Connectors was the quality of the training that had been provided by the NDIA. While Community Connectors indicated that they appreciated the opportunity for training, they indicated deficits in the training received to date, and there were multiple requests for further or ongoing training.

> *Sort of okay. I talked to the trainers at the course that was at the end of last year (2018) and we all agreed that it was just an introduction, but I said we need more training and information about NDIS, how it works. Not enough information was provided to us.* (Community Connector)

Some Community Connectors indicated that with the training provided, they were only starting to understand the NDIS, and that further training would help expand this understanding.

> ***Interviewer:** And Day 2 or Day 3 did they give you any Canberra story or money story ...?*
> ***Community Connector:** No, I forget what we talked about, that training was 2 years ago.*
> *We need to go to Gove for more course to learn more about NDIS. And when we return, the we can understand more what NDIA staff are saying about NDIS.* (Community Connector)

In discussing how to improve the training, the importance of NDIA staff being open and listening to attendees was stressed, as was the inclusion of Aboriginal concepts and ways of doing things. The following quote illustrates the skill of one community connector in using Aboriginal concepts to facilitate participant understanding of how the NDIS works.

> ***Interviewer:*** *Were you the one who introduced that term* 'molu-rrupiya' *into that conversation? Because that's* mirithirr mayali'mirr, manymak nhakun (excellent education technique for those NDIS family and participants to hear about where NDIS money comes from)*. Did someone else use it, or just you?*
> ***Community Connector:*** *I feel like to use that language.*
> ***Interviewer:*** *(affirming) Because it is rich language ...*
> ***Community Connector****: .... rich language.*

In the quote below, a Community Connector speaks about the importance of ensuring that the training is relevant to Yolŋu community members, participants and ways of doing things. However, this is expressed alongside the belief that the NDIA staff members coordinating the training were not open to hearing and understanding Yolŋu training attendees.

> ***Interviewer:*** *In that one week training, were some people saying we have to do this NDIS work in our Yolŋu way, not just always thinking Balanda ways?*
> ***Community Connector:*** *Yes, Yolŋu from [community] were saying that they wanted the training to be relevant to Yolŋu life and Yolŋu ways of doing things where NDIS participants are living. Yolŋu from other communities strongly agreed with and supported this idea.*
> ***Interviewer:*** *And how did the NDIA people respond when they heard that idea coming from Yolŋu workshop participants?*
> ***Community Connector:*** *They didn't really hear what we Yolŋu people were saying, only half of them were really interested and understanding.*
> ***Interviewer:*** *(clarifying) so only half of them were listening, and open-hearted and thinking about what would work well for Yolŋu.*
> ***Community Connector:*** *Yes, half open-hearted and half of them not really trying to understand from a Yolŋu point of view.*

During discussion with PRG members, support was expressed for reviewing the content and model of delivery for Community Connector training. PRG members indicated that this review may include opportunities for two-way learning and the creation of communities of practice in relation to the NDIS. PRG members also echoed the point made by the Community Connector above, that in order to be effective the training needs to be localised and recognise the diversity of Aboriginal and Torres Strait Islander communities, rather than homogenised.

Recruiting support providers to the NDIS

The central objective of the NDIS is to give people living with disabilities choice in deciding their providers. However, while this is fairly straightforward in urban areas, where there is a wide variety of disability support providers, in remote areas a thin market places limits around the extent to which participants are truly able to choose.

For this reason, a well-designed and communicated strategy to increase the number of registered providers is important to expanding participant choice and has been a key focus of the NDIA.

> *…for the Northern Territory we have a thin market comparatively to other jurisdictions. So, we work well with our provider market engagement team to identify where the demands are to go out to market. To try and, you know, source those services that participants would need.* (NDIA staff)

Interviewees spoke about some of the factors that contributed to reluctance on the part of providers to register with the NDIS. Many interviewees spoke about the initial insecurity providers felt during the NDIS roll-out, as there was a great deal of uncertainty regarding funding for providers.

> *It is a big question because the agency hasn't been able to give any assurance to providers on what the market looks like and where they should be investing their services, the market was very, very scared and reluctant to register for the scheme and didn't know where they should invest their effort.* (NDIA staff)

This was corroborated by the below provider working with an ACCHS:

> *The key thing for me is that in terms of…the demand for service, we have no accurate data. No one has any accurate data around disability….. Now, it's not only around disability…it's the likelihood of eligibility for NDIS in terms of disability.* (Provider)

As part of this attempt to increase the market, the Northern Territory Government provided Innovation Grants in order to enhance the ability of support providers to deliver supports, collaborate and come up with new methods for providing supports (30). The NDIA has also offered Information, Linkages and Capacity Building (ILC) grants since 2017 in order to build capacity within organisations to provide support to people living with disabilities (31).

> *There was a huge amount of Innovation Grants that were deployed by Northern Territory Government, and there was a huge amount of ILC grants. This is big money, this is like $800,000 plus. …That's Innovation Linkage and Capacity Building grants that are issued by the National Disability Insurance Agency….there's a plethora of reasons behind them to support market development, to support communication around the scheme.* (NDIA staff)

At the same time, NDIA staff indicated that there has been limited direct business support allocated to increasing participation in the scheme by ACCHSs , but there had been initiatives to increase understanding of the scheme.

> *…so they're the State Indigenous Affairs department, we partnered with them to run a series of workshops, two years ago now, to bring Indigenous-specific providers in to help them better understand the scheme. To facilitate registration and to encourage providers to consider registering and operating within the scheme. That's some of the things we did in various locations where we knew we had thin markets to contend with, to try and help facilitate and encourage this sector to join in the NDIS.* (NDIA staff)

In addition, organisations such as Indigenous Business Australia have taken steps to determine what type of support could be useful for Aboriginal and Torres Strait Islander providers.

> *… wherever I've gone and spoken with Indigenous councils in discrete Indigenous communities… one of the first things I get asked is, 'Is there any support out there, any business support to assist those organisations to become a viable operator in an open market context of the scheme.'… Really any direct support in that regard has been quite limited. … Indigenous Business Australia is running a unique trial pilot, and I think again, because they've listened again to some of the advice from the NDIA….Particularly around some of the gaps in support for Indigenous providers out there. So*

> *they're running a specific trial with a handful of registered Indigenous specific, disability providers … to try and analyse what type of support would be useful in terms of business related support.* (NDIA staff)

The below provider from an ACCHS identifies the need to build a local workforce in order to reduce costs and increase financial viability for providers, as well as ensuring that support provided is culturally acceptable and includes families and communities.

> *…that's why I build network workforce capability in community. It removes the issue of the cost of flying in clinical staff because you've got these people that can continue the work. You might get them to come every couple of months. It's a block funded model. You've got the funding there to engage and employ these clinicians and staff, and it's a holistic approach. It treats the family, supports the family. It takes place in the home, takes place in community environments.... It's more culturally appropriate, put it that way.* (Provider)

Interviewees from support providers and the NDIA agreed that the number of providers in the Northern Territory and Queensland has been increasing. However, there continued to be ongoing concern that the market remained insufficient to effectively provide meaningful choice to people in remote communities.

> *I liked the concept of choice and control. Which is the major concept. However, what I'm simply saying is while choice and control is very good in metropolitan areas, because you've got the choice, but you don't have the choice when it comes to remote Australia. That's where the difference is. You've got choice in Sydney, you've got choice in Melbourne, you've got choice in Newcastle, you've got choice probably in Darwin, but you don't have choice in Tennant Creek, you don't have choice in Lajamanu, you don't have a choice in Kalkarindji that's what we are talking about.* (Provider)

Part of this concern stemmed from indications that while there was an increase in the number of providers, there may still not be the necessary geographical spread that would allow adequate reach and access to remote areas. However, as the provider below indicates, this initial concentration may continue to expand as some areas become saturated.

> *What I see at the moment is a situation whereby people are waking up to the fact that NDIS can, make money out of being an NDIS provider. …But, the risk question that's going on in the Northern Territory is just adding providers in the same place. Yeah. Not so much adding providers where they are needed. However, maybe it might have a knock-on effect that those providers when they are reached at, and they are now fighting for delivery in one geographic area….They will start to spread out maybe…And like I said in the beginning of this conversation, we start to see some improvement in some of these places…They're starting to slowly coming into those areas to provide services.* (Provider)

NDIA staff also indicated that the number of Aboriginal and Torres Strait Islander providers was slowly starting to increase, as well as seeing an increase in mainstream providers expanding their reach to rural and remote areas.

> *There is, we are seeing some good Indigenous-owned and Indigenous-specific providers emerging here and there. It's very small numbers of course, they are beginning to emerge and we are seeing some larger non-Indigenous providers who have good track record of service provision to*

Indigenous people, and good cultural practice and policy, also making affirmative steps to deliver services in rural and remote locations. Specifically to Indigenous cohorts. So, again, early days, but we are starting to see that emerge. (NDIA staff)

Developing participant plans

The following sections explore issues raised around participant plans, which form the basis of the funding allocated for disability supports under the NDIS. The following section covers the planning meeting, where discussion is held regarding participant needs with participants, NDIA staff and family members, Community Connectors or organisations at the participant's discretion. This planning meeting informs what is included in the participant plan, which is the subject of the next section, before the topic of implementation of participant plans is considered.

Planning meetings

A key component of the planning process is that participants are able to exercise choice over who is included in the planning meeting. There was agreement across NDIA staff, providers and participants that there was capacity to have family members or supporting individuals from organisations included in planning meetings according to the wants and needs of the participant. Community Connectors were also sometimes involved in this process and provided a bridge between NDIA staff and the participant and family members. Community Connectors were more frequently reported to be involved in the planning process in the Northern Territory than in Queensland.

