

MARNIWARNTIKURA



WOMEN'S RESOURCE CENTRE



THE UNIVERSITY OF  
SYDNEY

WOMEN BUILDING BELONGING

29 March 2021

Committee Secretary  
Joint Standing Committee on the National Disability Insurance Scheme  
Department of the Senate  
PO Box 6100  
Parliament House  
CANBERRA ACT 2600  
AUSTRALIA

Dear Committee Secretary,

**Re: Joint Standing Committee on the National Disability Insurance Scheme inquiry into Independent Assessments**

Our submission outlines key issues with the current Independent Assessment model for remote Australia Aboriginal Communities.

**Executive Summary**

1. Due to insufficient services, people living in remote Aboriginal communities have low health, mental health and disability literacy and little experience in disability services. These limitations coupled with language and cultural barriers means high quality support is required to ensure people understand the NDIS and Independent Assessment process.
2. Funding an NDIS representative with disability experience to work alongside key senior people in Aboriginal communities ensures there is both disability expertise and local community knowledge working together to guarantee the NDIS and Independent Assessor processes are understood. We recommend this model for the Remote Community Connector Role in the Fitzroy Valley.
3. An NDIS representative with disability knowledge could help train and upskill RCC's in the signs of physical and cognitive functional impairments. The RCC's could then share this knowledge with parents so they are better prepared to answer informant report questionnaires in the Independent Assessments.
4. Having an NDIS representative on-the-ground would also mean support is available for ACOs and other stakeholders who want to become disability service providers as there is someone who can help them navigate the complexity of the NDIS to establish themselves as a new service.
5. The measures proposed for the Independent Assessments are not culturally appropriate and some (the PEDICAT) have poor psychometric properties. The NDIA need to fund research to develop culturally appropriate tools for use in Aboriginal communities that include a combination of direct assessment and informant report questionnaires.

### **About our organisations**

Marninwarntikura Women's resource Centre (MWRC) is an Aboriginal-Controlled Organisation in the Fitzroy Valley, of Western Australia. MWRC provides families with a place for inspiration, positive change and leadership. MWRC supports Fitzroy Valley families by providing mentoring, advocacy, and access to culturally sensitive services, including a domestic violence shelter, legal services, a preschool, family and child services and opportunities for social enterprise. Marninwarntikura is a Walmajarri word. 'Marnin' means 'women', 'Warnti' means 'big mobs of women', and 'Kura' means 'belonging to'.

The University of Sydney's (USYD) Discipline of Child and Adolescent Health (part of Sydney Medical School) is based at the Children's Hospital, Westmead, a leading paediatric institution. The Discipline undertakes teaching and research in paediatric and adolescent health and medicine and supports over 100 higher degree research students. For many years the Discipline's research has encompassed work to improve health outcomes for Aboriginal Communities. Several of the Discipline's researchers, including Professor Elizabeth Elliott, are world leaders in this area.

In 2009, MWRC partnered with USYD on the Marulu Strategy, a Community initiative to overcome Fetal Alcohol Spectrum Disorder (FASD) and Early Life Trauma in the Fitzroy Valley. As part of the Strategy, Indigenous leaders invited USYD to lead the Lililwan Project to examine the impact of alcohol use during pregnancy. We found almost all children aged 7-8 in 2010 had early life trauma, 55% had prenatal alcohol exposure and 19% had FASD – among the highest rates globally. Other chronic complex conditions were also identified, and children were referred for ongoing care. USYD and MWRC have been working closely ever since on a range of projects to support children with FASD and other disabilities in remote Aboriginal communities. This submission is a reflection of their experience.

### **A summary of the NDIS rollout in the Fitzroy Valley**

Western Australia (WA) trialled a state version of the National Disability Insurance Scheme (NDIS) before moving to the national version. The process of moving from the old Disability Services model to the state NDIS and then the national NDIS severely delayed access to the scheme for people living in the Kimberley. As such many people living in remote communities, like the Fitzroy Valley, are only learning about the NDIS for the first time in 2020 and 2021.

