Joint Standing Committee on the National Disability Insurance Scheme
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Miwatj Health Aboriginal Corporation Submission to the Inquiry into the NDIS Participant Experience in Rural, Regional, and Remote Australia

The Miwatj Health Aboriginal Corporation thanks the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) for the opportunity to make a submission to the Inquiry into the NDIS participant experience in rural, regional, and remote Australia. Miwatj Health has operated in East Arnhem as an Aboriginal Health Corporation since 1992, and as a NDIS provider since 2016. Miwatj became the first nationally appointed trial site for the NDIS Remote Community Connector program in 2017, where we were entrusted to provide cultural brokerage to NDIS Participants in East Arnhem Land. As part of this role, the RCCs support with every stage of the NDIS Journey, from NDIS Education and Access support, all the way through to Plan Implementation and Plan Review. The RCCs work with NDIS providers to ensure Participants can make informed decisions and understand their NDIS supports effectively.

As a registered provider, Miwatj predominately provides Support Coordination, which involves supporting NDIS Participants to implement their NDIS plans, while building their capacity to manage their supports independently. Miwatj Health is the largest Support Coordination provider in East Arnhem Land, with 210 of approximately 250 Participants in the region choosing Miwatj Health to support them. Support Coordinators are required to engage with other NDIS providers and refer Participants for services. However this can be a significant challenge in a very remote context as demonstrated by the 51% Plan Utilisation rate in East Arnhem Land. While we cannot speak on behalf of all providers, this submission aims to highlight the common themes that have impacted service delivery across the region, as per our understanding as a NDIS provider and facilitator of NDIS service consumption.

Miwatj has listened intently to the voices of First Nations people living with a disability and advocates strongly on behalf of the communities we represent. Here are some of the things we have learnt from the stories we have been told:

The particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS:

Language

For Yolngu living in East Arnhem, English can be their 3rd of 4th language. Yolngu are raised to speak at least 2 dialects of the Yolngu Matha (language), their mother and father's tongue, with all Yolngu engaging with the infant/child required to speak to them in appropriate Yolngu Matha dialect. Children often begin learning English once they start childcare, attending programs such as Families as First Teachers (FAFT) or school. However in more remote schools, it is very common to maintain strong Yolngu Matha within the classroom and formal bi-lingual education programs operate in towns such as Yirrkala. Without a strong understanding

of the English language, it is extremely difficult for a participant to understand the fundamentals of the NDIS and therefore make informed decisions about their NDIS supports.

Under NDIS rules, NDIS plans may only fund interpreters for disability related communication barriers, not for language interpretation. This severely inhibits people who are not able to communicate effectively in English to safely access their NDIS Supports and other services.

The NDIA fund Miwatj Health to be a Remote Community Connector partner, to provide cultural brokerage and contextual interpretation, however in our experience, this funding does not meet the interpretation need for all NDIS Participants to safely access their NDIS supports, considering this support is required throughout the entire NDIS journey.

To highlight the difficulty of explaining the NDIS to most Yolngu Participants, it is important to understand that there is no direct translation for "disability" in Yolngu Matha.

Numeracy and Literacy

For those Participants who can communicate effectively in English, there are further barriers when it comes to Numeracy and Literacy skills. According to the Story of Our Children and Young People 2021 Report by Menzies School of Health[1], First Nations people from East Arnhem Land have a 26.7% completion rate for Year 12 or equivalent, compared to the non-Indigenous completion rate of 69%.

Understanding the documentation that is required to implement a NDIS plan is extremely difficult for Participants from East Arnhem. From the initial Access Request Form to the Service Agreements and Schedules of Supports for every service provider engaged in a Participants support network; the paperwork and administrative workload is significant. This also repeats each new plan period.

Retention of Information

With a focus on capacity building, the Miwatj Health NDIS programs work hard to ensure the Participants can make informed decisions about their NDIS journey. This can lead to information overload and Participants losing interest in these vital supports. Given the significant socio-economic concerns in remote communities and other competing priorities, the NDIS is often a low priority to learn and therefore retain. This often means that Support Providers are having to repeat and reiterate fundamental NDIS education during every interaction with the Participant.

