

# Submission to the NDIS Thin Markets Project May 2019

About the Aboriginal and Torres Strait Islander Disability Network of Queensland (ATSIDNQ)

The ATSIDNQ is a growing network of over 900 Aboriginal and Torres Strait Islander people with disability, their families, carers and supporters.

The Network offers a culturally safe space for members to connect, share and raise awareness of the issues they are facing.

The Network gives members the opportunity to celebrate their strengths, share their stories and contribute to the conversation about disability in positive ways.

The Network employs Indigenous staff who work with members to understand the variety of issues Aboriginal and Torres Strait Islander people with disability face and ensure this information is fed back to government policy makers.

The ATSIDNQ receives funding from QDN (Queenslanders with Disability Network) with Aged and Disability Advocacy Australia providing the auspice for the Network.

## ATSINDQ Submission to the NDIS Thin Markets Project

The ATSIDNQ welcomes the opportunity to provide feedback to the NDIS Thin Markets Project. The ATSIDNQ submission will respond to the following discussion paper questions targeted at peak bodies representing participants:

- In your organisation's experience, what barriers are affecting the availability of services, and the ability of participants to access services?
- What short-term and long-term approaches do you believe would address thin market issues for you?

In preparing responses to these questions, the ATSIDNQ Project Officer, Bruce Simpson, travelled to the following towns and engaged over 75 ATSIDNQ members and supporters in discussion (yarning groups) about the NDIS:

- Dalby (rural)
- Oakey (rural)
- St George (rural)
- Hervey Bay (regional)
- Maryborough (regional)
- Logan (metropolitan)
- Brisbane (metropolitan)
- Bamaga (remote)
- Seisia (remote)
- Umagico (remote)
- Injinoo (remote)
- New Mapoon (remote)

These communities are representative of metropolitan, regional, rural and remote communities. However, it must be noted that the responses prepared in this submission, may not be reflective of the views and experiences of all Aboriginal and Torres Strait Islander communities.

In addition to engaging with ATSIDNQ members face to face, two online surveys were developed and distributed via email, the ATSIDNQ newsletter and the ATSIDNQ Facebook page. Survey questions included

- How could your life as an Aboriginal and Torres Strait Islander person with disability (or the life of a family member with disability) be improved?
- Have you had any experiences with the NDIS? Tell us about it both good and bad.
- What are the barriers currently preventing people in your community from accessing the NDIS?
- What do you think is needed to address these barriers?
- Is the NDIS meeting the needs of people who are receiving a package?
- How could NDIS supports and services be improved?

In total these surveys were successful in gathering the view and experiences of 26 ATSIDNQ members.

The views and experiences of ATSIDNQ members engaged face to face and via online survey are expressed in the feedback provided in this submission.

In your organisation's experience, what barriers are affecting the availability of services, and the ability of participants to access services? (e.g. access to information, diversity of services, location and travel, plan budget etc)

The following issues were identified by ATSIDNQ members and supporters as barriers affecting access to the NDIS:

#### • Information:

ATSIDNQ members indicated that they needed access to easy to understand, jargon free, culturally appropriate information on the NDIS. Comments from ATSIDNQ members included

"(I)Do not know who to contact and too many service providers and confused about funding for home assistance vs. package."

"They never explain it (the NDIS) properly."

"Basic English, face to face no telephone because they leave you hanging, while they find out the answer."

Some of the communities the ATSIDNQ project officer visited requested information sessions on the NDIS. Other communities explained that they have participated in NDIS roll out information sessions in their area, but found the sessions were too rushed and used new and confusing language. Some people said they put the NDIS in the "too hard basket" after attending information sessions.

#### Support to access services

Throughout the consultations ATSIDNQ members described an urgent need for one on one support/case management to support Aboriginal and Torres Strait Islander people with disability to access the NDIS.

"Low literacy is a major issue for Aboriginal and Torres Strait Islander people and the need to undertake a several step process is daunting for them. For this reason, they either never commence the process or start and discontinue due to the difficulties."

"No one to talk to and help get my application in and done."

"Access is challenging. Support is required but not necessarily readily available in all aspects of the scheme."

"Many people within our community don't identify as having a disability, particularly those with mental health issues. They also often don't have anyone to assist them to navigate the system. As health professionals we have difficulty navigating the system so cannot imagine what it is like for them."

There were also several comments made with regards to the requirement to present evidence of disability as part of the application process:

"Gathering evidence for our mob seems to be a bit of a battle and needs to be streamlined a little better."

"There are major challenges around the evidence and information required which is impacting client wellbeing."

"There is very limited support in this area to conduct assessments and provide diagnosis. Where there is a service available it is very costly and clearly many of our community do not have access to the funds required, often \$2000+."

"There are many issues for people with a disability diagnosed as a child and now in adulthood having access to supporting evidence to submit to the NDIA."

### Service capability

Service capability was a common theme raised through consultation with the ATSINQ membership.

Comments were made in relation to health professionals and their role in informing and supporting people to access the NDIS

"A lot of medical staff shy away from hearing the full story and inadequately fill out forms. Staff are time poor, or make inadequate judgements."

"I have recently been diagnosed with a disability but no NDIS mentioned by my GP....I don't go to an Aboriginal medical centre...I go to a mainstream medical centre".

