

HOW TO IMPROVE THE NATIONAL DISABILITY INSURANCE SCHEME FOR ABORIGINAL PEOPLE IN REMOTE AUSTRALIA

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Introduction

Submission Purpose

The purpose of this submission is to inform policy and decision-makers of significant current issues about the delivery of the National Disability Insurance Scheme (NDIS) for Aboriginal people with disability living in remote¹ areas of the Northern Territory (NT). While the MJD Foundation works specifically with Aboriginal people and their families living with Machado-Joseph Disease (MJD), the issues are pertinent to all Aboriginal and Torres Strait Islander people living with disability in remote communities.

This submission proposes some short term and longer term recommended actions to improve the delivery of disability services under the NDIS to this cohort in the NT.

Priority issues for immediate attention

The MJD Foundation works with Aboriginal communities in remote Australia, and has a sound track record of delivering on its promises based on established relationships with Aboriginal clients. It has been involved with the NDIS since the rollout began in the NT. The MJDF is, therefore, in a prime position to understand and advise on the way in which the NDIS is implemented in remote Aboriginal communities, particularly in East Arnhem.

Based on this experience and expertise, the MJDF suggests that the following issues require immediate attention by an incoming Government.

1. Broader systemic issues

- a. **Provider of last resort:** This has been an unresolved issue since the rollout of the NDIS. Without a provider of last resort, participants in remote areas in particular, may miss out on supports they need and for which they are funded. It may result in serious deprivation or harm occurring. As it stands there has been no meaningful consultation with relevant organisations regarding who or how such a provider might be let alone operate. Many inquiries including that of the Productivity Commission have recommended improved transparency of governance arrangements on this issue. An announcement of the provider of last resort is long overdue.

The Federal Parliamentary Joint Standing Committee on the NDIS recommended that “the NDIA publicly release the outcomes of the Maintaining Critical Supports project and its policy on provider of last resort (PLR) arrangements as a matter of urgency”.²

- b. **Addressing thin markets:** Thin markets are a given in remote Australia. Despite numerous enquiries and recommendations there is still no published process about how the NDIA will identify and address thin markets so that service providers can plan accordingly, have confidence in the policy and ensure participants are not disadvantaged.

Precise information on exactly how, when and where the NDIA will intervene to improve thin markets needs to be published immediately. The Federal Parliamentary Joint Standing Committee on the NDIS has recommended that

¹ This submission will use the word ‘remote’ to include both ‘remote’ and ‘very remote’ as defined by the NDIA

² Joint Standing Committee on the National Disability Insurance Scheme, Report on Market Readiness for the Provision of Services under the NDIS, September 2018, recommendation 24.

“the NDIA develop and publically release a strategy to address thin markets”.³

Alarming, a significant number of year 2 NDIS plans for MJDF clients in very remote communities are seeing a reduction in Support Coordination and Core Support hours, with correspondence from the NDIA communicating the plan was reduced because of ‘underutilisation’. Adopting a ‘use it or lose it’ policy will not provide any confidence to potential support providers looking to expand their remote supports, and is counter intuitive to ensuring participants get the supports they need in the longer term.

Additionally, the NDIA should be open and transparent around the skill/support gaps in remote communities, which may assist to stimulate the market.

- c. **Funding interpreter support:** English is not the first language for many Aboriginal people with disability in the NT. Aboriginal participants are not able to exercise their choice, achieve their goals, nor use the funding in their plans effectively without interpreter assistance. It is reasonable and necessary that Aboriginal participants in remote Australia have interpreter funding included in their plans to enable them to formulate and implement every aspect of their plan. It discriminates against Aboriginal people in remote Australia to exclude such funding.

A second aspect of interpreter support is the current need for interpreters to be qualified under the National Accreditation Authority for Translators and Interpreters Ltd (NAATI)⁴. Aboriginal people in the NT who can act as interpreters are rarely in a position to meet the mainly written training and certification requirements of registration with NAATI.