Socio-Economic Barriers

When our teams visit Participants, they are often met with questions or concerns regarding their social situations; getting cut off from Centrelink, housing maintenance, overcrowding, health concerns, food security etc. For example, discussing something like which speech pathology provider that the Participant would like to utilise to implement their Improved Daily Living funds is not a priority when there are much bigger issues facing their daily survival. Participants in remote regions are far more likely to utilise funds that are going to give them the most amount of reprieve for the least amount of emotional and mental fatigue – for

[1] Menzies School of Health Research. 2021. *Story of Our Children and Young People – East Arnhem 2021. Page 23.* Available from: https://www.menzies.edu.au/page/Research/Projects/Population_Health_and_Wellbeing/Story_of_Our_Children_and_Young_People

example, case management, meal preparation and delivery, laundry services, transport, and Short-Term Accommodation to name a few.

It is imperative that the NDIA is realistic in its expectations around how capacity can be improved in remote settings and that it celebrates the small wins that the support teams are able to achieve.

Yolngu culture is based around family and kinship and other relationships. It is very much a collective rather than an individual culture and the practice of traditional culture is widespread. As an Aboriginal Community Controlled Health Organisation (ACCHO), delivering services that are culturally safe is non-negotiable for Miwatj Health. Recognising this, the Miwatj Health NDIS team has a saying that *"the NDIS Participant is not our client; their household is our client"*. This stems from the need to support the entire family to meet the Participant's socio-economic needs, prior to trying to achieve NDIS goals for the Participant. This not only builds trust with the Participant and their family and provides the foundation for a culturally safe service but allows the Participants to engage with their NDIS supports more effectively since other competing factors have been managed.

Trust & Relationships

In a remote context, building trust with Participants and their family is integral to implementing NDIS support services effectively. As a government led scheme, the NDIS is foreign and scary for a lot of Participants. It is also a different support model than they are used to receiving, so there is significant amount of upfront education and training required to ensuring Participants are making informed decisions about how their funding is spent. Some of the challenges in delivering that education have been discussed in the previous section.

As an ACCHO that has operated in remote locations since 1992, Miwatj Health has established relationships and built trust with our communities across East Arnhem Land. NDIS Providers are often very new to the region and struggle to establish their business – especially when they are generally based in the larger towns/cities and provide FIFO models of service. New providers often lean on the community-based providers to facilitate community visits, for example providing assets and infrastructure (housing, office space, vehicles etc.), utilising Remote Community Connectors for interpreting and getting paperwork signed etc. While this is a valuable role to play, it can be difficult to maintain independence and avoid conflicts of interest. It should be noted that this work, that is vital to the success of the program, is generally not funded. Closely supporting providers that may not uphold Miwatj's values poses risks to the program and organisation's reputation.

To appreciate the reputational risk to providers, it is essential to understand the concept of associated blame in remote East Arnhem Land communities. When incidents occur in community that are not easily explained or understood, Yolngu may blame a person, or spiritual being to conceptualise the matter. For example, a clan leader passes away after collapsing from a heart attack at a community meeting. Despite clinicians facilitating a family meeting to explain the cause of death, the family may blame another clan for casting "black magic" as the family may struggle to understand something that they cannot see. This matter can be applied to any number of scenarios, including when a Remote Community Connector supports another (non Miwatj) provider to engage with a NDIS Participant. If the provider engages inappropriately with the

Participant, the Participant and/or family could blame the RCC who can be seen as "endorsing" the provider by way of association.

The availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;

Most NDIS Participants in East Arnhem Land don't have direct access to a NDIA representative outside of their planning meeting, so the sentiment of this area of enquiry is somewhat redundant. In our communities, the NDIA utilise Partner organisations (RCC and EACP) to engage with Participants. This model is understood to accommodate funding and staffing models in the NDIA, while subsequently facilitating culturally safe and localised supports for vulnerable NDIS Participants.

To meet the need of Participants in East Arnhem, Miwatj Health is currently funded to deliver the Evidence, Access Coordination and Planning program as part of the Remote Community Connector funding. We are the only partner organisation in the NT with this specific funding due to our availability and funding has made a significant impact on successful applications and positive experiences for the families involved. At Miwatj Health we have a clinician coordinate the access process. This ensures the functional impairment related to the disability is captured appropriately in the supporting evidence. If there are any concerns or questions, then the NDIA can communicate directly with the EACP clinician and rectify any paperwork quickly. Evidence that this approach is working is that the Miwatj Health EACP program has not had any access requests denied due to the quality of the evidence provided and the successful applicants have been overwhelmingly impressed by their experience in the program.