A really good thing is like for example, if we're talking to someone who has loss of hearing and requires an Auslan interpreter, you'll have the Auslan interpreter with them, you'll have maybe their guardian, you might have a support worker with them that they've asked to come along. Generally we don't include providers because we want the participant to have choice and control, but, the participant will tell us if they want them there. So, we honour that. We let them tell us what it is that they want to do part of those conversations. Some conversations might require disability advocates to attend as well. (NDIA staff)

[Our] health service is really family orientated where at the approval [of] the patient or participant, we involve families. So that's where our Community Connectors are really important is that they know the families, because they've lived in the community all their life. And they're able to bring them to the planning meetings rather than an interpreter, and in most of our places English is a third or fourth language. And they have three or four dialects that they speak before even engaging English. So it's really important that these Connectors engage with the families and get into the meetings where practical. (Organisational partner)

Participant comprehension of the role of reason for the planning meeting and the connection with the eventual delivery of supports was varied. In speaking to participants about what had happened during their planning meetings, it was clear that there was consistent confusion about what the meeting was about, what was expected from them or expected outcomes from the meeting. As the quote below demonstrates, this confusion tended to persist even when the participant had support during the meeting.

Interviewer: *Do you remember talking to anybody about what you wanted – before you went into that NDIS planning meeting?*

Participant: *No*
Interviewer: *You don't remember if you did that?*
Participant*: No?*
Interviewer: *Did anybody give you any help when you were making that plan with that lady? Anybody sit with you?*
Participant*: Yeah my Mum, G*
Interviewer: *G? And did that help was that good?*
Participant: *No*
Interviewer: *No? she didn't help?*
Participant: *No, no, yes she did help*
Interviewer: *She did help? Did you understand what was happening in that planning meeting?*
Participant: *Not – not really*

In other cases, participants understood what supports they received, but didn't connect it to the participant plan or the planning meeting, which stems from participants not understanding the change from previous provision models and the detail of how the NDIS works. Some participants did demonstrate understanding of the connection between the planning meeting, the eventual participant plan and outcomes from the plan; however, this was unusual.

Interviewer: *Do you feel like you told her a good strong story?*
Participant: *Yeah*
Interviewer: *Did you tell her maybe you needed good strong equipment? Wheelchair and shower chair?*
Participant: *Yeah – gestures to wheelchair*
Interviewer: *And then that plan made that happen?*
Participant: *Yeah*

Family support during the planning process was regarded as essential; however, the PRG noted that effective family support of participants during the planning process requires additional explanatory resources. Planning meetings may need to be contextualised and further structure provided as well as prioritising the development of resources to guide these conversations.

Confusion related to the development of participant plans was noted to be extensive; members of the PRG noted that for some participants it can take until their third or fourth plan to really know what the NDIS can do for them. This can be for various reasons, such as initial plans constructed to prioritise having important early needs stabilised and a perceived lack of connection with future plans. It may also take time for participants and providers to develop their understanding of the possibilities and limitations of the scheme and what is covered by the NDIS or is in the remit of mainstream services.

Increasing participants' and providers' understanding of the scope of the scheme is critical to the development of plans that are responsive to the needs of the participants and can increase their capacity to live more independent, accessible and connected lives. Innovation and alternative non-traditional disability supports that may be covered under the participant plans were not well understood—for example, activities such as the inclusion of cooking classes designed to increase the participants independence. Understanding the shift towards being a 'consumer' who has the choice of different types of 'services' will require ongoing support and explanation. Participants may also lack engagement and motivation to explore possibilities due to a lack of trust in a new government scheme.

Established relationships resulting in trust, particularly the trust between participants and some support providers, were noted as an important theme by the PRG. In some instances, participants may want providers such as MJDF and Synapse to 'speak for them' because of the trust that has been established, referred to as a cultural bond. However, providers are normally discouraged from attending planning meetings in order to prevent what may be perceived as advocacy on the part of providers and to ensure participants are able to freely choose providers, as can be seen in the first quote in this section. These restrictions around provider participation during planning meetings therefore have the potential to cause tensions and reduce the amount of support the participant receives during the planning process. This is of particular concern due to the evidence that some participants already have quite a limited understanding of the planning process. While clear processes to mitigate any potential conflicts of interests need to be in place, it is important that these accountability processes are undertaken in a way that does not directly affect the participant. This would mean instituting accountability mechanisms directly with the support provider, rather than during the participant interaction or planning processes.

During the final PRG meeting there was also a substantial amount of discussion regarding the use of interpreters, which was a key theme in the interviews as well. Interviewees indicated that NDIA guidelines allow for the use of NAATI certified interpreters during participant planning meetings—however, it was difficult to find interpreters who had this qualification, even if they were otherwise very skilled.

> *And the other thing is there's no way you could expect remote Aboriginal community workers that are very good interpreters and translators because it'd be very hard to expect them to have the national accreditation that the NDIA [are] wanting to have.* (Provider)

> *Interpreters are able to be funded as part of NDIS supports for the planning process, but only for the planning process. And the interpreters are only able to be funded if they've got national accreditation. The issue that we face in the Northern Territory is that it's very difficult to accredit nationally a lot of the Aboriginal languages…. Which then means that you can't necessarily fund people and the right people, because it's not just that the person can speak the language. There's a whole lot of other factors that need to be considered as to whether they're appropriate to provide that interpretation for that individual.* (Provider)

The PRG asserted that appropriate interpreting practice involves not only changing words from one language to another, but also an understanding of both cultures, as well as body language and nuance. Having access not only to an interpreter but to the correct interpreter, taking into account kinship and cultural relationships, is therefore essential to providing culturally appropriate support. There was agreement that the NDIA restrictions regarding using only certified interpreters and only for planning meetings represent a barrier to delivery of appropriate support. The following quote illustrates some of the complexity that can present in balancing cultural considerations with the need for a NAATI certified interpreter.

> *It is so complicated. One of the most complex planning meetings that we've had involved 12 people. We had Aboriginal interpreter services there, that Aboriginal interpreter services had a poisoned relationship with the participant, but the participant absolutely needed Aboriginal interpreter services. So we had AIS at one side of the room in a chair facing the wall and the participant at the other side of the room with his family around them so they couldn't see the AIS interpreter but they were still able to interpret.* (NDIA staff)

Use of interpreters for delivery of supports under the plan, and having interpreter supports funded in the plan has been flagged within the NDIA for further work. There is also acknowledgment from the NDIA that there are legitimate concerns and issues around this area.

While the issue of interpreting services was seen as particularly relevant to the Northern Territory, appropriate use of interpreters is also important in North Queensland. The PRG noted that some participants speak an amalgam of English and local language, and nuance may be lost if skilled interpreters are not used. This was also seen to be the case for Aboriginal and Torres Strait Islander people in urban areas, where participants may use Aboriginal English or rely on local understanding that does not translate effectively.

The concept of an 'expanded Community Connector' role was also discussed by the PRG. Under this design the Community Connector role would include assistance with translating concepts and enable people who have direct access to knowledge about the NDIS and who speak in the participant's first language to facilitate stronger understanding between the participant and other planning meeting attendees. However, as discussed earlier, the effectiveness of this approach would depend on Community Connectors having sufficient training regarding the NDIS.

Participant plans

PRG meeting attendees confirmed findings from provider interviews that the gap between what participants and others understand from the planning meeting and what is eventually included in the participant plan can be substantial.

> *We do notice that a lot of the plans that come out are much more generic than we would have anticipated from the content of the planning meeting discussions…. It would seem that there are some preset determinants that the NDIA has. If we, for example, take an Aboriginal female living in Katherine who has cerebral palsy, there's a predetermined kind of formula for what they think her support needs might be. And then what we would see is, every participant who can tick those boxes, regardless of the other, like, any comorbidity they might have or their individual situation or their goals would tend to have a very similar content in their plan. We seriously question sometimes what has happened between the conversation that we've been a part of in the planning meeting to the plan that we then see. Because there's often very little correlation between what was discussed and what would then be funded in the plan.* (Provider)

As the provider below indicates, the skill and experience of the NDIA planning staff was a key contributing factor to the quality of participant plans.

> *Absolutely and often it comes down to who that planner is and how much, whether there's someone that's had experience or not…. You can get someone that just asks the most inappropriate questions, they have no disability background through to someone that we've had an Aboriginal woman that was a planner who is living in remote communities…could speak in a culturally appropriate way to Aboriginal people and just ask questions in a different way…We're talking the difference between someone that has done this for their career versus someone that's a down south beautician that's been transferred up to Darwin. That's the kind of extremes that we've seen.* (Provider)

As in the initial participant engagement stage, the need to actively collaborate with existing providers who had an established relationship with participants and utilise their knowledge was also highlighted as being crucial to the development of good quality plans. The provider below reflects on the process between initially being left out of the planning process to now being a more involved partner in the Northern Territory. However, they also indicate that they feel that the learnings from earlier phases have not been carried through to the roll-out in Queensland.

> *And the other thing about that first planning is that NDIA were solely using information that they received from the Northern Territory Government Office of Disability …we're being just overlooked completely from those initial plans. So after lots of to-ing and fro-ing, we developed quite a good relationship I think, with the NDIA in the Northern Territory…. However, then we started the whole process in Queensland and it was just like going back to scratch of being excluded from those meetings.* (Provider)

Interviewees were specifically asked about the inclusion of cultural elements in participant plans, and there was broad agreement that cultural elements were routinely included in the Northern Territory. Return to country, for example for people who had moved to urban areas to access disability supports, was the element most frequently mentioned.

