Submission to the Joint Standing Committee on the National Disability Insurance Scheme

Inquiry into the Capability and Culture of the National Disability Insurance Agency (NDIA)

16 December 2022

***In this document, unless quoting directly, the term Aboriginal is used in preference to the term Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. For the purpose of this document, the term Aboriginal is also respectfully inclusive of Torres Strait Islander peoples.*

The Aboriginal Health Council of Western Australia (AHCWA) welcomes the opportunity to make a submission to the Joint Standing Committee's inquiry into Capability and Culture of the NDIA.

AHCWA is the peak body for 23 Aboriginal Community Controlled Health Services (ACCHS) providing comprehensive and culturally secure primary health care across diverse regional, rural and remote locations in Western Australia. AHCWA exists to support and act on behalf of our Member ACCHS, and our principal vision is for Aboriginal people in Western Australia (WA) to enjoy the same level of health and wellbeing as all Western Australians.

The need for an effective and efficient NDIS service for Aboriginal communities is evident through the current gaps, barriers and inequity in access to the scheme which are exacerbated for those living in regional, remote and very remote WA. The aforementioned information should be considered with the understanding of the pivotal role ACCHS and Aboriginal Community Controlled Organisations (ACCOs) play in the delivery of the NDIS.

Prevalence of disability experienced by Aboriginal people in Australia

The NDIS brought one of the biggest changes to the disability sector by introducing an individualised, person-centred funding model. This fundamentally restricts collective and community level supports with little room for flexibility except in rare cases (for example, the coordinated funding proposals[1]). This segmented and complicated funding model steers further away from the established community-based holistic model of care Aboriginal people are accustomed to.

Since the inception of the NDIS, the NDIA has made multiple attempts to create and implement strategies to establish an inclusive scheme that delivers a fair NDIS. However, in our view, these efforts are yet to be successful.

In the 2018-19 National Aboriginal and Torres Strait Islander Health Survey, 42 per cent of Aboriginal people aged 15-64 in Western Australia self-reported having a disability or restrictive long-term health condition.[2] Among Aboriginal people of all ages living in private households in 2018:

- 24 per cent (139,700 people) were living with a disability;
- 8.8 per cent (51,100) of the total living with a disability had a severe or profound disability.[3]

1,762 (9.1 per cent) of the new active participants as of June 2022 identified as Aboriginal. This takes the total number of Aboriginal participants on the NDIS nationally to 38,846 (7.3 per cent).[4] Compared to non-Aboriginal people, Aboriginal people are 1.8 times as likely to have a disability and 2 times as likely to use disability support provided under the NDIS.[5] It must be noted that the above statistics do not account for Aboriginal people who are homeless, in institutions and the cohort under the age of 15

Aboriginal people with a disability face various challenges when trying to access essential care. This is reflected in the fact that Aboriginal people currently do not access the NDIS at the level that is equivalent to their needs. For example, plans are severely underutilised. Some of the known barriers that prevent or discourage Aboriginal people from accessing disability services, particularly in remote and very remote locations, include:

- geographic size of WA;
- thin or no markets;
- difficulty navigating the system;
- lack of service providers;

[1] National Disability Insurance Agency, 2022. Market monitoring and intervention.

[2] Aboriginal and Torres Strait Islander Health Performance Framework - Health status and outcomes 1.14 Disability

[3] Australian Institute of Health and Welfare, 2021, Disability support for Indigenous Australians Report, available at Disability support for Indigenous Australians - Australian Institute of Health and Welfare (aihw.gov.au)

[4] National Disability Insurance Scheme accessed from – National quarterly performance dashboard : 30 June 2022

[5] Australian Institute of Health and Welfare, 2021, Disability support for Indigenous Australians Report, available at Disability support for Indigenous Australians - Australian Institute of Health and Welfare (aihw.gov.au)

- lack of culturally appropriate and/or trauma-informed provision of care;
- experiences of racism; and
- distrust of institutional care because of both personal and historical experiences.[6]

Key roles of the Aboriginal community-controlled sector in delivering NDIS services

The importance of placing the design and delivery of programs into Aboriginal hands to attain outcomes identified in the National Agreement on Closing the Gap is acknowledged by all Australian governments. The evidence suggests that Aboriginal designed and delivered services will close the gap faster. Therefore, priority funding must be made accessible to Aboriginal organisations.[7] ACCHS are highly visible in Aboriginal communities with research showing they are best placed to respond to the social and cultural determinants of health.[8]