There are some cases where families participate in the NDIS Access process without the support of the EACP team as they are unaware of the program or in an area with limited support. Without case coordination support, potential Participants risk not meeting eligibility criteria due to poor evidence, or their NDIS access request form has not been completed correctly. In cases where the NDIA need to contact a potential Participant, there are communication barriers for remote Participants such as telephony reception issues, non-existent/lost/changed contact details and language barriers. If the NDIA are not able to contact the Participant, this can lead to them being excluded from the NDIS access pathway unfairly and prematurely.

If a client meets access requirements, they are then required to access the NDIS systems/portals to action their NDIS plan. Remote Participants are often unable to access the NDIS systems/portals as they do not have access to a smartphone or computer; cannot meet authentication and identification requirements; and struggle to remember passwords. The NDIA is required to attempt contact three times before transitioning the Participant to an *Unable to Contact (UTC)* list. This list is then sent to the RCC Partner Organisation to attempt to re-engage the Participant in the access pathway. This process is convoluted and in efficient.

If a Participant with genuine needs does not meet access requirements to the NDIS, this can significantly affect their trust in the NDIS and disability systems. As there are limited alternative support pathways, and no follow up support from the NDIA, not meeting NDIS access can have a detrimental effect on their quality of life.

For NDIS Plans that don't meet the Participant's needs, there are local contacts for the RCC and EACP teams that can action the changes accordingly. It is important to note that without these roles, it is much harder to

receive comprehensive and efficient support from the NDIA. For example, if you were to contact the NDIS 1800 number, the authentication processes do not accommodate the remote context well and have often left the Participant's confused and frustrated. Wherever possible, we encourage and support NDIS Participants to utilise the RCCs and EACP team to support.

Participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;

The NDIS teams at Miwatj work tirelessly to educate NDIS Participants on their role in their NDIS Journey. The team ensures Participants understand they are the "bunggawa" (translates loosely to boss) of their NDIS Journey, having choice and control over how and where their NDIS funds are utilised. This notion is implemented consistently in the communities we represent. However, it is an extremely difficult concept to explain to a culture that has consistently been stripped of this right since colonisation. Participants are often apprehensive to assert themselves as Yolngu are typically conflict averse. Some consistent themes that have impacted Participants being able to effectively practice Choice and Control in their communities are:

1. Thin markets
    a. Very remote localities limiting supply and therefore limiting Participant's buying power
    b. Limited options to practice choice and control with few NDIS Provider options
    c. Quality of options can be reduced due to difficult operating environment.
    d. Limited access to disability specific providers, meaning supports may not be fit-for-purpose.
    e. Limited access to providers with in-depth understanding of specific or complex disabilities, which can limit success of
2. Effective service delivery
    a. Providers are often limited to the services they can provide
    b. Providers unable to employ skilled, qualified people
    c. Providers struggle to cover costs of overheads due to price limits & rules
    d. Lack of language interpreting funding, limiting ability to engage effectively with Participants
3. Assets & Infrastructure
    a. Difficult to obtain land, build, rent in communities
    b. Assets not meeting disability access requirements, including disability accessible vehicles and buildings. The cost and practicality to bring assets up to disability standards is often unobtainable in a very remote context, when buildings are decades old, riddled with asbestos and cost considerably more to build/renovate in the remote space.
    c. Sharing of space is difficult with competitive market and conflict of interest matters
    d. Significant upfront costs that are not covered by the NDIS such as purchasing vehicles and resources, obtaining office space, or hiring staff. These costs are not able to be recovered until the Provider is billing, which is a significant financial and services risk to small businesses or not-for-profit entities.
4. Risk Management

a. Providers are often skimping on risk management due to limited repairs & maintenance services, or skilled employees to develop and implement risk management processes
b. Participants can be unaware or unwilling to follow risk management processes such as seatbelts, car seats, vehicle checks, 4x4 etc.
c. It is difficult to develop risk management systems for activities such as hunting, fishing etc. when these activities post significant risks to Participant's health and safety. It may be inappropriate to enforce risk management processes when the activities are culturally engrained in the Participants' lives. Engagement in a safer, fit for purpose alternative is often lower as it is not the Participant's preferred choice.
d. As one of the core principals of Disability Rights, it is imperative that Participants can practice Dignity of Risk. However, there can be significant reputational, financial and services risk to the Providers in these circumstances if Dignity of Risk is practiced as it is difficult to apply an urban or mainstream approach to health and safety in the remote and cultural context in which remote providers like Miwatj Health operate. While activities may seem dangerous, or inappropriate on paper, it is business as usual for East Arnhem Land. Examples of practicing Dignity of Risk in our context, include:
    i. Facilitating Return to Country trips to very remote homelands, where formal supports are unable to be offered, for Participants with complex medical, behavioural, or cognitive factors. This scenario empowers Participants to retain connection to culture and manage their own supports, however, poses significant risk to the Participant's health and wellbeing,
    ii. Participants are often requesting to engage in traditional activities that pose a risk to their health and safety, such as hunting with a spear, waist deep in a crocodile infested river. While this activity offers high reward for the Participant, it poses a significant reputational and services risk to the Provider in facilitating the activity, on top and due of the safety risk to the Participant.
    iii. A Participant who resides in a Supported Independent Living arrangement, where the support provider is unable to effectively manage chronic scabies and diabetes due to the Participant's regular engagement with family in a low socio-economic region. While committing to supporting the Participant to maintain connection to family and culture, this activity risks ongoing hospital admissions and reputational risk to the provider.