> *I've never seen a plan which doesn't talk about cultural connection. The aim is to maintain culture, maintain connectivity to culture. Because most of the participants that are in the Northern Territory, especially in the metropolitan areas…they would have come from somewhere in the country…And, maybe because of their disability at one stage, it was decided that they move to where services are…But it is always part of the conversation that, yes, he's in town, but he has to visit country as part of his informal support as defined in an NDIS plan.* (Provider)

The provider above continues to illustrate the variation in activities that have been included in participant plans in order to maintain connections to culture.

> *I've got people who have been going to church, an Aboriginal specific church….Some will have the men's shed, some will have the woman's shed, some will go for arts and craft….. In Tennant Creek my participants go for kangaroo cook up, and go to the dam to do the kangaroo cook up. Pretty much sending them back to do things that are connected to their country, connected to themselves.* (Provider)

In Cairns, however, there has been less awareness of the need to include cultural elements in participant plans demonstrated. PRG members noted that there has been a lot of time spent with partners explaining why culture needs to be considered as part of a participant plan. This reinforces the perception discussed above that the lessons that have been learned by the NDIA in the Northern Territory are not necessarily transferred and reflected in practice in Queensland.

Implementing participant plans

Providers were in strong agreement that the system of funding individual supports as currently implemented was insufficient to provide adequate support for people living with disabilities in remote areas. Throughout provider interviews it was affirmed that provision of individual support is not feasible as the operational costs, such as transport and coordination, are too high to be sustainable on an individual basis.

> *…you can't fund individual supports in remote communities, because the parts that aren't funded which don't impact as much in an urban setting…The drive to the appointment in a remote community is a two-day drive one way, so that's not feasible. Unless they change other aspects of the funding significantly, I just think the block-funded model gives the ability for a main person, provider, support coordinator, participant themselves, doesn't matter who it is, to more effectively coordinate the supports. And if you did it by community, then you can bring one allied health professional to support the five people at once, or whatever it is…The individual support is too costly. It doesn't work. We need the economy of scale, and I don't think you're gonna get that effectively without block funding it.* (Provider)

Some providers spoke specifically about types of support that had previously been feasible under the block funding model, which no longer fit into a scheme that focuses on the individual.

> *Day programs is a perfect example. So day programs has been around for a long time, and were a model that worked under block funding. …It's a group-based support, and it's often been funded…And like I said, it's not necessarily the best thing, but it's prolific. There's always been quite a lot of them, and that's a particular area that it's immediately identifiable where the funding gaps are in NDIS for the model that we have.* (Provider)

In interviews, a number of providers voiced a desire to return to a block funding model, although there were acknowledgements that this system also had significant limitations. Providers referenced the increased flexibility possible under block funding as well as the capacity to improve planning and coordination between participants.

> *I would probably like to see going back to the old system of block funding. Because, you will probably have to fund an organisation like [ours] and say look, we're giving you this sort of money to go and service this and that and that in that location. It's up to you on how you're going to service that. To me that works better. Yeah, because then it's our job that we got the money. It's about the delivery. …Not many people are willing to go there because, accessibility, remoteness. There is no provider that's coming there, hence under-utilisation of plans in the Northern Territory.* (Provider)

> *What I would like to see is probably something a little bit closer to a block-funding model for providers. And support from all of the key areas, so it's not just the NDIA. It's housing, it's the infrastructure with the health facilities and the community facilities. And some transport improvements and also training providers.* (Provider)

PRG members were adamant a stand-alone block funding model was not sufficient or appropriate and has historically been unable to provide sufficient cover or support for people living with disabilities and their families (41). Concerns were raised that this model heavily relied on organisations having very good money management, which was frequently not the case. However, there was also agreement that this does not contradict any of the findings presented regarding the limitations of the individualised model.
NDIA representatives on the PRG indicated that there was a constant revision of the price guide. While there was no indication of returning to block funding, there was some examination of how to allow for planning, such as by pooling funds across multiple participants plans in the case of having six people in a community that each need a physio once a fortnight. The organisational partner below also suggests that in order to provide adequate support, the financial reality of remote areas must also be taken into account.

> *I just hope that the price guide, the remote price guide is actually looked at in the next review because just for an example, just going into a remote community to get a kilo of tomatoes can cost you $10. So goods and services aren't cheap. And the price guide doesn't reflect the very remote which is Indigenous communities that are very remote, which have, in particular water surrounding, so they're islands, et cetera. They need to look at the very remote price guide and ensure that the price guide is adequate to deliver services in the bush.* (Organisational partner)

Implementing cultural elements of participant plans

As noted, the inclusion of cultural elements in plans was common in the Northern Territory, particularly provisions for return to country. Implementation of this has been problematic, however, and providers consistently detailed that resources allocated within the plans have been insufficient to allow this to occur.

> *But like I said, yes the will is there but, resources might be difficult, to get someone to country because for instance [needing a] disability-specific vehicle that can take wheelchairs, that can possibly take people to country. But, there is probably limited availability of that sort of transport to take people to country… Do we have the right support to take him to country that would protect people once is there? Those are some of the challenges that come that's associated with the goal of engaging with country.* (Provider)

The provider below indicates that the tendency to inadequately fund return to country in the participant plans is part of a systemic issue. Here, the provider expresses a need for the NDIA to take return to country more seriously as an element of the participant plan, as part of a change in how connection to culture and country is considered more broadly.

> *The biggest issue that we face is seeing what we call return to country…. The NDIA won't fund return to country for them. They treat it as a holiday. They don't have sufficient funding in the plan to enable providers to support people to go back to their community as they need to, which is disappointing. Because people die in communities, and it might be the participant needs to go back unexpectedly for that reason…. So a massive shift in how the NDIA thinks about connection to culture and country needs to happen, I think.* (Provider)

The organisational partner below reiterates that cultural elements are not included in the price guide, with the result being that resources for return to country and other cultural activities are routinely taken from other parts of a participant's funding.

> *So, because the plans are so flexible, we as a coordination support service will engage in these cultural activities if required. So if they have a ceremony that they need to attend, then we'll take them out of the clinic and into community and we're quite open with what we're doing, but there isn't actual cultural activity component within the price guide and there really should be because this is a big part of Aboriginal people in particular in remote and their obligations and if they don't have any there, then it needs to come out of the rest of their funding. But in the price guide it doesn't have cultural activities and it really should.* (Organisational partner)

The benefits of increased access to appropriate and innovative assistive technology (AT) through individualised plans was seen as an exciting option for increasing connection to culture and country. NDIA

staff spoke about how AT was increasingly being used to allow participants to participate in ceremonies and other important cultural activities. This excitement around the innovative possibilities of AT was also reflected in the PRG meeting. Attendees noted that while the tendency is to think of AT in the home-based or work setting, rather than in relation to the community, innovation in developing these approaches could provide substantial support.

> *We've been able to provide some wonderfully unique options around assistive technology to help people participate in ceremony …where the ceremony occurs, some customised assistive technology… to support them play their musical instrument and participating in song and dance …. And also some customised assistive technology to support them participate in meal preparation out on community.* (NDIA staff)

Critical role of support coordination

NDIA staff, disability support providers and organisations concurred that coordination of supports is vital in the remote context. In the quotes below, an NDIA staff member and an organisational partner talk about the role of support coordination in facilitating access to disability supports.

> *So, the coordination of support that is developed in the Northern Territory they're local run organisations that have a long history with these particular participants. So, they've just facilitated and supported the participant to access appropriate services. So we're talking about organisations like Miwatj, the MJD Foundation. So basically, our approach is that we understand that participants in remote and very remote regions need that additional support to coordinate and access services because there's no services in community or where there is they're quite limited. So, we fund the coordination of support to facilitate that for them and support them in actually accessing culturally appropriate services.* (NDIA staff)

> *But that's what the scheme's about, and I sat down with them and said, 'You know, there's a whole lot of other services that you can provide within that plan. All we're doing is coordinating the services. We don't want to deliver activity; we don't want to orchestrate the travel and all that stuff. You guys already do that. We can refer those services to you… it's just that we will coordinate those services.'* (Organisational partner)

However, there was a recurring concern raised in interviews that the level of funding allocated to support coordination was insufficient.

> *I think that the number one… for me, is that coordination support hours must be increased to be able to service our clients. Organisations can't, for example we took a hit because they reduced the hours of coordination support. We took a hit of about $175,000 in fees, which we need to put people off. Health organisations aren't used to a business model. We're used to funding model. And if they decide not to engage because there's not enough dollars attached to the funding stream or the business, then the scheme will fail. And that's my 25 years of experience talking there, as well.* (Organisational partner)

Moreover, interviewees raised concerns that current NDIS policies that presume a reduction in the need for coordination of support hours over time – supposing that the participant gains skills and the plan becomes more established—are problematic and should not be applied in this context.

> *And then I think we support coordination especially in remote communities and with remote Aboriginal participants. I think it's really important that the support coordination doesn't disappear over time. Because there is a lot of work and turning that needs to be done and over time to try, and get more supports to be available.* (Provider)

Adequately funded support coordination in plans is essential for remote Aboriginal and Torres Strait Islander participants who need assistance to navigate the system, locate and organise providers and implement their plan. Rather than diminishing over time, for people living with degenerative conditions such as MJD, the need for support coordination increases as their disease progresses. The assumption that support coordination in subsequent plans should be decreased as the participant has increased their capacity to undertake this work is therefore incorrect and has the potential to further disadvantage remote Aboriginal and Torres Strait Islander participants (5).

Under-utilisation of plans

A number of providers indicated that following annual plan reviews, they were starting to see a reduction in allocated funding. Providers interpreted this as the result of an under-utilisation of the previous plan, as participants could not access all the funding allocated due to the thin provider market in remote areas. In one case, a provider reported that the NDIA had provided written advice that the plan budget was reduced due to being 'under-utilised' in the previous plan. Providers therefore expressed concern that an implicit 'use it or lose it' policy was being established.