- d. **Plan utilisation rates in remote areas:** In remote Australia, plan funding is often not fully expended due to many factors such as not enough service providers, not enough knowledge about how to find and use service providers, insufficient transport or difficulty of getting providers to remote locations. In first plans, there is often a gap of up to 3-4 months between when the plans were activated and the handover meeting occurred, which further reduced utilisation rates over the year.

It is unacceptable that the NDIA is reducing funding in subsequent plans because insufficient funds were utilised in the first plan. Under-utilisation is not a function of lack of need.

The NDIA should be directed immediately to stop arbitrary reduction in funding of second and subsequent plans under a ‘use it or lose it’ policy.

- e. **Support Coordination for remote Aboriginal participants:** Funding for Support Coordination in plans is absolutely essential for remote Aboriginal participants. Aboriginal participants in remote Australia need assistance to navigate the system, locate and organise providers and implement their plan. This need does not disappear over time.

In addition, for people living with MJD the need for Support Coordination increases,

³ Joint Standing Committee on the National Disability Insurance Scheme, Report into NDIS transition, February 2018, recommendation 17.

⁴ As noted in the NDIS Guide to Suitability

because of the degenerative nature of the disease. Arbitrarily reducing the amount of support coordination in subsequent plans on the assumption that the participant has built their capacity to undertake this work is wrong, short-sighted and will disadvantage remote Aboriginal participants even more.

The NDIA should revise its planning guidelines and price guide to acknowledge that in some diseases, 'time limited' support coordination is unrealistic.

The Federal Parliamentary Joint Standing Committee on the NDIS reinforced this approach with its recommendation that “the NDIA ensure support coordination is adequately funded in Plans to meet Participants' needs and not limited to a fixed period”.⁵

2. NDIA Issues

- a. **Reinstatement of NDIA NT Manager:** The MJDF, along with a number of other NT disability organisations, has raised concerns with the NDIA management over its arbitrary decision to reduce costs by abolishing the NT Regional Manager's position, and combining the NT and South Australian operations under an Adelaide-based Manager.

Unfortunately, a number of concerns we raised are now being realised. Specifically, a significant reduction in direct engagement by senior NDIA officials with NT service providers has meant that they have no understanding of the complexities (and required flexibility) in delivering a market-driven scheme in remote Aboriginal communities. It only serves to move critical decision-making further away from arguably the already most disadvantaged Aboriginal participants living with a disability and undermine the mutually beneficial working relationships that have developed between the MJD Foundation and NDIA staff.

Another consequence of this decision is that visits to remote communities for planning meetings by the NDIA with clients of the MJDF (who is also the support coordinator) has become poorly coordinated. Because of the time and cost of travel, this is inefficient, and has meant that poor quality plans have been developed by the NDIA which have then needed to be reviewed to reinstate lost funding.

⁵ Joint Standing Committee on the National Disability Insurance Scheme, Report on Market Readiness for the Provision of Services under the NDIS, September 2018, recommendation 3.

- b. **Disability experience of the NDIA Board:** The abovementioned staffing and other decisions have coincided with the appointment of new NDIA Board members over the last 18 months with the focus appearing to shift from addressing disability needs to reducing costs. While acknowledging that the Scheme's costs need to be managed to ensure that it remains viable, reducing staffing and arbitrary decisions about plan funding, especially during the rollout of the Scheme, leads to unfair and inconsistent outcomes for participants.

The NDIA Board should be required to ensure that participants' interests are at least on a par with managing Scheme's costs. Board members should have more experience with people with lived disability, to be able to understand its impact. NDIA staffing levels should be sufficient to manage the transition to full rollout fairly and efficiently.

- c. **Loss of Aboriginal and remote focus (eg. pathways):** In the first years of the NDIS, the MJDF was involved in NDIA working groups which focused on developing an Aboriginal and Torres Strait Islander Policy and a Rural and Remote Policy for the NDIA. Since those policies have been finalised and published there has been no confirmation that the policies are being implemented or incorporated into existing strategic plans.

While welcoming the recent creation of a dedicated policy position in the NT to examine issues relating to remote service delivery (Remote Branch), because of past inaction serious questions remain as to whether this work will in fact be translated into practical policies.