5. Staffing
    a. Difficulty in Miwatj Health employing and retaining staff in a remote locations
    b. Community Staff are living in the same socio-economic situations as the Participants they service
    c. It is difficult to offer adequate support to staff in the form of coordination, learning, training etc. due to remote locations, staff retention challenges, financial limitations, and access to services.
    d. Managing Conflicts of Interest with Community staff due to their relationships with Participants (all Yolngu are related in one way or another).

6. NDIS Engagement – rules, staffing, supports
    a. It can be difficult to implement NDIS plans in remote locations when the rules can be inflexible and not fit for purpose for the location and client group
    b. Providers feel unsupported by the NDIS when it comes to being flexible/innovative with NDIS funds.
    c. Price limits have not changed for some NDIS line items for 3+years, making it difficult for providers to meet the financial needs of their organisations.
    d. The NDIA utilise RCCs and Support Coordinators to engage with Participants, meaning they are not witnessing the Participant's needs themselves. This can make it difficult to highlight Participant's needs effectively and often involves more evidence and justification.
    e. NDIA Planners often make Participants feel like they are asking for too much when highlighting their support requests, which can severely impact the Participant's willingness to engage in the NDIS process. This is largely due to the holistic and coordination level supports required to achieve NDIS goals, on top of their general NDIS funding. Funding a simple goal such as *I will engage in Occupational Therapy to improve my safe access to my home*, does not just require therapeutic support funding for remote Participants. It requires Support Coordination funding, allied health assistant funding, skills development funding etc. This then requires extensive coordination and planning and is supported by an RCC to implement in a culturally safe manner.
7. Competitive Markets
    a. The NDIS brought about a competition that rarely existed in remote communities prior to its development. While this has certainly improved the quality and choice of providers, it has also adversely impacted provider relationships in the remote spaces.
    b. Outcomes for Participants are often reduced by Providers not being able to or are unwilling to share information easily regarding Participant's supports.
    c. In some cases, Providers can become desperate to obtain or retain Participants, which can lead to Participants accessing services that may not be best placed to support them.

The implementation of the National Remote Services Branch in the NDIA has had a positive impact on NDIS Participants in East Arnhem Land, with specific mention to the Hospital and Justice Liaison teams. NDIS Planners that understand a Participant's circumstances and can apply their knowledge to the planning process has resulted in better funded plans and more flexibility in remote regions. Further to this, the Complex Support Needs Branch has also improved interactions between the NDIA and Participants due to their ability to enact swift actions, leading to positive outcomes. It is recommended that proactive approaches such as these practised by the targeted branches are maintained. Branches that are staffed by subject matter experts, ensures Participants can focus on developing goals and aren't exhausted by having to constantly repeat their story.

Alternative Commissioning

It is a common theme that providers are not receiving adequate return on investment in the NDIS space. The cost of overheads can easily become unmanageable following significant increases in inflation and little or no increase in the NDIS Price Limits, Providers struggle to accommodate the extreme costs of operating in a very remote space. It is strongly recommended that AACHOs are commissioned and appropriately funded to provide NDIS education, eligibility, access, language interpreting and where appropriate, therapy services to implement the NDIS in a culturally safe and sustainable way in remote locations generally and East Arnhem Land specifically.

Miwatj Health welcomes any further questions or clarification around the information provided in this submission. If an opportunity is made available to present to the Joint Standing Committee, Miwatj Health is appropriately placed to provide further context regarding the impact of the NDIS in the very remote East Arnhem Land communities.

Thank you for your giving Miwatj Health the opportunity to contribute to this Inquiry.

If you have any questions, please do not hesitate to contact:

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