> ***Provider:*** *And I think doing it when it's toward the end of the plans in the plan reviews before their new plans come through…I don't wanna see their funding cut because they're more remote because they're not accessing more of their funds because there really is no…..*
> ***Interviewer:*** *So, would they every year to your understanding, that money that's been allocated to them, is it stopped, taken away, then they get a new load of funding even if there was some leftover?*
> ***Provider:*** *Yes and it's usually cut off to the amount that they've spent. I think that's a bit unfair. Especially when it's not…when they just don't have the services that are available around here.*

This practice is problematic in various ways. First, it is an indication that funding is not being allocated according to participant needs and goals as expressed in planning and review meetings. Secondly, as indicated by the provider below, this practice may be an inhibiting factor for support organisations, as it does not allow sufficient time for organisations to build their capacity to the level needed and introduces uncertainty into organisations' capacity to plan adequately and have the confidence to build capacity.

> *…We're starting to see the second year plans being reduced. So we're seeing a reduction in support coordination and core support hours across a lot of the second year plans … I have received one of the reasons for that from the NDIA in writing is under-utilisation of the first plan. So we're quite alarmed at that because we're being told there is no policy of use it or lose it ... One year is not enough time for an organisation to invest in a particular community and try and build their capacity. And certainly if the NDIA are reducing people's plans that will give support organisations no confidence to try, and grow that capacity. So it's really working against them, building or stimulating a thin market. They really, really need to make a commitment to not reduce the plan because it's under-utilised. (Provider)*

NDIA representatives on the PRG clarified that participants should not be having funding cut due to under-utilisation. It was acknowledged that while having a thin market impacts on supports delivered to the participant, this should not mean that the plan is reduced following review. It was also raised that providers sometimes did not understand the process around submitting recommendations, or what the NDIS could and could not provide, particularly around the 'reasonable and necessary' requirement, which comes before choice and control. Because of this, some providers may have raised expectations or feel frustrated that they have provided a report/suggestion that hasn't been taken up into the plan following review. Reports and recommendations are assessed by the NDIS considering the dual criteria of reasonable and necessary and enhancing choice and control and are not always implemented or re-implemented upon review of a plan.

Providing culturally safe support

Providers were in agreement that ensuring Aboriginal and Torres Strait Islander organisations are at the centre of delivering the NDIS in remote communities is essential for the provision of culturally safe support.

> *Cultural safe care is care provided by support that are aware of cultural sensitivities. Fortunately for [our organisation], our pool of support workers are Indigenous themselves, so they understand the culture, and for people like me who are non-Indigenous, we always access cultural training. The care that we talk about, which is person centered, which is culturally sensitive, and which is tailor made that it doesn't cross barriers of culture, that's the key I think with culturally appropriate for our Indigenous people here in the Northern Territory, and I believe elsewhere.* (Provider)

This provider from an ACCHS speaks about building a local workforce as being critical to keeping people living with disabilities in community longer and expresses some hope that the NDIS may serve to build local employment opportunities as it progresses.

> *All our clinical expertise is flown into communities. There's no locally-based clinical expertise…And then you've got the support work itself is increasingly locally based, which is fantastic. With the NDIS model, as you progress and you might get some numbers, you would actually be able to increase employment opportunities for individual support workers because you could cross them with the Aged Care. So as we're managing to get people to live longer in community, then you've also got the Aged Care from age 50 onwards. Those are positive. There's opportunity to build capacity for future growth in disability and age care support.* (Provider)

The same provider questioned the structure of the NDIS and its emphasis on the individual, indicating that this is not necessarily appropriate for Aboriginal and Torres Strait Islander people.

> *The NDIS itself is standard on participant. It's all about the individual, which doesn't fit with ... Well, it certainly does not fit with [our] model of care, that's for sure, and it doesn't fit the community.* (Provider)

As discussed previously, access to appropriate interpreters—taking into account kinship and cultural considerations—is central to the provision of culturally safe support by providers and PRG members. This issue was raised repeatedly during interviews with providers in the Northern Territory. Under NDIS guidelines, use of interpreters is funded by the NDIA for planning meetings; however, as the provider below explains, funding for interpreting services are not included in participant NDIS plans. This has drastic implications for the capacity of providers and supporting organisations to provide culturally safe and appropriate support.

> *And the unfortunate aspect also is that, ongoing, even if you can find the person that you can fund through the plan to do the planning process interpretation, you can't then necessarily get that carried through the rest of the plan life, so you'll have support coordinators and school providers and other providers involved in supporting that person, but the first-language interpreter funding can't be drawn down for any of those functions. And so that drastically affects the cultural safety for the individual receiving those supports.* (Provider)

The following quote from a provider highlights the NDIA's reasoning for this policy—that language support is not related to the participant's disability and therefore is not appropriate for inclusion in participant plans—while contrasting this position with accepted standards for equitable access to health care.

> *Well the NDIA enable interpreters, translators to come into planning meetings …but they're saying to us that there's no funding in a person plan for their support provider to be able to engage or bring in first language support. We're going to take this one on because we think it's discrimination. The NDIA said that everything in a plan needs to be because of the person's disability, and the fact that they don't speak English as their first language is not because of their disability. But that argument doesn't ring true when you look at anything around ... If you go to a hospital, you get the right to have an interpreter.* (Provider)

With regards to NDIA staff, an interviewee indicated that cultural competence and cultural awareness training was provided as part of the induction process. This included training in local cultural protocols, facilitated by Community Connectors and local organisations. However, there was no indication that this training was ongoing or reinforced over the course of employment with the NDIA. The same staff member also spoke about approaches to employ local and Aboriginal and Torres Strait Islander people such as advertising in local papers and ensuring that selection panels included local people as well as Aboriginal and Torres Strait Islander people and people living with disabilities.

Increasing the participation of ACCHSs is crucial in ensuring that participants have access to culturally safe and appropriate supports. However, as detailed in the following section, interviewees indicated that the structure of the NDIA has made it particularly difficult for Aboriginal and Torres Strait Islander organisations to be able to become registered NDIS providers.

Timeliness, bureaucracy and communication

Issues regarding timeliness, bureaucracy and general communication processes between the NDIA and providers were highlighted as areas for improvement. With regards to timeliness and bureaucracy, the following quotes indicate that these issues have negative impacts for participants. In the first quote, the provider speaks about the lengthy process and resulting long wait times for participants to receive essential equipment.

> *The amount of time we're waiting for equipment to be available. You understand it's horrible…. You go through the assessment with the occupational therapist. You finish that the occupational therapist, quotation, finish that, then from there turn to NDIS, NDIS probably will take long to approve that. When they approve that, then the supplier has to wait for the equipment to come from down south, somewhere. It will be four months later before someone gets the wheelchair. It will be six months later before someone gets the wheelchair. There is a lot of red tape involved in the NDIS, in*

> *the equipment space. And, when we even talk about home modifications, pretty much worse. We can wait for that a year or for more years.* (Provider)

As discussed previously, providers indicated that there could be significant differences between what was discussed in planning meetings and what is then included in the participant plans. This provider goes on to speak about the process for applying for a review when the participant plan is not adequately aligned to what was discussed in the planning meeting. In this case, the impact is not only on the participant, who is left without an active participant plan for the period of the review, but on the provider organisation as well. Providers are faced with the prospect of either covering participant supports for a period when there is no active plan in place and no guarantee of receiving funding for supports provided, or leaving a participant without support.

> *For things like a typo…it's pretty simple. We get a lot of plans that have somebody else's name in it. The NDIA has introduced kind of an administrative review where they can just go and change that and then reissue the plan. But for anything beyond that, it needs to be a formal plan review process…. And then it's assessed again, and a new plan is put in place. …The biggest issue to be honest is probably the time it takes. Where we've been part of requesting a plan review, it generally won't happen within six months. In some cases, the longest one for us was 18 months…. And the impact, just purely from a provider perspective, but I do think it's relevant…we carry the debt of providing the service without funding for the period of time that that plan isn't in play. So the potential for a negative impact on the participant themselves is significant. If they're not funded for the support, then a provider can't afford to carry that debt. That leaves a participant unsupported.* (Provider)

The provider speaking below also makes the point that the funding structure and bureaucratic nature of the NDIS likely has a stronger negative impact on smaller Aboriginal and Torres Strait Islander organisations.

> *You know it can bring their company down. It is actually probably killing off Aboriginal corporations. NDIS has probably done a lot more harm than good for a lot of the smaller…Like it's never gonna happen. And then there's only 10 people in community that can use that service. And there's only $100,000 maximum, which they struggle to get. They will struggle to use the system because it's so bureaucratic. And so unfortunately really for the smaller Indigenous enterprises it's gonna have to be block funding. Which will have to be grant funding.* (Provider)

The importance of face-to-face contact, appropriate communication and relationship building was previously discussed in relation to participants and communities. Providers spoke about needing these things as well. The following quote from a provider illustrates the process of reducing the means of communication and contact between providers and the NDIA and ties it to difficulties that participants also experience in communicating with the Agency.

> *I mean, at the beginning. We still lucky that some of us that we still can call the local office. But, they're taking away those powers to call centre, and you know what it means, you got to wait on the telephone line for an hour to get through. At the moment we're still lucky we can talk to, but they're starting to change. Like payments now you got to centralised place. But when we started there was a local office you just call, you know them, well easy. It's getting taken away slowly, slowly. That's what making NDIS more difficult to access. Not so much for me as someone who is capable to fight my way in, but for that participant who has got difficulties with communication, who has got*

> *difficulties with understanding where they are because of their disability. That's what I'm talking about.* (Provider)

In 2018, the NDIA merged the Northern Territory and South Australia into one region, and the Northern Territory NDIA manager role was removed. The Northern Territory/South Australia NDIA region is now managed from Adelaide, as referenced by the provider below. Here, the provider talks about the frustrations in attempting to communicate through extremely impersonal and inefficient means.