This is already reflected in the issues that the MJDF is having with North Queensland NDIA officials, that we initially encountered in the NT. The MJDF is expending time and funds in educating Queensland NDIA staff about matters that have been previously accepted in the NT context. It is far from being a national scheme, when each jurisdiction has different approaches because NDIA staff are not apprised of what is happening in other jurisdictions.

There should be a renewed focus on Aboriginal participants and remote markets, rather than just as an add-on to the NDIA complex pathways. The NDIA's Rural and Remote Strategy should be reviewed and revised with this aim in mind, as it is due to expire on 30 June 2019.

The Federal Parliamentary Joint Standing Committee on the NDIS recommended that "the NDIA develop, in collaboration with Aboriginal and Torres Strait Islander organisations and the Aboriginal community controlled health, an Aboriginal and Torres Strait Islander Workforce Strategy".⁶

Longer term issues

In the longer term there are other issues that must be addressed to overcome the inequality in service provision for Aboriginal people with disability in remote Australia.

- a. **Remote service provision: There is a need for a program of infrastructure to be built in remote Aboriginal communities (similar to the Aged Care Flexible funding model which provides Infrastructure grants).**

⁶ Joint Standing Committee on the National Disability Insurance Scheme, Report into NDIS transition, February 2018, recommendation 26.

Governments should look at specifically targeted initiatives to address shortfalls in transport and infrastructure and work in partnership with communities and locally based established organisations, rather than impose restraints on innovation and flexibility. Until these mainstream services (such as housing and infrastructure) are improved, plans cannot be used to their fullest extent.

- b. A different approach in the remote context:** There is a need for a different approach in relation to remote areas under the NDIS, especially to accommodate the realities of remote Aboriginal community life. This would involve more flexibility around support coordination, respite (short term accommodation), and transport.

In remote areas, the NDIA should be encouraging better service provision by governments, and more collaboration with and between service providers.

The NDIA also needs to review its workforce planning model for remote communities and more fully address the various underlying factors involved in developing and maintaining employment and training opportunities for local people that are sustainable over the longer term.

One such approach to consider is a Community of Practice Model⁷ developed by PricewaterhouseCoopers Indigenous Consulting Pty Limited (PIC). This hybrid funding model (based on the Aged Care: Flexible Aged Care funding model) would involve a series of innovative pilot sites in several remote NT communities, to allow for inevitable local differences.

The pilots envisage individual plan funding for participants, supported by secure block base funding for three years to a community-based organisation (e.g. to an Aboriginal Community Controlled Health Organisation, or to established disability support providers). Provision of regular Remote Infrastructure grants would also be part of this solution.

That block funding would require the organisation to deliver:

- culturally appropriate interpreters and community connectors;
- flexible, integrated services;
- linkages with CDP and workforce development, and overcoming existing CDP barriers to engagement;
- advocacy and community engagement; and
- coordination of supports.

External support from a trusted partner would also be provided as needed to build technical capacity. The three-year funding would be an upfront investment for the first 12 months tapering over the 3 years as capacity is built and the pilots are evaluated.

The Productivity Commission recommended that “the NDIA should address thin markets by considering a range of approaches, including block-funding”.⁸

⁷ NDIS Communities of Practice: the NDIS in remote Northern Territory (Oct 2018) NT Dept of Health
<https://hdl.handle.net/10137/7230>

⁸ Productivity Commission study report on NDIS costs, October 2017, recommendation 7.1.

NDIS Remote Sector Development

A proposed hybrid funding model to build capacity and deliver outcomes for remote participants