Aboriginal people have a holistic conceptualisation of health. Community, family, culture, spirituality, language, Country, emotions and the physical are all seen as integral in both an individual, and a community, for achieving and sustaining optimal health. This conceptualisation of health is upheld by the Western Australian ACCHS Model of Care, and guides the delivery of healthcare across communities. We understand that providing holistic health care is critical in the pursuit of health equity for Aboriginal people. WA ACCHS are well positioned to refine and expand our delivery of holistic health care by including disability services that are culturally responsive, affordable and ensure equity in access.[9]

Aboriginal people often have difficulty navigating health systems, including the NDIS. For instance, NDIS eligibility requirements and application processes are often not well understood. Furthermore Aboriginal people are often reluctant to access government services due to historical and personal experiences of institutionalised racism and a lack of cultural safety. For these reasons, ACCOs and ACCHS have identified a need to expand into disability services and/or support mainstream disability services to ensure cultural safety for Aboriginal people with disabilities.[10]

Gaps

Consultations with AHCWA's disability working groups and community of practice meetings have identified NDIS gaps. The feedback from these consultations informs the following section.

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[6] NACCHO statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Accessed from nacho.org.au

[7] Institute for Urban Indigenous Health (2020) – Submission to the Royal Commission into Violence, Abuse, Neglect, and exploitation of people with disability. Transforming Disability Access for Indigenous Australians. Accessed from iuih.org.au

[8] Int. J. Environ. Res. Public Health **2021**, 18, 8907. Equity in Access: A mixed methods exploration of the National disability Insurance Scheme Access program for the Kimberley region, Western Australia. https://doi.org/10.3390/ijerph18178907 https://www.mdpi.com/journal/ijerph

[9] AHCWA : ACCHS Social 7 Emotional Wellbeing Service Model | KAMS : Kimberley supports service model

[10] NACCHO statement to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

a. The capability and culture of the National Disability Insurance Agency (NDIA), with reference to operational processes and procedures, and nature of staff employment.

The slow and complicated pathways under NDIS

Accessing the NDIS can be a complex process and the challenges are exacerbated for Aboriginal people. The NDIS access pathway remains difficult to navigate. The difficulty revolves around:

- Lengthy process of the access request, caused by fragmented communication, which leads to disengagement and people not seeing the value of the scheme. In combination with negative historical experiences with government agencies, these issues have resulted in a deep lack of trust in government services and programs.
- Extent of evidence requested by the NDIA without understanding the inequitable access to services, specialists and resources some people face when trying to attain the evidence.
- Lack of investment from the NDIA to upskill health professionals to complete NDIS reports and forms so that they are in line with what is expected by the NDIA.
- The NDIA needs to review its current communication channels associated with access requests. Requesting further evidence via letters and expecting a response from participants within a 30-90 day period is unreasonable. This does not take into account the complexities of logistics and people's lives in regional, remote and very remote WA. Access requests should not be void for the applicant if the NDIA was not able to receive correspondence from an applicant within the timeframe. The process should be outcome focused.
- 'Access not met' applications are not given sufficient information as to why this is the case. NDIA letters often quote the relevant section of the NDIS Act where the person did not meet the criteria but the letter does not describe what this means to the individual. This causes great confusion and contributes to the lack of trust in the government.[11]

The NDIA's performance on key deliverables promised through the scheme are yet to be met. Furthermore, these deliverables should be measured on outcomes achieved instead of the current focus of quantitative data. The access request pathways are complicated and time-consuming. Without the support of current information linkages and capacity building (ILC) programs such as the Remote community connector (RCC) and Evidence and access program coordinator (EACP), these pathways are incredibly difficult to navigate.

Case Study – Disability Service Manager

A Disability Service Manager that oversees Support Coordination, RCC and EACP programs in WA commented: "The NDIA's timeframe guarantee associated with the access request, correspondence with the NDIA and plan review meetings has an inbuilt mechanism that allows people to fall through the cracks and the NDIA to evade responsibility without achieving outcome-based results." This nature of measuring outcomes from a purely quantitative nature is not effective or successful when working with Aboriginal people and communities.