> *Unfortunately,…there's no longer a Northern Territory NDIA manager. That role went and it's now being combined with South Australia, and Northern Territory has one manager that sits in Adelaide... all those sort of personal connections and help we were getting disappeared. So now, sometimes the only thing you can do is send an email just to provider.payment@ndis.gov.au and they just don't respond. It disappears. So there's a provider payments plan and there's another one provider around the portal and literally I reckon between myself and our chief financial officer, we've probably sent 20 emails and never once got a response.* (Provider)

The PRG was strongly in agreement with the difficulties in communication with the NDIA, and related this to a larger issue. Problems with communication were framed within an underlying inequality in the relationship between the NDIA and providers as a whole, which existed even if there was a good relationship between the NDIA and individual providers.

Performance against Aboriginal and Torres Strait Islander Engagement Strategy principles

Table 4 provides a snapshot of the performance of NDIS implementation against the principles laid out in the Aboriginal and Torres Strait Islander Engagement Strategy (1).

Table 4: Performance against Aboriginal and Torres Strait Islander Engagement Strategy (1) principles

NDIA principles and proposals	Rating	Summary
Engaging in the 'proper way' Engaging with Aboriginal and Torres Strait Islander people and communities in a manner that establishes trust, demonstrates respectful behaviour and is coherent with communities' values and customs.		
Displaying cultural competence Education of NDIA staff in importance of community cultural practices, language and importance of staff implementation of the '*listen, learn, build and deliver'* pillars for NDIS success.		While the NDIA does offer cultural competence training to its staff, there was little information available about what this training entailed. Cultural competence training seems mainly offered at the beginning of staff employment, rather than being reinforced on a regular basis. When first approached by NDIA staff, participants frequently reported being apprehensive or uncertain, indicating that this engagement is being undertaken inappropriately. Providers indicated that ensuring planning staff had an appropriate background and were able to communicate in a way that elicited important information sensitively was crucial to the creation of plans that reflect participant needs. However, some planners demonstrated low levels of cultural competence, ultimately impacting on the quality of participant plans. Moreover, lack of communication as new sites transitioned to the NDIS meant that the NDIA was not necessarily evolving cultural competency approaches as a result of previous experience.
Understanding Country, Culture and Community Acknowledgement by the NDIA of the importance of Country to Aboriginal and Torres Strait Islander people's emotional, spiritual and physical health. Inclusion and recognition of this importance in participant plans and in provision of supports.		Engaging with community and traditional leaders has been an important first step when entering communities. However, the engagement with community leaders conducted to date has not been effective in gaining community support and is not always known to stakeholders. For example, Community Connectors, organisational partners and support providers have reported being unaware of this engagement taking place.

		Employing Community Connectors in some communities has been valuable to the uptake of the NDIS for Aboriginal and Torres Strait Islander people, families and communities. At present, the Community Connector role has the possibility to be expanded both to more communities and in terms of the scope of the role. While connection and return to country is a frequent feature in participant plans, the realisation of this element is perceived by providers as having a low priority for the NDIA, and there are reports that cultural elements of plans are regularly underfunded. At the same time, the innovative use of assistive technology has been identified as a positive practice to support connection to country, culture and community.
Communication NDIA staff will recognise and acknowledge language may differ between Aboriginal and Torres Strait Islander communities. NDIA staff will respect that language is a way in which communities practice culture. The NDIA will utilise available translators to aid Aboriginal and Torres Strait Islander engagement. Staff will use appropriate and understandable terms when engaging with Aboriginal and Torres Strait Islander people which may include less formal language. The NDIA will utilise talking posters in traditional language and plan English fact sheets as a tool to aid engagement and understanding.	🟡	The use of interpreters in planning meetings was frequent and NDIA staff went to some lengths to ensure that interpreters were present in planning meetings as needed. However, the restrictions to using only NAATI certified interpreters are a severe limitation, as there are few certified interpreters of Aboriginal languages. Moreover, as there are cultural considerations with respect to who is permissible to have present at planning meetings, even in cases where there is a NAATI certified interpreter present, that person may not be appropriate for cultural reasons. Additionally, the policy to not include funding for interpreting supports outside of the planning meeting leads to significant negative impacts on quality of supports provided, or the necessity for support providers to fund this from other means.
Engagement Strategy Implementation of the 3 phase 'I' model as an approach to Aboriginal and Torres Strait Islander engagement.		
The 3 phases or 'I's in the model include: • *Introduction* by a local community member • *Initiate* follow up contact to demonstrate commitment • *Invitation* to return by the community	✘	Community Connectors and others within the community were largely unaware of engagement being undertaken with community leaders. This indicates that such engagement was insufficient to establish a trusting, sustainable relationship.
Aboriginal and Torres Strait Islander engagement priorities		

The NDIA has identified ten key priority areas for Aboriginal and Torres Strait Islander peoples living with a disability.		
Communication and sharing of information Information sharing between communities and stakeholders regarding the NDIS.	🟡	Support providers indicated that relationships with the NDIA are better when there are mechanisms in place for direct communication, such as to a local office. However, there have been recent changes that have made such communication more difficult. This includes the decision to merge the Northern Territory and South Australia NDIA regions into one, which is now managed from Adelaide, and a move towards centralised e-mail accounts and call centres. Providers also noted an inequity in the relationship between themselves and the NDIA that meant they did not feel respected, included or listened to in decision-making processes.
Sharing best practice Ongoing internal and external feedback on lessons learnt from participants experience and implementation of the 'proper way'	✘	Support providers reported that lessons that had been hard learned in earlier NDIS sites—such as the utilisation of existing relationships and processes to support appropriate participant plans—have not been carried over into the NDIS roll-out to new sites.
Local solutions Development and implementation of place-based approaches of the NDIS	✘	As indicated above, there has been a gradual shift towards a centralised approach with regards to NDIS governance and management, which limits the possibility of place-based implementation and development.
Participant-centric design NDIS delivery that is based on the individual physical and cultural needs of Aboriginal and Torres Strait Islander peoples. Taking into consideration flexible support delivery due to geographical challenges, culturally inclusive environments, recognition of broader family and cultural responsibilities and provision of materials which are culturally inclusive and language appropriate.	🟡	NDIA staff spoke about the principle of centering the participant even in the midst of challenging circumstances and the importance of flexibility and making accommodations to ensure culturally inclusive environments. There was reportedly wide variation in the quality of participant plans, depending on skill of the planner. Providers indicated that with less skilled planners, plans were frequently generic rather than tailored to the participants' individual needs. In sites where the scheme is more established this has improved, but in newer areas the process has reportedly started again from scratch. Innovative use of assistive technology is an exciting approach which has the potential to provide ways of incorporating flexibility and responsivity in responding to individuals' cultural needs.
Market enablement Enabling market providers to provide the right supports in the 'proper way'	🟡	There have been a range of initiatives put in place to support a stronger provider market, such as the ILC grants established by the NDIA and Innovation grants from the Northern Territory Government. There have also been indications that the number of registered providers,

		including ACCHSs, is increasing. However, there continues to be concern that the geographic spread of providers is still insufficient to deliver adequate supports to remote communities. Some practices of the NDIA have also been tied to undermining provider confidence, such as reducing plan funding following under-utilisation of previous plan funds. Interviewees suggested that the structure and bureaucracy of the NDIS makes it particularly difficult for ACCHSs to become registered providers.
Leveraging and linking Use of already existing approaches, knowledges and infrastructure to support the 'proper way'		Providers indicated that in early stages of the roll-out, existing relationships between providers and participants were under-utilised by the NDIA, leading to redundancy and engagement practices that were ineffective for participants and did not take advantage of existing knowledge about the 'proper way' of doing things. While this has improved in sites that are more established, the same pattern has emerged in sites that are currently in earlier stages of the NDIS.
Cultural leadership NDIA leadership and partners demonstrate the values and expected behaviours to align with the 'proper way' engagement strategy		The employment and utilisation of Community Connectors is important for the NDIA to be able to engage in the 'proper way' with communities. As referenced above, there are a number of areas where the NDIA's practice is misaligned with the principle of cultural leadership. This includes the restrictions around use of interpreters, insufficient engagement with community leadership, inconsistent utilisation of existing relationships between participants and support providers, limited cultural competence training for NDIA staff and insufficient allocation of supports for connection to country and culture in participant plans.
Supporting internal infrastructure Altering organisational policies, procedures, systems and practice guidance to align with the 'proper way' engagement strategy		Changes in internal NDIA organisational structure have increased difficulties in communication between providers and the NDIA. Providers also highlighted the amount of bureaucracy and delays involved in a number of basic NDIS processes, such as acquiring assistive technology, making an enquiry, seeking support for portal problems and requesting a plan be reviewed. Each of these have the effect of reducing the quality of supports for participants and increasing the administrative burden on providers, which may be particularly problematic for ACCHSs and other small organisations. Providers also highlighted the restrictions around providers acting in an advocacy role for participants as

		undermining the amount of support available for participants in the planning process and not accommodating the existing relationships between providers and participants.
Tracking progress Tracking the progress of proposed strategies for Aboriginal and Torres Strait Islander engagement and outcomes	✘	Tracking the progress of Aboriginal and Torres Strait Islander engagement and outcomes has been minimal to date. There were no data on Aboriginal and Torres Strait Islander people included in the interim evaluation report and the Aboriginal and Torres Strait Islander Engagement Strategy does not include any indicators or way of measuring progress or success. While the NDIA Quarterly Reports detail the number of Aboriginal and Torres Strait Islander people enrolled in the scheme, data regarding participant outcomes and participant experiences are not disaggregated. It is therefore difficult to identify the progress of strategies and outcomes for Aboriginal and Torres Strait Islander people.