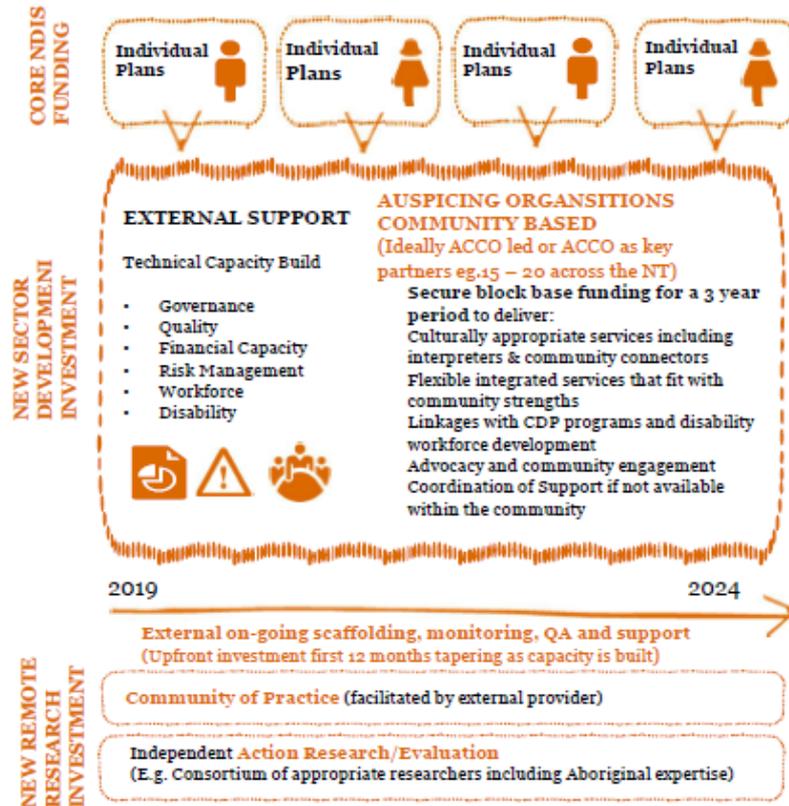


Figure 1: Proposed remote sector development model utilising a hybrid funding approach

- c. **Monitoring outcomes for participants in remote areas:** The MJDF is undertaking analysis of changes in its clients' plans since 1 January 2017 and will report on trends and issues arising later in 2019.

Background

Machado-Joseph Disease Foundation

The MJD Foundation (MJDF) is a specialist disability support organisation operating across remote North Australia. It provides care to Aboriginal⁹ families affected by a genetic, progressive, neurodegenerative condition known as Machado-Joseph disease (MJD). The MJDF works in partnership with Aboriginal Australians, their families and communities living with Machado-Joseph Disease (MJD) to provide comprehensive supports and engage in research, providing hope for the future.

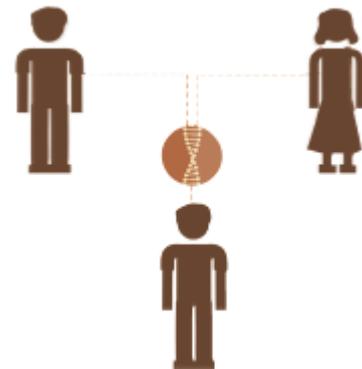
Initially established in 2008 across the Groote Archipelago communities of Angurugu, Umbakumba, Milyakburra, the MJDF is now providing supports to clients and families in: Darwin, Alice Springs, Groote Archipelago, Nhulunbuy and the Gove Peninsula, Galiwin'ku (Elcho Island), Ngukurr, Urapunga, Numbulwar, Papunya, Ntaria (Hermannsburg), Santa Teresa, Gunbalanya (Oenpelli) and Far North Queensland (FNQ).

The majority of the MJDF's clients live in very remote Aboriginal communities. Those who live in urban centres such as Darwin, Alice Springs or Cairns have tended to do so in order to access specialist disability or high level support services as their disease progresses.

Machado-Joseph Disease

MJD is an inherited genetic neurodegenerative condition. It is in a family of neurodegenerative diseases that includes Huntington's Disease. Initial muscular weakness progresses over time to a total lack of voluntary muscle control and very significant permanent physical disability.