[11] KAMS: Statement of the Kimberley Aboriginal Medical Services (Inc) for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Lack of training and resources available through NDIA

- As evidenced above, accessing the NDIS is overly complicated and cumbersome for many people, including Aboriginal people across WA.
- The role of Level 2 Support connection-based ILC grants in bridging the gaps of NDIS service delivery is invaluable and has proven outcomes.
- As evidenced in the Kimberley Aboriginal Medical Services' (KAMS) statement to the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability, there is a lack of training and support for staff engaged in NDIS programs of RCC and EACP.
- While the NDIS promised to deliver a standardised training package to accommodate the staff employed under the ILC programs, it was not delivered to the West Kimberley region as of June 2022. This was following a request made by KAMS for staff training in 2019. KAMS stated that 'while the training was comprehensive, it was a PowerPoint based presentation and was a lot for everyone to get their head around.'[12]
- Long delays from the NDIA to train staff in vital positions such as RCC and EACP demonstrates the lack of support received by ACCHS, who wish to work in partnership with government to implement the scheme.
- AHCWA Members who are active NDIS providers have also commented that they come across planners and Local Area Coordinators (LACs) with varying levels of understanding about the NDIS. There is similar variability in their understanding of how to work with Aboriginal people and communities.

There is also a lack of local support and engagement from the NDIA. This includes lack of or ineffective communication, lack of staffing and inability to access information directly from the NDIA. The importance of implementing the scheme on a local level is crucial. This is not occurring in many regions across WA, especially in regional, remote and very remote communities. Most AHCWA Members operating out of Modified Monash Model (MMM) level 4 and above have voiced the following concerns:

- There are no in-person planning meetings even after COVID-19 restrictions were eased.
- Few locally based staff are present to accommodate the needs of participants. Some major regional towns with populations over 15,000 report having only one regular planner and complex needs planner. This is nowhere near adequate.
- Members report that accessing NDIS information through their local NDIA office is very difficult. Local NDIA offices are vacant with NDIA staff operating out of local Centrelink offices making it impossible to see NDIA staff without having a Centrelink appointment.
- Seeking information through the national contact line is not timely and often seen as "a waste of time". Staff are not often well-informed, lack general understanding on internal NDIA processes, disability and WA's geography, and often relay varied information which makes it unreliable.

[12] KAMS: Statement of the Kimberley Aboriginal Medical Services (Inc) for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

b. The impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency

Case Study – Support Coordinator servicing the Kimberley region

"I had an urgent situation happen for one of my participants where I had to contact the agency to request a change in circumstances review. The participant had become homeless. I rang the 1800 number and was told that I was not authorised to seek information or contact the NDIA on behalf of the participant as I had no consent forms signed. I checked that I had all the consent forms in place and submitted to the NDIA. So I rang back and they said I don't have any on the system, so I re-submitted them and rang back again. I got a different lady, who was extremely helpful. A point to note here is that I got 3 different individuals each time, making it extremely time consuming. She put me directly through to her supervisor to address the concern, which they did. But this was on my third attempt, where the first two times I got blocked and no one would speak to me. The third person was able to find the consent and informed they were on the system for over 12 months. Communicating with the NDIA can be extremely difficult and this difficulty is only increased for someone living in the community with a disability."

Administration and expenditure

The safeguarding measures established to keep participants safe can sometimes act as obstacles. Situations of this nature include:

- The requirement of 100 points of ID, service agreements, consent, nominees and other key safeguarding practices in their current iteration provide little to no flexibility. This often makes it difficult to communicate and access support from the NDIA. It is acknowledged that these measures are necessary to protect participant confidentiality and safety, but some flexibility in their application would be appropriate. A direct contact centre for Aboriginal participants under the NDIA state and regional branches is worth exploring. A similar model was previously implemented for the RCC and EACP program where staff in these roles had direct contact with the WA NDIS access team for correspondence associated with the applications they submitted. It is recommended that the ACCHS sector be engaged to identify how flexibility can be introduced to ensure both safeguarding and positive outcomes for participants are achieved simultaneously.
- Locally based staff that are available to assist participants in a one-to-one, person-centred manner is essential.
- Presently there are too many disparities between the requirements for registered and unregistered providers. While it is acknowledged that accessibility to providers regardless of NDIS registration increases participant choice and control, there needs to be common safeguarding practices. For example, service agreements, invoicing, conflict of interest declarations and related matters should be mandated for both registered and non-registered providers, which is currently not enforced. This would

ensure participants are empowered to make informed decisions while exercising choice and control.