✘= not implemented ● =partly implemented ✓=fully implemented

Conclusions

The study highlighted a number of ways in which the implementation of the NDIS could be strengthened to increase the benefits to Aboriginal and Torres Strait Islander people living with a disability. Overall it appears that the Aboriginal and Torres Strait Islander Engagement Strategy (1) was not implemented in a consistent way. This occurred both in communities where Community Connectors were employed and in communities where they were not. The strategy did not appear to be well socialised with NDIA staff. Similarly, many of the principles outlined in the strategy were also not consistently implemented. Table 4 summarises implementation of the principles based on the data collected.

An exception to this was the inclusion of cultural elements in NDIS plans. Participant plans frequently included cultural elements reflecting a shared understanding of the importance of culture to the wellbeing of Aboriginal and Torres Strait Islander people, particularly in the Northern Territory. There were positive exemplars of innovative ways to maintain connection to culture and community (such as the use of assistive technology to participate in ceremony). However, there were also indications that cultural elements such as return to country were viewed as less relevant and essential than other aspects of participant plans and were therefore consistently insufficiently funded and supported. There was also concern that the individualised approach of the NDIS did not always resonate with family-based approaches to care and decision-making in some communities and that there was a need to recognise that a person-centered approach for Aboriginal and Torres Strait Islander people should also incorporate both family and community contexts. The recognition of this need to be flexible and adapt to the preferences of people living with disabilities at the centre of the planning process has led to enabling family and other support organisations to be present during planning.

The results of the NATSISS analysis highlight the need to implement the NDIS in a culturally safe way given participants' possible past exposures to discrimination and safety issues. They also suggest 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. The development of a cultural competency framework and associated training program as outlined in the strategy would be invaluable in translating the principles into action.

The implementation of the NDIS is an ambitious enterprise and the level of support required for such a major shift in ways of working is considerable. Despite this, there has not been a strong and consistent focus on market analysis, workforce development and supporting organisational change and capacity building. This has impacted not only on service delivery but also on the planning process. According to interviewees the implementation of the scheme was hindered by a relatively inexperienced workforce leading to both a lack of continuity and the NDIS being implemented in a way that was inconsistent with its intent (e.g. generic participant plans that did not reflect the needs and goals of individual participants). It should be noted that in some areas an emergent local workforce had led to improvements in implementation.

Finally, support providers found it difficult to transition from block funding to funding based on individualised plans. This change was anticipated and is consistent with a shift from focusing on the needs of people living with disabilities rather than service organisations. Consequently, a shift back to a reliance on block funding is likely to be a retrograde step from the perspective of people living with disabilities. However, a hybrid funding model with greater support to assist organisations to manage pooling or aggregation across plans may be beneficial to support the changes required to implement the NDIS. This may also assist in addressing the

problem of thin markets by supporting resource-sharing and by encouraging the involvement of new players, including ACCHSs, who see the organisational change required to support a completely different funding models as a disincentive to participation.

Overall, the NDIS is a scheme that has the potential to significantly benefit Aboriginal and Torres Strait Islander people living with disability. The NDIA has acknowledged that culturally appropriate engagement and delivery is a necessary component of the support required by Aboriginal and Torres Strait Islander people living with disabilities. However, there remain significant issues in the on-the-ground implementation of the NDIS, particularly in remote locations. The results of the study have informed recommendations for the implementation of the Aboriginal and Torres Strait Islander Engagement Strategy and development of the cultural competency framework, communication and engagement with Aboriginal and Torres Strait Islander people and communities, improving participant plans and the provision of disability supports, and strengthening the capacity of organisations to provide appropriate disability support.

Recommendations

Overall, the NDIS is a scheme that has the potential to significantly benefit Aboriginal and Torres Strait Islander people living with disability. The NDIA has acknowledged that culturally appropriate engagement and delivery is a necessary component of the support required by Aboriginal and Torres Strait Islander people living with disabilities. However, there remain significant issues in the on-the-ground implementation of the NDIS, particularly in remote locations. The results of the study have informed recommendations for the implementation of the Aboriginal and Torres Strait Islander Engagement Strategy and development of the cultural competency framework, communication and engagement with Aboriginal and Torres Strait Islander people and communities, improving participant plans and the provision of disability supports, and strengthening the capacity of organisations to provide appropriate disability support.

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 cultural competency framework developed. The specific recommendations below outline how the implementation of the Aboriginal and Torres Strait Islander Engagement Strategy could be strengthened. It is particularly important to ensure that NDIS participants' preferences around support and decision-making during planning are respected. In some cases, where a collective rather than individual approach is preferred, 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 results of NATSISS analysis suggest that across all ages groups, Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and Torres Strait Islander people to experience unfair treatment and avoid places where they have previously been treated unfairly. Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and Torres Strait Islander people to experience violence, threats and removal from their natural families. They also suggest 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

Community engagement is essential in ensuring community 'buy-in' for the NDIS and is recognised in the Aboriginal and Torres Strait Islander Engagement Strategy. It was clear in this study that in many communities the triple 'I' process outlined in the strategy (Introduction by a local community member, Initiate follow up contact to demonstrate commitment, and Invitation to return by the community) (1) was either not implemented or implemented in a manner that had little impact on 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. In this way, Community Connectors could facilitate 'place based' responses by providing information on community needs and contextual factors that may affect how the NDIS functions. Community

Connectors should also be more strongly involved in the process of engaging community/traditional leaders. This would both ensure that Community Connectors are aware of the degree of support of community leaders and can provide an opportunity to open a channel of communication between these leaders and the NDIA.

Recommendation 4: Expanding, strengthening and supporting Community Connectors

The importance of enhanced involvement of Community Connectors in community engagement is outlined above. Community Connectors are also unique in their positioning 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. They are therefore in an ideal position to facilitate better communication during planning meetings. In conjunction with Recommendation 7, 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. The development of explicit guidelines around the Community Connector role could facilitate a clearer understanding of how they could be best utilised.

However, in order for Community Connectors to operate effectively, they must be adequately supported and integrated into the community engagement process. Interviewed Community Connectors highlighted the need for enhanced and ongoing training from the NDIA to broaden their understanding of the NDIS and its components. Training could also be used as an opportunity to clarify the Community Connector roles. This training should be underpinned by a place-based approach, tailored to communities and incorporate Aboriginal and Torres Strait Islander ways of understanding and acting, in order to improve relevance to the local context. The interviewed Community Connectors were particularly supportive of activities such as role playing in training. Using a peer-to-peer approach where more experienced Community Connectors take on parts of the training may also increase relevance, understanding and acceptance.

Given the importance of the Community Connector position, Community Connectors should be employed and appropriately resourced within all remote communities. Having a stable workforce of locally based people will further develop local capacity. It is essential that adequate resources are allocated for the attraction, retention and supervision of appropriate personnel. Engaging and retaining Community Connectors necessitates honouring their connections to community, including their cultural obligations. A flexible approach that supports these obligations will involve allowing for adequate amounts of cultural leave.

Recommendation 5: Development of resources for participants and their families

Lack of understanding of the NDIS particularly leading into and during the planning process highlighted the need for the development of additional resources for participants and their families. It was reported that resources should be developed to support planning meetings. For example, Synapse developed ‘Yarn Up’ cards to help participants identify their needs during planning meetings (4). Specifically, it was felt that the planning process would be enhanced if resources 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. Such resources should include pictorial representation and a minimal amount of text, keeping language simple or translated. 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 and disseminated locally.

Recommendation 6: Improved communication with participants before initial face-to-face meetings

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 a sense that 'purple people were popping up' and a fear that the outcome of the meeting might be to cut funding or deprive participants of existing benefits. In many remote communities it is difficult to contact people directly (e.g. no mailing addresses and unreliable mobile phone connections) and communication can only be managed via facilitation through third parties. This again highlights the importance of Community Connectors and local support providers in engaging with participants to ensure that the process is clear and that their fears are allayed prior to the planning meeting. In order 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

Local support providers have existing relationships with participants and a good understanding of their needs. However, the role of local support providers in planning meetings has been limited and unfunded. Even if they are attending at the request of the participant, providers have been unable to speak on behalf of the participant because of concern that they will represent their own interests and not that of the participant--a situation characterised as shameful for both the provider and the participant. While it is critical that conflicts of interest are managed, it is also important that participants are able to access support that will enable meetings to be held in a culturally safe way. Provider involvement where appropriate will also enable the NDIA to capitalise on existing provider relationships to build trust with participants. Privileging participant preferences for the conduct of meetings is important for cultural safety particularly in initial engagement. 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

The requirement to use interpreters with NAATI certifiation is laudable in terms of ensuring the quality of interpretation. However, lack of certified interpreters made implementing this policy difficult and in some cases led to situations that were culturally confronting, for example where the interpreter was culturally inappropriate to be involved in the transmission of intimate information. 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 then other options (e.g. use of Community Connectors as language and cultural 'brokers') should be considered. This is particularly important if the only alternative is delays in implementation or the use of culturally inappropriate interpreters. Currently, use of interpreters is not funded beyond the planning meeting, as not having English as a first language is not regarded as related to a participant's disability. The ability to communicate and represent participant needs is, however, important to the development and implementation of an effective plan. The inclusion of funding for interpreting services is therefore 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

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. The Aboriginal and Torres Strait Islander Engagement Strategy recognises the centrality of culture, particularly connection to country, for Aboriginal and Torres Strait Islander people. It is therefore necessary to ensure that implementation of participant plans and associated funding reflect the importance of culture to Aboriginal and Torres Strait Islander participants.