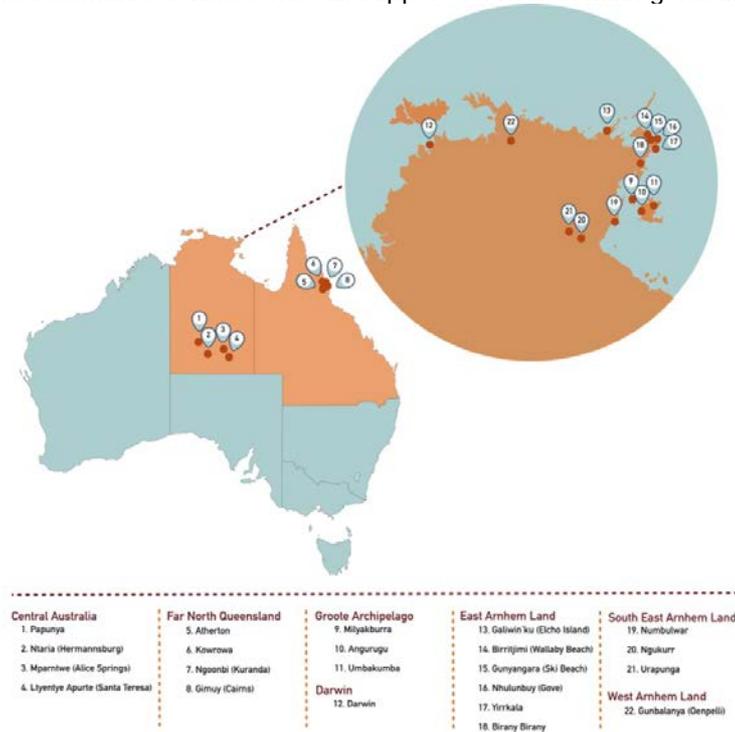
There is no known cure for MJD. Progression to dependence occurs over five to ten years after the onset of symptoms. Most people are dependent on wheelchair use for their mobility and fully dependent for all activities of daily living within ten to fifteen years of the first symptoms emerging.



⁹ MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander in recognition that Aboriginal people are the original inhabitants of Arnhem Land. Aboriginal and Torres Strait Islander is referred to in the national context.
MJD Foundation – Submission on the NDIS

MJD Prevalence

Aboriginal Australians with MJD are mostly concentrated in the Top End of the NT but also live in Central Australia and Far North Queensland. Although it is impossible to predict the number of people who will inherit MJD, there are currently over 700 Aboriginal Australians alive today thought to be at-risk¹⁰ of developing the disease across the NT and FNQ. Apart from those individuals who are symptomatic, the disease has far-reaching and disproportionate impacts on these people's extended families and carers, in communities where normal support services remain generally absent.



This map shows the locations where the MJDF's clients live and where the MJDF provides services.

MJD Foundation Supports/Services

First and foremost, the MJDF delivers and organises community services for our families with MJD such as therapy, community access, transport, interpret/translate, assistive technology provision and home modifications. The MJDF also provides: education, equipment, and engages in research and advocacy for its clients and families living with MJD. MJDF is registered under the National Disability Insurance Scheme (NDIS) for these supports.



However, the full scope of MJDF's education and community services delivery, and the provision of some equipment, are not funded by the NDIS. MJDF supports clients at a much earlier stage in their MJD journey than the NDIS recognises as disability, and we acknowledge the importance of family by also supporting our clients' families and children. This is essential to providing comprehensive and quality care.

The MJDF educates its clients, families and other service providers about the cause (genetics),

¹⁰ For every child born to someone with MJD, the child has a 50% chance of having inherited the disease, and is therefore defined as 'at risk'

management and treatment of MJD, and conducts research into better ways to manage the impact of MJD and possible prevention/treatments. Research and advocacy are a strategic priority for the MJDF.

MJDF's Way of Working ("Our-Way") with Client, Family and Community

Relationships and respect for family and culture are at the heart of successful support for Aboriginal people with disabilities. The MJDF is only able to do the work it does with its Aboriginal clients because it puts the client, family and community needs at the centre of its working culture.



The MJDF prides itself on strong community and family connections - always working from a grassroots perspective - ensuring we are listening to the needs and desires of families affected by MJD.

To achieve this client-centred approach, the MJDF's engagement model is to always partner non-Aboriginal staff with local Aboriginal staff called MJDF Aboriginal Community Workers (ACW). This model values and respects a 'two-way' approach.

This bi-cultural service delivery model is a component of what MJDF refers to as 'Our way'. It has enabled the clients of the MJDF to be the effective drivers of the supports they receive, with their needs and priorities reflected in the programs developed and the way that they are implemented. This has enabled the MJDF to deliver genuine person and family-centred supports and tailor its workforce in response. The MJDF's workforce includes Aboriginal people with lived experience of disability.

Realities of MJDF's work

MJDF's clients are Aboriginal Australians living with MJD, mostly living in remote locations across the Northern Territory and in Far North Queensland. The MJDF started working with these families in 2008, filling in the gaps in service delivery that, unfortunately, are all too common for remote Aboriginal communities.



The remoteness of the communities means that there are high delivery costs, high staff turnover, lack of accessible community infrastructure (kerbs, drainage, gutters, street lighting, sealed roads), lack of staff housing, lack of accessible housing for people with disabilities, lack of accessible vehicles for community transport, lack of tradesman to fix assistive technology, a small range of service providers, and minimal or poor quality mainstream services.

The location in remote Northern Australia carries with it the extreme weather conditions which can impede delivery of services (cyclones, floods, impassable roads in the wet season and very hot and humid conditions).

Working with Aboriginal people with disability also involves culturally oriented community issues (closure for respect, gender matching for workforce/clients, family based decision making),

communication issues (interpreting, different priorities, 'two way' working) and differences in the conceptualisation of disability in western medical terms in an Indigenous context.

MJDF and the NDIS

The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. Supports are delivered in response to the expressed needs of the client base, consistently, despite very high costs. The additional funding required (on top of government funding) for MJDF to provide holistic and comprehensive family supports is funded through non-government sources such as Aboriginal Land Councils, Corporate sponsorship, philanthropic grants and donations.

The NDIS commenced in the NT in July 2014 with a trial site in the Barkly Region. The MJDF has been 'ahead of the game' in relation to the NDIS in the NT, anticipating its commencement and preparing its Board, staff, clients and families since February 2015. Thus, the MJDF has been informed about the NDIS from an early stage and has been able to capitalise as much as possible on the rollout to maximise the benefits to its clients.

The MJDF was registered with the NDIS in the NT in 2017 and is registered in Queensland from 2018. Under the NDIS the supports that the MJDF is registered to provide include support coordination, improved health and wellbeing, assistance to access community, assistance with social and community participation, and improving life choices.

The MJDF underwent an independent Quality and Safeguards Framework Assessment process for its registration as a service provider under the NDIS in March 2017. That independent assessment found that:

*"clients, their families and their kin willingly engage with the organisation, and make decisions based on cultural and social needs. Family, extended kin networks, and community members are involved in support delivery. Clients interviewed were open, direct, confident and engaging about their experiences with MJD and how the Foundation was helping them and their families."*¹¹

The MJDF's clients started to become participants under the NDIS in 1 January 2017 when the rollout of the NDIS started in the NT. Some of the MJDF's clients are now on their 2nd or 3rd plan.

As at end February 2019 the MJD Foundation had 34 clients with plans in Darwin and Alice Springs supported accommodation, East Arnhem, Darwin remote, Darwin urban, Central Australia and Cairns.

The advent of the NDIS was seen by the MJDF as an opportunity, but it also posed significant risks. Employing an iterative process of education and resource allocation (including allocation of non-Government funds) has culminated in tailored processes and meant that the MJDF has managed to navigate the implementation of the NDIS in the NT.

This has not been without cost. The MJDF has invested substantial financial, in kind and dedicated resources up front (to educate staff and clients, to ensure internal systems could deal with the NDIA Provider Portal requirements, to cost its services, to register, and to prepare and assist clients with their first plan), for which there has been no recompense. The process has revealed a lack of appropriate support from the NDIA and the NTG for the important transition period.

Further resource costs are now being imposed on the MJDF in relation to our Queensland clients, to deal with issues that have already been resolved in the NT. This is despite the NDIS being a national system.

¹¹ Report of MJDF Services Assessed by HDAA to the Northern Territory Quality and Safeguarding Framework, 31 March 2017.
MJD Foundation – Submission on the NDIS