- There is ample market research that shows the administrative burden of NDIS is cumbersome and often beyond what is manageable, especially for small organisations. This is especially the case for regional, remote and very remote providers who deliver NDIS services while managing multiple complexities, as noted above.[13]
- The NDIS model of doing business is relatively new for the ACCHS/ACCO sector. The sector requires further support and assistance to undertake business development. AHCWA recommends that the NDIA undertakes further market consultation and continues supports past the early phase of NDIS service delivery, to support organisations to manage the complexity of the scheme.
- Nationally facilitated ILC programs administered by the Aboriginal community-controlled sector, such as the National Aboriginal Community Controlled Health Organisation (NACCHO) NDIS Ready program funded by Department of Social Services, has shown great results and is a testament to the benefits that can be gained by investing in preparing the sector.[14]
- There needs to be more funding allocated for nationally consistent ILC programs that will bring together the Aboriginal community-controlled sector under the disability umbrella to lay strong foundations and to build capacity in the sector.

Without addressing the aforementioned key areas of engagement with the NDIA, the NDIS will continue to overpromise but under-deliver, which causes further disengagement from participants. This is evident in NDIS data showing consistent underutilisation of funding packages of Aboriginal people compared to non-Aboriginal people.[15]

To empower people with disability, more effort and resources should be allocated to marketing to ensure that the positive impacts of the scheme are also understood by the community, with a focus on participant outcomes and good news stories. In combination with reforms to improve the function of the NDIS, this will ensure that people continue to access the supports to which they are entitled. More research needs to be conducted (such as the Per Capita report on the economic benefit of the NDIS) to understand the scheme's true impact on people with disability, carers and the Australian economy.[16]

Conclusion

Aboriginal people prefer to access Aboriginal community-controlled services, including disability and health services. Many Aboriginal people will avoid mainstream services to ensure they receive care from a provider that can deliver culturally safe services.[17] Many WA

[13] Centre for Social Impact, University of New South Wales, Sydney, New South Wales, Australia. Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals (2021) DOI: 10.1111/1467-8500.12508

[14] NDIS Ready: Aboriginal and Torres Strait Islander market Capability, Final Report. Prepared by National Aboriginal Community Controlled Health Organsiation (NACCHO) for Department of Social Services (DSS). Accessed on 07 September 2022

[15] National Disability Insurance Agency, Report - Aboriginal and Torres Strait Islander participants (2019). Accessed from www.ndis.gov.au

[16] Per Capita – Analysis report for the National Disability Services, 2021. False Economy: The economic benefits of the National Disability Insurance Scheme and the consequences of movement cost cutting. Accessed from Per_Capita_Report_teamworks.pdf (afdo.org.au)

[17] NACCHO: National Disability Strategy (2021), Accessed from nacchoo.org.au

ACCHS/ACCOs were approached by the NDIA to enter the disability service space after identifying a gap in culturally safe and appropriate disability services. To make the transition successful, the NDIA, and other relevant government agencies and policymakers, must work in partnership with the Aboriginal community-controlled sector to co-design a scheme that addresses the barriers that make it difficult for Aboriginal people to access essential disability services. An equitable NDIS that works for Aboriginal people and organisations can only be delivered by sharing decision-making and working in genuine partnership (as per Priority Reform One of the National Agreement on Closing the Gap).

Recommendations

In line with feedback provided by WA ACCHS, AHCWA recommends that:

- Aboriginal people and communities are put at the centre of the design and delivery of disability services across WA.[18] A community led effort is essential to increase access to disability support for Aboriginal people and their families. Community based disability services are a vital part of Aboriginal self-determination. With support from key partners, Aboriginal organisations are best placed to determine the issues impacting their communities and develop solutions to meet their communities' needs.

- Further investment is made in Level 2 support connection and grants-based programs and advocacy programs that will support Aboriginal people who are having their eligibility assessed or have a disability but are not eligible for the NDIS. Programs and funding should be established with longevity in mind – the current use of fragmented short term grants is not as effective or sustainable.

- There needs to be increased transparency from the NDIA and policy makers concerning changes to the scheme, processes, demand data and market trends. This would help providers to be more prepared and empower participants.

- A program within the NDIA is created to address the needs of Aboriginal people with a disability. This would work similarly to the LAC program building partnership with Aboriginal Community Controlled sector as partners in the community. This will streamline communication, and provide practical support to Aboriginal providers and participants, grounded in a clear understanding of the needs of Aboriginal communities. This kind of support is not currently provided by the NDIA. For this reason, AHCWA also recommends that a team is established within the NDIA which is dedicated to supporting the Aboriginal Community Controlled sector in delivering NDIS services.

- Appropriately funded Aboriginal Cultural Competency Training is mandated for NDIS service provision throughout Australia.

[18] KAMS: Statement of the Kimberley Aboriginal Medical Services (Inc) for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability