

# Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

### **MJD Foundation Submission**

## September 2020

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# **Submission Purpose**

On 9 June 2020, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission) released an Issues paper on First Nations Peoples with Disability. The Issues paper seeks information about the experiences of First Nations People with disability and the changes that are needed to support them across the course of their lives.

The purpose of this submission is to respond to the request for comment on the Issues Paper.

## **Previous MJDF Submission**

In March 2020, in response to a 11<sup>th</sup> February visit from Commissioners Mason, McEwin and Atkinson, the MJD Foundation (MJDF) provided a submission to the Disability Royal Commission. That submission set out MJDF's experiences in delivering services to Aboriginal Australians living with disability (principally Machado-Joseph Disease) in very remote communities. (That submission is included in Appendix B).

It described those programs that have worked well for MJDF clients including the On Country program, the Kin Connect program, the Holiday of a Lifetime and MJD House. It also outlined the challenges MJDF faces in delivering services to First Nations people living with disability in remote NT and Far North Queensland communities, in particular under the National Disability Insurance Scheme (NDIS).

Some challenges are common in remote locations and include lack of remote infrastructure, high cost of staff and travel, thin markets and remote staff retention. Other challenges are specific to the NDIS and/or Aboriginal participants in remote locations, such as inadequate pricing levels, lack of



interpreter funding, non-recognition of the need for continuing support coordination funding, and under-utilisation of plan funding.

The MJDF, in that previous submission, concluded that without appropriate mechanisms to overcome thin markets, the provision of funding for appropriate interpreters, the recognition of the ongoing need for support coordination and the acceptance of the validity of collective choice and control, our clients will continue to struggle to live free from neglect and exploitation.

This submission builds on that previous Submission by outlining some changes that could be made to overcome the challenges of service delivery to First Nations people with disability in remote Australia.

## **Submission**

The MJDF works in partnership with Aboriginal<sup>1</sup> Australians, their families and communities living with Machado-Joseph Disease (MJD) in remote and very remote communities, and urban centres across the Northern Territory and in Far North Queensland. Its clients include NDIS participants, non-NDIS participants and family carers.

The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. This service provision was historically frequently designed to fill gaps in government service provision. More information about the MJDF is in Appendix A.

# **Productivity Commission Report on Expenditure on Children in the Northern Territory**

The Productivity Commission produced a report on *Expenditure of Children in the Northern Territory* in March 2020. The Productivity Commission was given the reference to undertake this work as a result of a report by the Royal Commission into the Protection and Detention of Children in the Northern Territory (the Royal Commission) which found that funding arrangements in the Northern Territory appeared to be characterised by a lack of coordination between the Northern Territory and Commonwealth Governments, and within each government.

A joint funding framework was recommended by the Royal Commission, so the Productivity Commission report into expenditure in the Northern Territory was commissioned to support the development of that funding framework. The report explores how governments can work together more effectively so that their funding develops the strengths and protective factors that keep children safe and well. This can be seen to be in parallel with the purpose of funding in the disability sphere.

While the report deals specifically with funding for children and family services in the Northern Territory, many of the challenges that are encountered such as poor decision making, inadequate government coordination, and lack of data on outcomes at the community level, are also present in other locations and policy areas (including the NDIS), with their impacts being felt more acutely in areas of high disadvantage.

Also, while the report looks at outcomes for all children in the Northern Territory, the recommendations take account of the experience of Aboriginal children in particular that is shaped by

<sup>&</sup>lt;sup>1</sup> The 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. No disrespect is intended to our Torres Strait Islander families and communities. The MJDF acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.



intergenerational trauma stemming from the results of colonization. The result is that the need for flexible and culturally capable services is particularly acute.

Therefore, while the Productivity Commission report, on its face deals solely with funding child and family services in the Northern Territory, it has ramifications for the funding of other services, such as disability, in regional and remote Australia, and for First Nations people with disability living in those areas.

## **Findings**

The relevant findings of the Productivity Commission are that current grant funding approaches do not facilitate a focus on long-term outcomes and create funding uncertainty for service providers. This is because grant funding has short-term funding periods and insufficient funding for capital expenses required for service delivery, capacity building, and for monitoring and evaluation. This means there are staffing gaps, and substantial amount of time devoted to preparing and managing grant applications and cobbling together funding from various sources.