Recommendation 10: Ensure participant plans are consistently funded according to needs discussed in planning meetings

In some cases there was a lack of continuity between what was discussed at the planning meeting and the funded plan from the perspective of providers. 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. 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. NDIA staff on the PRG 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 Torres Strait Islander support workforce

There is a clear need to build a local Aboriginal and 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

Many providers familiar with block funding mechanisms found it difficult to transition to a more individualised approach to funding. However, there was also a recognition that block funding alone did not meet the needs of Aboriginal and Torres Strait Islander people living with disabilities. In remote areas, an 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. Features of this model would include more flexibility around support coordination, respite (short term accommodation), and transport. In remote areas, better support provision by governments, and more collaboration with and between support providers is needed (5).

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 need for organisational change and the associated administrative burden can be a disincentive to participating in the NDIS for current and potential providers, including for providers whose core business is not disability services but who might be well equipped to provide such supports, such as ACCHSs. The NDIS therefore requires a different approach to funding models to support the organisational changes and capacity building for support providers. 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. Support for organisational change around participation in the NDIS may be important to expanding markets and strengthening the participation of ACCHSs.

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Appendix 1: Participant interview schedule

Is the National Disability Insurance Scheme meeting the needs of Aboriginal and Torres Strait Islander people? Evaluating the roll-out in Queensland and the Northern Territory

Participant interview protocol

The interviewer will begin by discussing the purpose of the research study. S/he will talk through the 'plain language statement' and make sure the NDIS participant has given informed consent to be interviewed. S/he will also check whether consent has been given to allow audio recording of the interview.

Demographics
To start off let's talk a little bit about your background and family.

1. Where do you live?
2. Which communities or homelands do you often visit? What clan and language groups do you belong to?
3. How old are you? (Age in years)
4. Do you have a partner? Are you married? Yes/No
5. Do you have any children? If so what ages are your children? (Age in years each child)
6. Are you working at the moment? (Full-time/part-time /unemployed)
7. How far did you go at school?
    a. Did you study after school?
8. Do you have a health care card? (Yes/No)

Disability
Now I am going to ask some questions about your disability and your everyday life.

9. Tell me a little bit about your disability.
10. How is your daily life affected? (i.e. participation with family, body movement and other health impacts)?
11. Do you have any health conditions that your doctor/nurse knows about? Does this affect your disability?
12. Do you have someone who cares for you, helps you with your life? Who is the person who helps you the most?
    a. Who is your number one carer?
    b. What things do you need special help with?
13. What special help do you receive?
14. What was your part in getting the kinds of help you are receiving?

15. What are the main things where you would like extra support? What changes do you want to see with the support you are receiving now?
16. Over the last full year (12 months) do you feel that you have been treated unfairly by others? Have you experienced other problems? Where did this happen?
    a. Why do you think they treated you this way (i.e. because you are disabled, Aboriginal/other)?
    b. What effect did this have on you?

Initial engagement with the NDIS

Starting up the NDIS has changed the way disability services are provided. I want to ask you some questions about what you've heard and understand about the NDIS.

17. Have you heard about the NDIS? Do you know what the NDIS is?
18. Who first told you about the NDIS? When?
19. Did they explain about the NDIS to you in your own language? Did what they say give you a clear picture about the NDIS? Tell me what you understand about the reason for the NDIS and what it is aiming to do.
20. Did you think it would be good to 'sign up' for the NDIS?
21. Did you complete an Access Request Form (ARF) to access the NDIS? Did you have help to complete the ARF to access the NDIS?
22. Did you understand how to complete the ARF? Did you understand the questions?
23. How was your ARF sent to the NDIS?
24. Have you heard back from the NDIS? Did the NDIS get back in touch with you?
    a. Was your ARF accepted?
    b. Was your ARF rejected? If so, did you know you could appeal the NDIA decision? Did you appeal? Was your appeal successful?
25. Are you a participant in the NDIS (National Disability Insurance Scheme)? If yes, for how long?

→If the interviewee is a participant of the NDIS (i.e. has a participant plan), continue
→If the interviewee is not a participant of the NDIS, go to 'National Disability Insurance Scheme (Non-participants)

National Disability Insurance Scheme

I'd like to ask you some questions about how some things may have changed since you've been on the NDIS.

26. Why did you decide to start using the NDIS? Can you tell me what you thought about how the NDIS might help you?
27. Have you noticed changes in the care/support you receive since you got an NDIS plan?
    a. How have these changes affected the way you are cared for?
    b. Have these changes made your life better?
    c. Have there been some changes that were not good?
    d. What things have helped make your care better? What are some of the problems that stop you receiving good care?

Planning

All people in the NDIS have a participant plan for their care. Each person's approved participant plan is like the 'law' (or rules) for how that person with a disability receives help for their disability. Let's talk together about the way plans were made for your care.

28. When did you first start talking about having a plan for NDIS help?
29. Did anyone talk to you about the steps involved in making a participant plan? Who talked to you and when? Were you given any help to get ready for making your plan? If Yes, how did this information help you with the different planning steps?
30. What were you thinking would happen in the planning meetings?
31. Where did the planning meetings take place? Was it face-to-face or over the phone? Was it a good way to talk about plans?
    a. Did you understand what happened in those meetings?
32. How do you feel about the way your plan was made?
33. Do you think making plans should be done a different way?
34. What do you hope comes from your plan? What do you want to see happen?
35. Who was the main person in charge of the planning?
    a. Do you think this person was the right person to be in charge? If Yes, why? If No, why not? Who might have done a better job?
36. Were there other people you wanted to talk in the planning meeting (e.g. your family)? Were you able to talk with them or ask them about helping with planning?
    a. If No, what made it hard?
    b. If Yes, did they like being in the planning meetings?
37. Who helped you talk about the things you would like to see in your plan? What made it easy to talk about making a plan? What made it hard to talk about making your plan?
38. Do you think other people involved really understood what you were saying and feeling, or only a little bit?
39. What things in your plan make you feel good about being a Warnindilyakwa / Yolŋu/Yugul Mangi person? Do you want more activities from your culture to be included? What types of activities do you enjoy doing?
40. Does your NDIS plan fit with the things you need help with? If No, what is the reason for that?
41. What do you think you can do to change what is in your plan?
42. What things about the visit by NDIA staff were helpful and made you feel like they understood how you felt as a Warnindilyakwa/Yolŋu/Yugul Mangi person? What things about their visit were not helpful?
43. What would you like to see happen to make future planning more easy?

Implementation

Now let's talk about what care and support you are receiving.

44. Do you feel you now have more choice in the care and support you receive? Do you like being in the NDIS?
45. What were the main points you wanted to see in your plan?

46. Have any Warnindilyakwa / Yolŋu/Yugul Mangi culture activities been part of your care? Do you think they should be?
47. How much care/support that is written in your plan do you receive right now? What helped? What things stopped good care from happening?
48. Who are the different people or organisations you go to for your care or support? Is there someone else you would like to see to help with your care? Is there anyone you currently see who you are unhappy with?
49. What care/support is working well for you that you are happy about? What are your main concerns about the care/support you are receiving?
50. What things about your care helped you feel good as a Warnindilyakwa/Yolŋu/Yugul Mangi person?
51. In what ways has your care become better? What are main things you would like to see for a better future?

→If a participant of the NDIS, go to 'Other services'

National Disability Insurance Scheme (Non-participants)

Starting up the NDIS has changed the way disability services are provided.

26. Why did you decide not to use the NDIS?
27. Do you think you might like to join with the NDIS in the future?
    a. What is your reason for saying that?
28. Starting with the NDIS is sometimes a bit difficult. Are you interested in finding out some more about the NDIS in your first language?

Other services

People living with disabilities use a range of services (e.g. health, social services).

29. What types of disability help are there for you to use?
30. How well do different services work together to give you good care? How could this be done better?

Overall

31. How could disability care and support be done better so Aboriginal and Torres Strait Islander people feel they are being cared for properly by the NDIS?
32. Is there anything else you would like to talk about?

Appendix 2: NDIA staff interview schedule

Is the National Disability Insurance Scheme meeting the needs of Aboriginal and Torres Strait Islander people? Evaluating the roll-out in Queensland and the Northern Territory

NDIA staff interview protocol

The interviewer will begin by discussing the purpose of the research study. S/he will talk through the 'plain language statement' and make sure the interviewee has given informed consent to be interviewed. S/he will also confirm that consent has been given to allow audio recording of the interview.

Background

Let's start off talking a little bit about your history of working with the NDIS.

1. What is the name of your work position?
2. Who do you work for?
3. Are you Aboriginal or Torres Strait Islander?
4. What is your role with regards to the NDIS?
5. How long have you been doing NDIS work?
6. What do you understand is the main reason for the NDIS?
7. What are the barriers and facilitators to NDIA staff delivering this?
8. What do you know of the NDIS's Aboriginal and Torres Strait Islander Engagement Strategy? How does it inform you in your daily work?
9. What activities to you undertake within Aboriginal and Torres Strait Islander communities to promote access to the scheme?

Signing up providers

One the first steps to implementing the NDIS was signing up disability support providers.