Only a small number of people with a disability in the Fitzroy Valley accessed services through the Disability Service model. So, for many people, the NDIS will be the first time they learn about and can access disability services. The limited and under resourced health services in remote communities means there are also many people living with an undiagnosed disability. The lack of understanding of disability and disability services coupled with language and cultural barriers means extensive support is needed to ensure people understand the NDIS and the independent assessment process.

### C. The human and financial resources needed to effectively implement independent assessments

In the Kimberley, the National Disability Insurance Agency (NDIA) are asking Aboriginal-Controlled Organisations (ACOs) to take on the role of the Remote Community Connector (RCC) to explain the NDIS to community members. However, in the Kimberley many ACOs don't have any experience in the disability sector and the NDIA is not providing ACO's with the training and supports they need to establish themselves as a disability service. To be effective in remote Aboriginal communities, the RCC role requires local cultural knowledge, language and strong ties with the community. To have these attributes a person needs to have lived in the community for a long time, which means they are less likely to have also had access to tertiary education or experience in the disability sector. The current model of the RCC sets ACO's up to fail as it expects organisations and Aboriginal people with no disability experience to understand the complexities of the NDIS, disability and mental health and then be able to communicate this information in a way that is understood to people with a disability for which English is a second or third language. Explaining the NDIS to people with a disability is challenging for even the most experienced doctors let alone someone with no disability experience.

The Fitzroy Valley is a collection of 36 remote Aboriginal communities spread over a 200 km radius and includes five Aboriginal language groups. It is unrealistic to expect one or even two people to have the cultural knowledge, language and ties to all five language groups. We at MWRC have established a model that successfully overcomes this issue. The model involves a government service, like the NDIS, having an on-the-ground presence through employing someone with experience in the sector to live in the community and work alongside key people from each language group. The local people are employed casually to act as a community navigator or RCCs. Having trusted community members as community navigators increases the likelihood of being able to find and engage the most vulnerable people in the community, such as those with a disability or chronic health/mental health problem. For the NDIA, this model would ensure there is both disability expertise and local community knowledge working together to ensure the NDIA and Independent Assessment process is understood. The model would also reduce cost as the community navigators would know where people are and when and how to engage them, minimising time wasted looking for people. MWRC and USYD are currently reviewing the roll-out of the NDIS in the Fitzroy Valley through interviews with people with a disability, service providers and other relevant stakeholders. NDIS-funded drive-in drive-out services (four hours each way) have told us that they currently spend half their time looking for people, often with no success.

Staff at MWRC have been consulting with the NDIA for the past 24 months and have consistently informed the NDIA that our proposed RCC model needs to be used instead of the standard model. The standard being employing one local person with no disability experience to understand the complexity of the NDIS and disability and explain it in five languages on their own, essentially setting one local person up to fail. An NDIA planner from Broome also offered to take on the role of the NDIS representative and live in the Valley but the model was still rejected by the NDIA. As a result, there is still no one based in the Fitzroy Valley supporting people with a disability in any aspect of the NDIS application process.

Aboriginal communities have experienced continual disadvantage. The ever-changing structure of services means people are used to being disappointed so have lost trust in drive-in drive-out services. Community members have seen success when there is a local presence working alongside Aboriginal people. They want to see someone who goes to sleep in the community and wakes up there as that assures them that the non-Aboriginal person understands what life is like for them. It takes significant time to build trust and relationships with people in remote Aboriginal communities. However, building face-to-face relationships is the foundation for success.

To build this face-to-face relationship, there needs to be an NDIS representative in the Fitzroy Valley. It can be co-located with Centrelink as this has been done in other Centrelink locations. There needs to be an NDIA face that anyone who needs support can go to. This may only need to be for the first few years when the NDIA support is really needed to establish better access to services and supports because current uptake of services is dismal. Having an on-the-ground presence would also mean support is available for ACOs and other stakeholders who want to become disability service providers as there is someone who can help them navigate the complexity of the NDIS and establish themselves.

Conducting any health assessment in remote Aboriginal communities is challenging due to the cultural and language barriers and low level of health, mental health and disability literacy. Using the proposed model of having one experienced NDIS representative living in the Fitzroy Valley (who most likely won't be an Aboriginal person) working alongside senior aboriginal people from the five language groups will help overcome some of these issues. The NDIS representative will understand disability so know what signs and behaviours to look out for and will be able to upskill the local RCC's in these signs so the RCC's can communicate this to family members to help them answer the assessment questions. Without this, having a non-Aboriginal Independent Assessor come into the Fitzroy Valley with no cultural knowledge and try to communicate with someone for which English is a second language will result in the collection of invalid and unreliable information. This process will lead to people not receiving the supports they need and be a waste of taxpayer dollars and everyone's time.

The NDIA must be willing to deliver the NDIS in a culturally appropriate way in Aboriginal communities, which means being willing to do things differently to urban settings. Expecting Aboriginal communities to adopt an urban non-Aboriginal model is perpetuating the systemic racism in Australia as it further ignores the existence and importance of Aboriginal and Torres Strait Islander people, and their language, knowledge and culture. The NDIA must also acknowledge that not all Aboriginal communities are the same and be willing to adapt to their varying needs.

#### **D. The independence, qualifications, training, expertise and quality assurance of assessors**

Independent Assessors need to be culturally trained before working in remote Aboriginal communities and they need to work alongside senior local Aboriginal people who can advise them along the way.

Aboriginal communities lack access to the same quality of health services as urban settings. So, having reliable assessment tools is even more important as people are less likely to have had formal health assessments. The short contracts and high turnover of health staff in remote communities also means people with a disability are less likely to have a health professional who knows their needs and can write a report for the NDIA. In the Fitzroy Valley, a person's health records can be spread over as many as 8 different databases and most doctors only have access to one or two. So, important information can be missed if the NDIA are only relying on a report from one doctor with access to only one or two databases.

People with a disability in remote Aboriginal communities are also less likely to have just one person as a primary caregiver who can complete an informant report interview, rather multiple family members care for them. So **independent assessors need to be more experienced than in urban settings as they need to have the skills to gather information from multiple people who likely have little understanding of disability or disability services.** Language is another significant barrier people will not be familiar with concepts like intellectual disability, autism spectrum disorder, social skills, impulsiveness, emotion regulation, etc. Without this shared language and understanding it is difficult to ascertain someone's function. Finally, parents might not understand their child's disability as well as in urban settings due to poor health literacy and services not taking the time to explain the child's needs in a way that is understood.

For example, a child with FASD might have brain damage that makes them impulsive, gullible and have poor emotion regulation, all of which puts them at risk of harming themselves and others if not supervised. If a caregiver has not been informed of the brain impairment and specific cognitive difficulties how can they tell an Independent Assessor? Rather a parent is forced to rely on the behaviour they see from their child and the knowledge they have gained from their upbringing. Their interpretation of the behaviour might be that the child is just naughty or out of control. The parent would then be hesitant to report these behaviours to the Independent Assessor out of fear the parent would be judged for not being good enough or fear that the child would be removed. As a result, the parent says the child is fine and the child doesn't receive the disability support and supervision they need and are at a higher risk of dropping out of school, coming into contact with the police and costing the government more money in the long-term.

One way to minimise this risk is to invest in proper assessments for people in remote Aboriginal communities. Having an NDIS representative experienced in understanding disability working alongside a respected Aboriginal person who knows the family will help minimise behaviours being overlooked and help ensure the families feel comfortable to open up. Direct assessments with the child can also help identify impairments and this information could then be shared to the parent to help them understand their child's behaviour and provide the child with the supervision and support they need.

In summary, Independent Assessors working in remote Aboriginal communities need to be highly experienced in understanding disability to help ensure they can identify physical, cognitive, behavioural and emotional functional impairments that the families and person with a disability cannot articulate. They must also work alongside respected senior Aboriginal people to overcome the language and cultural barriers.

**J. The appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds; and E. The appropriateness of the assessment tools selected for use in independent assessments to determine plan funding and**

The measures selected for the Independent Assessment process are culturally inappropriate for use in remote Aboriginal communities. Using assessment tools that are not valid or reliable in Aboriginal communities will result in people entitled to the scheme being denied access to essential services and vice versa. Investing in the development of culturally appropriate and psychometrically valid tools will minimise this risk, help create equity and reduce costs in the long run. Below are just some of the issues with the current measures.

- The PEDICAT is psychometrically invalid and this has been highlighted in Australian research<sup>1</sup>.
- The Vineland and WHODAS are not appropriate for use in remote Aboriginal communities for the following reasons:
  - The wording of the items is too complex for someone for which English is a second language and especially for parents who also have a cognitive impairment.
  - Some concepts are culturally inappropriate. One example is the Vineland item that asks parents if their child takes their shoes off before entering a house. In some Aboriginal communities, children don't wear shoes most of the time and when they do it is not customary to remove shoes before entering a house. Another item is asking whether children wash fruit before they eat it. Aboriginal people in the Kimberley have been collecting fruit for centuries and it may not be customary for them to wash the fruit they pick straight from the trees. These are just two of many items that don't fit with Aboriginal culture.



- Some concepts are also too complex and foreign. For example, asking parents for which English is a second language and who may have had limited access to schooling whether their child knows how to use a Table of Context or can write an essay. These items need to either be collected from school records, teacher reports or through direct assessment with the person with a disability. The latter is preferable given the high turnover of teachers and variability in data collected by schools.
- Informants might not provide honest responses for the following reasons:
  - The items focus on 'problems' – many Aboriginal people do not feel comfortable talking about their or their family members 'problems' and will say everything is fine when it is not to avoid talking negatively about someone. The items need to be written in a way that ensures Aboriginal people feel comfortable to be open and honest.
  - Parents worry about being judged as a bad parent or that their child will be reported to 'welfare' (child protection).
  - Children and adolescents, particularly boys who have gone through Lore, are given more independence in remote communities. So, parents may not supervise the adolescent as much as in an urban setting and therefore may not be able to report on all of the young person's skills, particularly in different settings.
  - Even when parents are comfortable opening up, we still notice a discrepancy between parent responses and their child's ability. This could be because the parent has not noticed a young person's impairments due to their own challenges. For example, if you ask a parent of an adolescent with a disability if their child checks their change at a store (Vineland item) the parent will very often say yes. However, if you then ask both the parent and adolescent separately how much change they would get if they pay with a \$5 note and an item costs \$2.30 some young people and parents cannot answer. It is for this reason that direct observation is highly recommended in addition to informant reports.

In the Fitzroy Valley there is high prevalence of FASD and mental health issues and the parent/carer answering the informant report may have a disability and/or mental health needs of their own that impacts the validity of the assessment.

The Fitzroy Valley is the only community in Australia where the prevalence of FASD has been evaluated. This study found that 20% of children aged 7-8 years living in the Valley in 2010 had FASD, which is among the highest rates in the world. None of the children diagnosed in the study have received disability services despite having a known diagnosis for the past 10 years. This is just another example of the systemic disadvantage faced by remote Aboriginal Communities.

Someone's post code should not determine what services someone is entitled to or can get.

Kindly,

Ms Emily Carter

Dr Lauren Rice

Prof Elizabeth Elliott

Ms Sue Thomas

## References

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2. Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final report to the Centers for Disease Control and Prevention (CDC). 1996 Aug;96-06.