Secondly, where there is an inadequate number of potential providers leading to NDIS plan underutilization (i.e. thin markets), <u>competitive</u> processes may disadvantage small, community-based organisations and Aboriginal organisations that are trusted by, and may be better able to meet the needs of, communities. It also creates disincentives for collaboration between providers and takes insufficient account of the longer-term benefits of community-based service providers (such as cultural competence and trust of communities).

## **NDIS** quarterly report

In regards to the NDIS, currently the largest 10 NDIS providers in the NT are predominantly Supported Independent Living (SIL) providers<sup>2</sup>, with a distinct lack of in community providers to deliver everyday essential and culturally appropriate core services needed to support people with disability to remain living in, and cared for in their remote community. Darwin remote, East Arnhem and Katherine regions are more than 10 percentage points below the national plan utilization average. This further supports an argument to provide additional supports to local, placed based organisations.

### Recommendations

As a result of these findings, the Productivity Commission recommended:

- increasing certainty in the contracting process by having default contract lengths that are set at a minimum of seven years;
- funding should reflect the full costs of providing services in the Northern Territory, taking into
  account the higher costs of delivering services in remote areas, capital investments needed to
  support service delivery, and the cost of monitoring and reporting on service delivery
  outcomes;
- government agencies need to look beyond the immediate grant funding decision, and consider how best to coordinate their expenditures on capital assets (such as staff housing) with their grant programs for services;
- when commissioning services primarily targeting First Nations people, funding should take
  into account the cultural competence of providers, their connection to community, and their
  ability to deliver improved outcomes.

<sup>&</sup>lt;sup>2</sup> NDIA quarterly report dashboard – 30/06/2020 page 2



governments should adopt a relational approach to contract management, in which
governments and service providers, in consultation with communities, work collaboratively
towards shared outcomes, with regional managers having the authority to make decisions
about service delivery in line with more flexible funding contracts that can be adjusted
without the need for variations to the contract.

As the Productivity Commission has noted, these changes will require a fundamental shift in how governments contract and fund providers of services. It will involve a transition away from short-term, transactional and output-based funding, to longer-term relational and outcomes-focused funding, where governments and service providers work collaboratively to improve service delivery outcomes.

To implement these changes to service delivery in remote Australia, governments will need to trust and authorise local staff and service providers to make decisions (in collaboration with regional managers) on the most appropriate ways to achieve the desired outcomes.

In this context it is crucial to note that in relation to recent joint decisions by the Commonwealth, States and Territories and the Coalition of Peaks on the National Agreement on Closing the Gap despite the adoption of 16 targets not one identified the crucial importance of Closing The Gap in relation Indigenous access to disability services.

## Conclusion

The MJDF supports these findings and recommendations of the Productivity Commission and considers that they have strong relevance to disability funding and service delivery.

Funding contracts of a minimum seven-year duration will provide the certainty needed to better plan service delivery based on the long term needs of First Nations people with disability. Funding that better reflects the true cost of providing culturally appropriate services in a remote area to First Nations people with disability would go a long way towards achieving equitable service delivery compared to mainstream urban areas.

This longer-term, collaborative approach to contracting service providers, if implemented in the disability area, would improve services to First Nations people with disability in remote locations so that they are better supported across the course of their lives.



# Appendix A – MJD Foundation

#### **MJD Foundation**

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal<sup>3</sup> Australians, their families and communities living with Machado-Joseph Disease (MJD) in a growing number of remote and very remote communities and urban centres across the Northern Territory (NT) and in Far North Queensland (QLD).

The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. Services are delivered in response to the expressed needs of the client base, consistently, despite very high costs. These services were historically frequently designed to fill gaps in government service provision. With the introduction of the National Disability Insurance Scheme (NDIS), the MJDF has increased its supports to further meet some of the supports previously provided by government.

### Machado-Joseph Disease

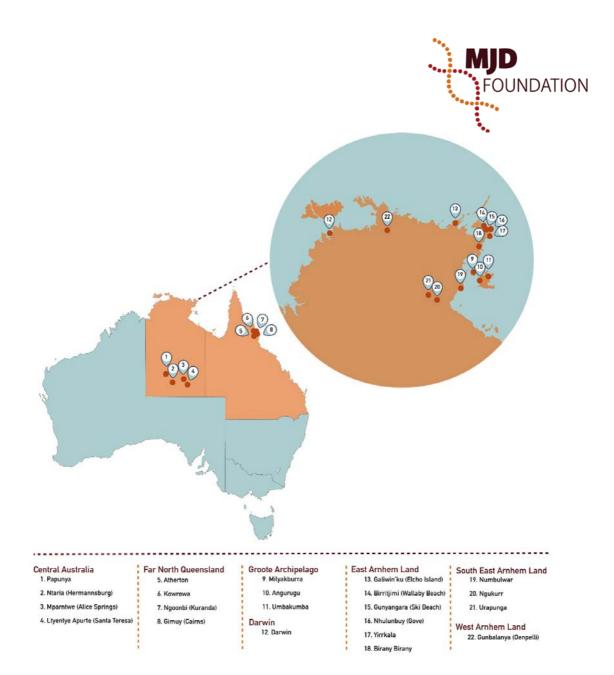
MJD is a very rare genetic neurodegenerative condition, experienced at the highest rates internationally among Aboriginal people in the NT. It is a terminal condition that gradually destroys independence and impacts on every facet of life.

The disease is extremely disabling, of significant duration - those affected experience progressive symptoms for up to 20 years. Genetic 'anticipation', a phenomenon whereby children of those with the disease experience symptoms earlier than their affected parent means that the age at which the disease manifests is variable, with symptomatic children as young as twelve (12) known to the MJDF. Deterioration of function with MJD is gradual but inexorable and progression is more rapid with earlier age of onset. There is no remission or effective treatments, people who are able to walk independently at the onset of the disease will *always* end up using a wheelchair. Functional change however, occurs gradually over a number of years. During this time care needs change significantly, necessitating regular assessment and good planning.

The vast majority of the MJDF's clients live in very remote Aboriginal communities<sup>4</sup>. 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.

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

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# Appendix B – March 2020 – Previous MJDF Submission



# ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

# MJD Foundation Submission March 2020

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# **Introduction/Background**

#### **Submission Purpose**

The MJD Foundation (MJDF) is making this submission in response to a request from Commissioners Mason, McEwin and Atkinson who visited MJDF in Darwin on 11 February 2020 to hear from us about the work we do.

This submission sets out MJDF's experiences in delivering services to Aboriginal Australians with disability (principally Machado-Joseph Disease) in very remote communities. Our aim is to share this expertise and knowledge to help the Commission determine what can be done to promote a more inclusive and equitable society that supports the independence of Aboriginal people living with disability in remote Australia and their right to live free from violence, abuse, neglect and exploitation.

#### **MJD Foundation**

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal<sup>1</sup> Australians, their families and communities living with Machado-Joseph Disease (MJD) in a growing number of remote and very remote communities and urban centres across the Northern Territory (NT) and in Far North Queensland (QLD).

The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. Services are delivered in response to the expressed needs of the client base, consistently, despite very high costs. These services were historically frequently designed to fill gaps in government service provision. With the introduction of the National Disability Insurance Scheme (NDIS), the MJDF has increased its supports to further meet some of the supports previously provided by government.

#### **Machado-Joseph Disease**

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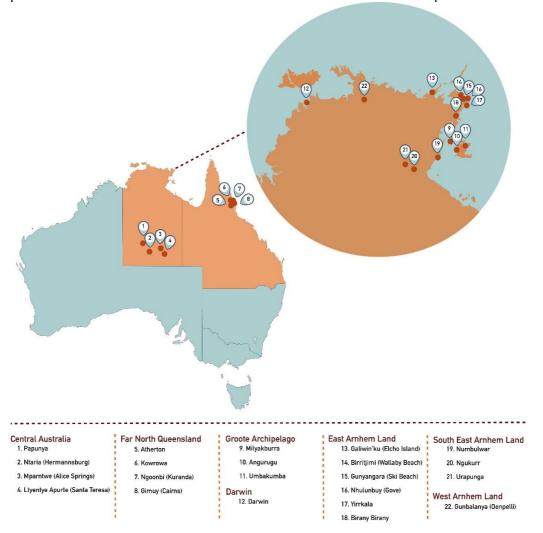
The disease is extremely disabling, of significant duration - those affected experience progressive symptoms for up to 20 years. Genetic 'anticipation', a phenomenon whereby children of those with the disease experience symptoms earlier than their affected parent means that the age at which the disease manifests is variable, with symptomatic children as young as twelve (12) known to the MJDF. Deterioration of function with MJD is gradual but inexorable and progression is more rapid with earlier age of onset. There is no remission or effective treatments, people who are able to walk independently at the onset of the disease will *always* end up using a wheelchair. Functional change however, occurs gradually over a number of years. During this time care needs change significantly, necessitating regular assessment and good planning.

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The vast majority of the MJDF's clients live in very remote Aboriginal communities<sup>2</sup>. 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.

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



<sup>&</sup>lt;sup>2</sup> MJDF defines remote and very remote as follows:

Remote – ASGC-RA rating of R4 <a href="http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator">http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator</a>
Very Remote – ASGC-RA rating of R5 <a href="http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator">http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator</a>
MJDF also utilises the NDIS rural/remote Modified Monash Model (MMM) which further breaks down the ASGC RA categories to better represent variation in population size in rural and remote areas.

http://www.health.gov.au/internet/main/publishing.nsf/content/modified-monash-model



#### **MJD Foundation Supports/Services**

The MJDF conducted a Disability Audit in 2013<sup>3</sup> in selected communities in North East Arnhem land and the NT Gulf region. The Audit analysed the current prevalence across all disability types (not just MJD) in these communities; the existing levels of service provision; the barriers to service provision; and the relevant issues for the National Disability Insurance Scheme (NDIS).

The Disability Audit found that people living with disability in these communities did not access the range of services they needed because the capacity to provide them did not exist at community level. In very remote communities the bulk of the existing services were provided by regional councils and consisted of meals on wheels, limited transport and some day respite and personal care. Even these inadequate services were not always available in some communities and were extremely variable both between communities and within communities over time. These limitations were strongly linked to availability of personnel and resources such as vehicles. Out of community respite in urban centres was frequently used as an urgent intervention in stressed care scenarios and was, in fact, de-facto care. High support needs clients required frequent urgent/crisis respite, and preventative provision to low and moderate needs clients was problematic.

With the introduction of the National Disability Insurance Scheme, the MJDF is progressively growing our supports to broaden the services we provide to clients, and to take on more clients.

The current and emerging services provided by the MJDF are:

- Occupational therapy
- Physiotherapy individual and group (expanding)
- Home Exercise Programs (projected as a new program in 2020 and 2021)
- Prescription of adaptive equipment
- Social and 'on country' outings (expanding)
- Communication group sessions
- Assistance to access community (expanding)
- Kin Connects supporting clients to visit their home community when they living in an urban residential care facility
- Holidays of a Lifetime
- MJD HOUSE (a new and large program for MJDF, growing in 2020 and 2021)

The MJDF also provides education and conducts and engages in research. It educates its clients', families and other service providers about the cause, management and treatment of MJD, and conducts research into better ways to manage the impact of MJD and possible prevention/treatments.

MJD HOUSE in particular, is a large new program for the MJD Foundation. MJD HOUSE will expand over 2020 and 2021 and is a wellbeing hub for clients living with MJD, to enable them to come to Darwin for respite, specialist therapy, relaxation, and connection with other families. MJD HOUSE will enable clients to stay stronger for longer so they can ultimately remain living in, and cared for in their remote communities.

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<sup>&</sup>lt;sup>3</sup> Disability Audit – NE Arnhem Land NT Gulf – A Snapshot of Indigenous Australian Disability in the Very Remote Communities of: Groote Eylandt Archipelago (Angurugu, Umbukumba, Milyakburra); Galiwin'ku; Ngukurr (including Urapunga) - <a href="http://mjd.org.au/cms/file\_library/Other/Other-592.pdf">http://mjd.org.au/cms/file\_library/Other/Other-592.pdf</a>



# MJDF's "Our Way" of Working with Clients, Family and Community

Working with Aboriginal people with disability involves culturally oriented community issues (closure for respect, gender matching for workforce/clients, family based "collective" decision making), communication in first language (interpreting, different priorities, 'two way' working) and differences in the conceptualisation of disability in western medical terms in an Indigenous context.

Relationships and respect for family and culture are at the heart of successful work for Aboriginal people living 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.

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. The role of the ACW is to reflect family support needs, facilitate and attend MJDF client home, clinical and other visits with relevant non-Aboriginal MJDF staff; interpret at medical, allied health relevant meetings and appointments; educate and mentor non-Aboriginal staff/volunteers about relevant elements of Kinship and Culture; interpret and translate MJDF resources into first language; travel to other communities to talk about MJD and the work of MJDF and plan/attend respite trips as appropriate.

This 'two-way' model also demonstrates MJDF's commitment to community capacity building and Aboriginal and disability employment.

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."

This positive feedback from our clients puts MJDF in a good position to recommend ways in which the NDIS should be operating to maximise the benefits for Aboriginal people with disability in remote Australia.

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<sup>&</sup>lt;sup>4</sup> Report of MJDF Services Assessed by HDAA to the Northern Territory Quality and Safeguarding Framework, 31 March 2017.



# What works for MJDF's clients, their families and communities

Below are a few examples of MJDF programs that work well for our clients and have been able to be supported, either fully or partially, under clients' NDIS Plans.

#### **On Country Program**

The key to the way that MJDF works is that we listen to our clients. Consistently, we hear from our clients that what matters to them in order to have their best possible life is community, culture and country. Our Groote Eylandt 'on country' visits are all about clients and family deciding where to go together on country, what to eat, transporting them there and spending the day enjoying family, culture and country. Activities that clients wish to do as part of their culture (such as collecting shells, swimming, hunting or fishing) is mixed with exercise, physiotherapy sessions or group exercise sessions. It engages experts from both cultures. The program is based on collective choice and control for our Aboriginal clients, as opposed to the western individual choice and control model promoted by the NDIS. It allows us to package traditional disability supports such as physiotherapy, speech therapy, transport and accessing community, in a way that is client driven and done in a culturally appropriate way. Our clients express that their social and emotional wellbeing is stronger than if they had to receive these traditional supports in individual, typically western settings.

The NDIA has supported this program by approving the traditional supports to be funded by 'pooling' funds from each of our clients' individual NDIS plans.

MJDF created a short DVD (funded by the NDIA) to demonstrate this program. <a href="https://www.youtube.com/watch?v=ki047Gw0z-k&feature=youtu.be">https://www.youtube.com/watch?v=ki047Gw0z-k&feature=youtu.be</a>
Or search YouTube for the MJD Foundation's Channel

### **Kin Connect Program**

This program also supports our Aboriginal clients' need for community, culture and country. The Kin Connect program supports clients who are no longer able to live in their remote community and are living away from home to maintain cultural connection by returning to their country, family and community for a short time. This experience increases our clients' well-being, and their community and cultural participation. Significant preparation, planning and collaboration is required to transport and care for a client with advanced MJD to return to country.

MJDF has varied success in being able to cover costs for this program utilising NDIS plans.

### **Holiday of a Lifetime**

Our 'Holiday of a Lifetime' program allows our clients to look forward to a special event that they might not otherwise ever experience. It requires immense planning and teamwork to take a client with MJD to parts of Australia that they have never been. Holidays have been organized to the Gold Coast, Sydney, Cairns and Melbourne.

MJDF has varied success in being able to cover costs for this program utilising NDIS plans, and frequently subsidise the program from other sources.



#### **MJD HOUSE**

MJD HOUSE is a Wellness Hub located in Darwin. There is a shortage of appropriate places in Darwin where clients could stay when they and their carers need a break, and there are no remote facilities that support overnight care. Historically, clients would come to Darwin when it had reached crisis point for the client or their carer.

MJDF has leased two dwellings (from the NTG), collectively called MJD HOUSE, to provide scheduled respite for clients and families to rest and access a range of supports (including therapy and specialist supports) that contribute to their wellbeing and to enable them to live their best possible lives.

Rather than waiting for it to reach crisis point, MJDF aims to have clients rotate through MJD HOUSE on a regular basis. It aims to keep our clients stronger for longer, so they can remain cared for and living in their communities.

Given the thin markets in remote communities, and inability for clients to receive all the daily supports they need, this program is of great importance to support informal family carers.

The program has been operating at full capacity for 4 weeks, is fully booked for all of 2020 (evidencing the demand/need), so we are yet to determine whether we can break even utilising our clients' NDIS Plans, drawing down on the Short Term Accommodation (STA) support items. MJDF applied to the NDIA for grant assistance for set-up costs, but this was not successful.



# Challenges for MJDF in delivering for its clients, their families and communities

#### **Lack of Remote Infrastructure**

The remoteness of the communities means that there is a 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. These issues are in fact deeply structural in nature and reflect ongoing exclusion of Aboriginal peoples from mainstream services that is particularly evident in remote Australia. For these to be addressed will require structural and institutional reforms to be pursued incrementally and sustained over time (Westbury and Dillon 2019)<sup>5</sup>.

### **High Cost of Staff, Travel and Service Delivery**

Delivering services in remote locations, even where there may be sufficient infrastructure can still mean high delivery costs of equipment, high staff turnover and high transport costs. 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).

#### **Thin Markets**

Because of the remoteness, lack of infrastructure and high costs of service delivery, there are often very few service providers, apart from some government services in remote communities. In terms of disability services there are few, if any, allied health specialists, equipment retailers or repairers, and minimal personal care and respite options. There is virtually no choice in providers and no provider of last resort when there is a crisis. MJDF aims to fill the gaps in services for its clients that exist in remote communities. NDIS plan funding is not sufficient to overcome these gaps. In fact, many plans are not fully utilised because the services are not there. Alternative funding models are needed to overcome the lack of services so that our clients have choice and control.

#### Remote staff retention

Attracting and retaining good staff in remote communities is extremely challenging. Adequate housing, isolation, extreme weather, security/safety issues, dry communities, adequate school options for staff with families, and high travel costs make it difficult to attract and retain staff. These challenges are well documented, and MJDF continues to look for innovative ways to attract and retain staff.

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<sup>&</sup>lt;sup>5</sup> Westbury. N and Dillon M, 2019. 'Overcoming Indigenous Exclusion: Very Hard, Plenty Humbug. CAEPR Policy Insights Paper, 1/2019, Centre for Aboriginal Economic Policy Research, ANU College of Arts and Social Sciences, Canberra.



#### **NDIS Remote Pricing**

Whilst increases to the NDIS remote and very remote loading has been welcomed, factors remain that result in NDIS pricing being inadequate to cover the cost of supports. Small numbers of participants and highly complex disabilities mean that a highly qualified allied health professional may be both delivering therapy, but also acting in a Support Worker capacity and supporting participants to access their community by going shopping etc. The funds that MJDF draws down from the NDIS Provider Portal do not cover the full costs of the supports MJDF provides under the NDIS.

### Lack of interpreter funding under the NDIS

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 who have English as their second language have interpreter funding included in their NDIS 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)<sup>6</sup>. 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.

Interpreter funding for Indigenous languages should be allowed in NDIS plans for all aspects of support provision (not just NDIS Planning), and the NDIS should be flexible enough not to require support providers who are interpreters of Aboriginal languages to be registered with NAATI, or to support the capacity of NAATI to increase this accreditation access for remote living Aboriginal Australians.

# Non-recognition of the continuing need for substantial support coordination funding under the NDIS

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, 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, limiting and will disadvantage remote Aboriginal participants even more.

## Under-utilisation of NDIS plan funding in remote Australia

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 funding is reduced in subsequent plans because insufficient funds were utilised in the first plan. Under-utilisation is <u>not</u> a function of lack of need. Despite the NDIA telling us this is not the case, we have seen significant reductions in plans.

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<sup>&</sup>lt;sup>6</sup> As noted in the NDIS Guide to Suitability



# **Conclusion**

The MJD Foundation believes that its work, done in concert with our clients and their families and communities, promotes a more inclusive society that supports the independence of Aboriginal people with disability in remote Australia and their right to live free from violence, abuse, neglect and exploitation

Aboriginal people living with MJD in remote communities have poor access to services compared to other parts of Australia. Their best possible life is one closely connected with community, culture and country.

The NDIS was designed to provide people with disability with individual choice and control no matter where they live. Without appropriate mechanisms to overcome thin markets, the provision of funding for interpreters, the recognition of the ongoing need for support coordination and the acceptance of the validity of collective choice and control, our clients will continue to struggle to live free from neglect and exploitation.