"Proper coordination of medical staff (is needed), someone to chase them up on things as we get burnt out as a family trying to decipher the jargon and pass it on to staff. Medical staff need a lot more training in patient's needs. Medical staff should be backed up by an NDIS support worker".

Feedback was also provided in relation to Local Area Coordinators:

"We have people with very complex social circumstances in addition to their disability so to expect them to navigate service provision with very limited assistance from the LAC is overwhelming."

"My experience of LACs has been less than positive with participants being given incorrect information about services available. Their lack of understanding about the needs of Aboriginal and Torres Strait Islander people is obvious."

"There seems to be an expectation by LACs that roles such as mine (social worker in a primary health clinic) take on the responsibility as a 'substitute support co-ordinator' for those who are not funded for this in their package. I've lost count of the times I've been asked 'well can't you do it' when questioning who is going to co-ordinate services as part of an individual's package."

"The LAC Coordinators need to have a clinical background to know how to support and refer onto the NGO sector to take the client through the NDIS application process."

The capacity of NDIS service providers was also discussed, with one ATSIDNQ member commenting:

"NDIS is not the problem. Service provider capacity, flexibility and willingness to accommodate our specific wants and needs, when and where we want and need them is a significant problem. Funding is allocated but we are simply unable to secure providers to deliver them in a way that maximises the benefit to us."

Others supported this sentiment by sharing the challenges they have faced in accessing the care they needed:

"(There are no) services willing to travel to remote communities"

"(I'm) not getting support staff when I want. not getting the type of staff I want - female and aboriginal who can help with my mental health."

"(It is difficult) finding appropriate service providers who will consider taking on new client no matter how large or SMALL their NDIS package is."

"There are very long wait lists for services particularly therapeutic services such as allied health."

"Having difficulty finding some of the people that are required to implement the plan... which results in under usage of funds which will result in the next years funds being less. Definitely an anti-user bias in that structure."

These types of issues are heightened in remote areas such as Bamaga and surrounds where service assess is an ongoing issue. For example, one Bamaga resident explained that they wanted to meet with the NDIA to tell of their story of being eligible for an NDIS package, but the NDIA office in their area was located in the Torres Strait Islands and only visited Bamaga once a year.

A number of ATSIDNQ members expressed a need for more culturally appropriate services. Dedicated NDIS Aboriginal Health Services have been successful in fulfilling this need in some areas, whilst in other areas some Aboriginal health services expressed that they did not have the capacity to deliver NDIS related supports in their community.

A couple of ATSIDNQ members reported that they did originally approach an Aboriginal and Torres Strait Islander service provider to receive NDIS information, however they could see the service provider was overwhelmed with distributing that information These members choose to go to a non-Indigenous service provider instead as they did not feel adequately supported by the service.

This feedback highlights the importance of supporting the capacity of Aboriginal and Torres Strait Islander services as well as ensuring the cultural competency of non-Indigenous services.

What short-term and long-term approaches do you believe would best address thin market issues for you?

ATSIDNQ members and their supporters offer a range of suggestions on how access to the NDIS could be improved for Aboriginal and Torres Strait Islander people with disability in their area.

Suggestion included:

"Less paperwork and easy access."

"A home visit to explain it."

"A case worker who is there from beginning to end, to help with everything involved."

"Better assistance on a one on one."

"Having a one stop shop to meet all of a person's need.s"

"Indigenous trained NDIS support workers to visit AMS (Aboriginal medical centres) or health workers trained in NDIS application processe.s"

"A couple of meetings per year with assigned case worke.r"

"A mainstream office situated in our community where everybody can access somebody who knows about the NDIS."

"Information made readily available on what condition is eligible and what services are available with that condition."

"Support co-ordination included for everyone and an opt out system introduced for those who wish to self-manage their packages."

"More culturally specific NGO (non-government organisations) created, supported and developed to address the needs of the community."

"Less paperwork, more face to face contact..."

"Service info made available through my GP."

"Basic English, face to face, no telephone."

"More community advocacy."

"Simplified access such as online forms so people don't have to telephone and be on hold for a lengthy period of time."

This feedback offers a diverse range of solutions with some favouring one stop shops, mainstream offices and online forms, whilst others call for face to face support, in home visits and Indigenous NDIS support workers.

The breadth of this feedback highlights that a 'one-size-fits-all' approach will not be an effective solution for addressing NDIS access issues in Aboriginal and Torres Strait Islander communities.

The ATSIDNQ recommends that funding be provided for community led responses aimed at addressing NDIS access and service needs within individual Aboriginal and Torres Strait Islander communities.

The ATSIDNQ would like to stress the importance of not rushing the implementation of community led approaches. Local communities should be supported adequately explore the needs of their communities, identify which organisations are best placed to meet those needs and then grant those organisations sufficient time and resources to build their capacity and the capacity of their employees and support networks.

The ATSIDNQ has observed that initiatives that are rolled out under constrained timeframes set by the government do not have the flexibility or the level of knowledge (NDIS and community

knowledge) required to meet the information and access needs of Aboriginal and Torres Strait Islander people with disability.

# Contact ATSIDNQ

Thank you for the opportunity to provide input into *NDIS Thin Markets Project*. Should you have any queries regarding the content of this submission, please do not hesitate in contacting ATSIDNQ Project Officer, Bruce Simpson on 1800 718 969 or <a href="mailto:bruce.simpson@adaaustralia.com.au">bruce.simpson@adaaustralia.com.au</a>