10. Can you tell me about the process of signing up providers? What worked well? What could have been improved?
11. How satisfied are you with the number and diversity of providers who signed up?
    a. Where did the group of the providers need strengthening?
    b. Were any strategies implemented to support this?
12. For support providers that have signed up with the NDIS:
    a. What level of experience do they have in working with Aboriginal and Torres Strait Islander people and communities?
    b. For those providers that did not have much experience in this area or were hesitant, was there any support provided? If so, what kind of support and if not, what type of support might have been useful?

13. What are levels of participation like among providers who work specifically with Aboriginal and Torres Strait Islander people?
    a. Were there any strategies implemented to support greater participation among these providers?
14. How much choice do people living with disabilities, especially Aboriginal and Torres Strait Islander people, have in their support given the range of participating providers?
    a. Is there any evidence of an emerging market?
15. What are the main learnings from the initial sign-up process?

Recruiting and training the workforce

The NDIS also required the recruitment and training of a new workforce. Now I would like to talk a bit about that process.

16. In what ways did the recruitment of NDIA staff in the Northern Territory/Queensland work well? What were the challenges?
17. Were there local applicants? What was the representation of diverse populations particularly Aboriginal and Torres Strait Islander people like?
    a. What strategies were implemented to address any issues with recruitment?
18. What were the strengths and weaknesses in the training NDIA staff?
    a. Have any strategies been put in place to improve training?
19. What provision was made to adapt training and recruitment to local context?
20. How were cultural concepts and understanding of disability and cultural safety addressed in training?
21. What were the key priorities of NDIA staff in terms of managing participants?
22. How could recruitment and training of staff be improved in the future?

Preparing for the roll-out

Now I would like to talk about what preparation there was for the roll-out of the NDIS in the Northern Territory/Queensland in terms of engaging with local support providers, Aboriginal and Torres Strait Islander organisations and Aboriginal and Torres Strait Islander communities.

23. What engagement was there with local support providers leading up to the roll-out of the NDIS? What worked well? What could have been improved?
24. What engagement was there with Aboriginal and Torres Strait Islander Community Controlled organisations and Aboriginal and Torres Strait Islander communities leading up to the roll-out of the NDIS? What worked well? What could have been improved?
25. How was engagement with Aboriginal and Torres Strait Islander communities undertaken? How was it decided and who decided which community members should be engaged with?
26. Have you worked with Aboriginal and Torres Strait Islander Community Connectors?
    a. How do you see their role?
    b. How have you worked with them?
    c. Have they been effective in building connections? How could this effectiveness be improved?
27. Has there been differences in how much services engage with the NDIS? In what way has this manifested? What drives these differences?
28. What are the main learnings from the engagement process?

Overall

29. What are the main things we can learn about how to do NDIS work better?
30. Are there any other things you would like to discuss?

Appendix 3: Providers and partner organisations interview schedule

Is the National Disability Insurance Scheme meeting the needs of Aboriginal and Torres Strait Islander people? Evaluating the roll-out in Queensland and the Northern Territory

Providers and partner organisations interview protocol

The interviewer will begin by discussing the purpose of the research study. S/he will talk through the 'plain language statement' and make sure the interviewee has given informed consent to be interviewed. S/he will also confirm that consent has been given to allow audio recording of the interview.

In this interview we will discuss the roll-out of NDIS (National Disability Insurance Scheme) in the Northern Territory/Queensland. We are really interested in the main points learnt along the way and also how things are working now.

Background
Let's start off talking a little bit about your history of working with the NDIS.

1. What is the name of your work position?
2. Who do you work for?
3. Are you Aboriginal or Torres Strait Islander?
4. What is your role with the NDIS?
5. How long have you been doing NDIS work?
6. What do you understand is the main reason for NDIS?
7. What are the barriers and facilitators to NDIA staff delivering this?
8. What do you know of the NDIS Aboriginal and Torres Strait Islander Engagement Strategy? How does it inform you in your daily work?
9. What activities to you undertake within Aboriginal and Torres Strait Islander communities to promote access to the scheme?

Implementing planning for participants
A key component of the NDIS is the development of participant plans to ensure that services better meet the needs of people living with disabilities. I am going to ask some questions about the implementation of the planning process in the Northern Territory/Queensland

10. To what extent was the planning process implemented as planned? What worked well? What were some of the challenges?
11. Have any changes been made to the planning processes or their support in response to these learnings?

12. Have there been differences in how planning has been done in different communities?
13. What evidence is there that the planning process was conducted in culturally safe ways for Aboriginal and Torres Strait Islander people?
    a. What are areas for improvement?
14. What scope is there for families to be included in the planning process?
    a. How is this implemented?
15. What scope is there for cultural activities to be included in participant plans? Does this vary according to who involved in the planning e.g. NDIS staff or LAC's or other agency/family or by geography (urban vs rural vs remote areas)?
    a. What are some instances where planning may include cultural activities?
    b. What types of activities may be included?
16. Is there scope for other organisations to be involved in the planning process (e.g. other services that may be providing care to the participant)?
17. What are the main learnings from the implementation of the planning process?

Providing support

Now I am going to ask you about the provision of support though the NDIS in the Northern Territory/Queensland

18. To what extent have people living with disabilities been able to receive the support outlined in their plans? What are the barriers and facilitating factors?
19. To what extent have Aboriginal and Torres Strait Islander people living with disabilities been able to receive the support outlined in their plans? What are the barriers and facilitating factors?
20. How is the NDIA working with support providers to ensure that appropriate support is provided?
    a. What policies are in place for ongoing communication with support providers?
21. What evidence is there that the support participants are receiving under the NDIS is better meeting their needs than previous arrangements? What areas for improvement are there?
22. What do you consider to be culturally safe support for Aboriginal and Torres Strait Islander people and communities?
    a. What evidence is there that supports are being provided in a culturally safe way for Aboriginal and Torres Strait Islander people?
    b. What are areas for improvement?
    c. What support is available for providers that struggle to provide culturally safe support?
23. Have there been differences in the way supports are provided in different communities?
24. What are the main learnings in terms of support provision?

Overall

25. What are the main things we can learn about how to do NDIS work better?
26. Are there any other things you would like to discuss?

Appendix 4: Community Connectors interview schedule

Is the National Disability Insurance Scheme meeting the needs of Aboriginal and Torres Strait Islander people? Evaluating the roll-out in Queensland and the Northern Territory

Community Connectors interview protocol

The interviewer will begin by discussing the purpose of the research study. S/he will talk through the 'plain language statement' and make sure the NDIS participant has given informed consent to be interviewed. S/he will also check whether consent has been given to allow audio recording of the interview.

In this interview we will discuss the roll-out of NDIS (National Disability Insurance Scheme) in the Northern Territory/Queensland. We are really interested in the main points learnt along the way and also how things are working now.

Background
Let's start off talking a little bit about your history of working with the NDIS.

1. What is the name of your work position?
2. Who do you work for?
3. Are you Aboriginal or Torres Strait Islander?
4. What is your role with the NDIS?
5. How long have you been doing NDIS work?
6. What do you understand is the main reason for the NDIS?
7. What are the barriers and facilitators to NDIA staff delivering this?
8. What do you know of the NDIS's Aboriginal and Torres Strait Islander Engagement Strategy? How does it inform you in your daily work?
9. What activities to you undertake within Aboriginal and Torres Strait Islander communities to promote access to the scheme?

Recruiting and training
I'd like to talk to you about the first steps of how you started working with the NDIS. What is your role with the NDIS?

10. Can you tell me how you first heard about the NDIS? How was your job as a Community Connector explained to you?
11. What are the communities where you do work with the NDIS?
12. What training was provided to you when you began your NDIS role? Did anyone talk with you about 'cultural safety' or feeling comfortable about your NDIS work?
13. Did you receive the training in your first language?

   a. How did you feel about the training you had?
   b. How do you think the training could be made better in future?
14. Has your role with the NDIS been different from what you expected? In what way was it different?
15. Did you work in more than one community?
   a. How is the work different in different places?
   b. Do you feel you could change the way you talked about the NDIS to help people better understand?

Preparing for the roll-out

Now I would like to talk about your job in preparing for the roll-out of the NDIS in the Northern Territory/Queensland and the way you worked with local support providers, and local organisations.

16. How did you help with getting ready for the NDIS to start in the communities you worked in?
   a. How did you help people get ready for the NDIS to start?
   b. Did you work with local support providers and local organisations?
17. What meetings happened with Aboriginal and Torres Strait Islander people and Aboriginal and Torres Strait Islander organisations before the NDIS started? What worked well? What might have been done better?
18. How did discussions with Aboriginal and Torres Strait Islander communities happen?
   a. Who decided which community leaders to talk with?
19. Has there been much interest in the NDIS?
   a. Have disability people received more help since the NDIS started?
   b. Have other people also received more help since the NDIS started?
   c. What extra help have you seen?
   d. What do you think are reasons for some things being better or different?
20. What are the main things you have learnt from helping the NDIS to start?

Implementing planning for participants

For the NDIS to happen, each participant has their own personal plan to say what help they can have and who will give that help. I am going to ask you some questions about what you did when plans were being made.

21. What was your role/job in helping people to have plans?
22. What worked well? What were some of the challenges/problems?
23. What strategies has the NDIA been implemented to improve planning?
   a. Can you think of some ways? (e.g. family being involved, cultural help)
24. Do you think the way plans were done helped Aboriginal and Torres Strait Islander people to feel comfortable?
   a. What are the best ways to make plans?
25. Tell me about the way you work with families to do plans?
26. How are Aboriginal and Torres Strait Islander ways included in the plans of people who have a disability?
   a. What types of activities things do people want to see included?

b. What are some good ways to include more Aboriginal and Torres Strait Islander ways of doing things in plans?

Overall

27. What are the main things we can learn about how to do NDIS work better?
28. Are there any other things you would like to discuss?