



PARLIAMENTATION JOINT STANDING COMMITTEE ON NDIS Inquiry into the NDIS Quality and Safeguards Commission

MJD Foundation Submission July 2020

Table of Contents

Submission Purpose	1
NDIS Practice Standards.....	2
MJD Background.....	3
MJD Foundation.....	3
Machado-Joseph Disease.....	3
MJD Foundation Supports/Services.....	5

Submission Purpose

The MJD Foundation (MJDF) is making this submission in response to the Parliamentary Joint Standing Committee on the NDIS and their request for submissions in regards to the NDIS Quality and Safeguards Commission.

In particular, MJDF is responding to the Terms of Reference part c). And the context of this submission is in regards to the COVID-19 pandemic.

"c. The adequacy and effectiveness of the NDIS Code of Conduct and the NDIS Practice Standards".

NDIS Practice Standards

The MJD Foundation is contributing a brief submission around the Practice Standards specifically in regards to PPE and infection control guidelines being covered under the title of “Management of Waste” which we believe to be too limited in scope.

The NDIS Practice Standards referred to are the “NDIS Practice Standards – NDIS Practice Standards and Quality Indicators – January 2020 – version 3”.¹

In the context of the COVID-19 Pandemic, it became obvious that the current Practice Standards were too limited in their scope, and we recommend the current title of “Management of Waste” is replaced with “Infection Prevention and Control”, with further changes to the outcomes and demonstrated criteria.

Our recommendation replacement of the current “Management of Waste” practice standards are as follows:

Infection Prevention and Control

Outcome: Each participant, worker, and any other person in the participant’s home is protected from harm as a result of exposure to infectious or hazardous substances or diseases and to waste generated during the delivery of supports.

To achieve this outcome, the following indicators should be demonstrated:

- Policies, procedures and practices, including a training plan for workers, are in place with the goal of preventing the spread of infectious disease, and to control outbreaks of infectious disease that comply with current legislation and local health district requirements.
- Policies, procedures and practices are in place for the safe and appropriate storage and disposal of waste, infectious or hazardous substances that comply with current legislation and local health district requirements.
- All incidents involving infectious material, body substances or hazardous substances are reported, recorded, investigated and reviewed.
- An emergency plan is in place to respond to infectious disease exposures, clinical waste or hazardous substance management issues and/or accidents. Where the plan is implemented, its effectiveness is evaluated, and revisions are made if required.
- A plan is in place to respond to a community outbreak of an infectious disease.
- All Workers receive training to ensure safe and appropriate infection prevention and control precautions. This includes training on any protective equipment and clothing required when there is a risk of exposure, handling waste or hazardous substances.
- Participants are engaged in the decision-making process regarding their care and supports and how they are delivered. This includes explaining the processes of infection prevention and control and use of PPE.

¹ <https://www.ndiscommission.gov.au/sites/default/files/documents/2019-12/ndis-practice-standards-and-quality-indicators.pdf>

MJD Background

MJD Foundation

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal² 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 communities³. 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.

² 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.

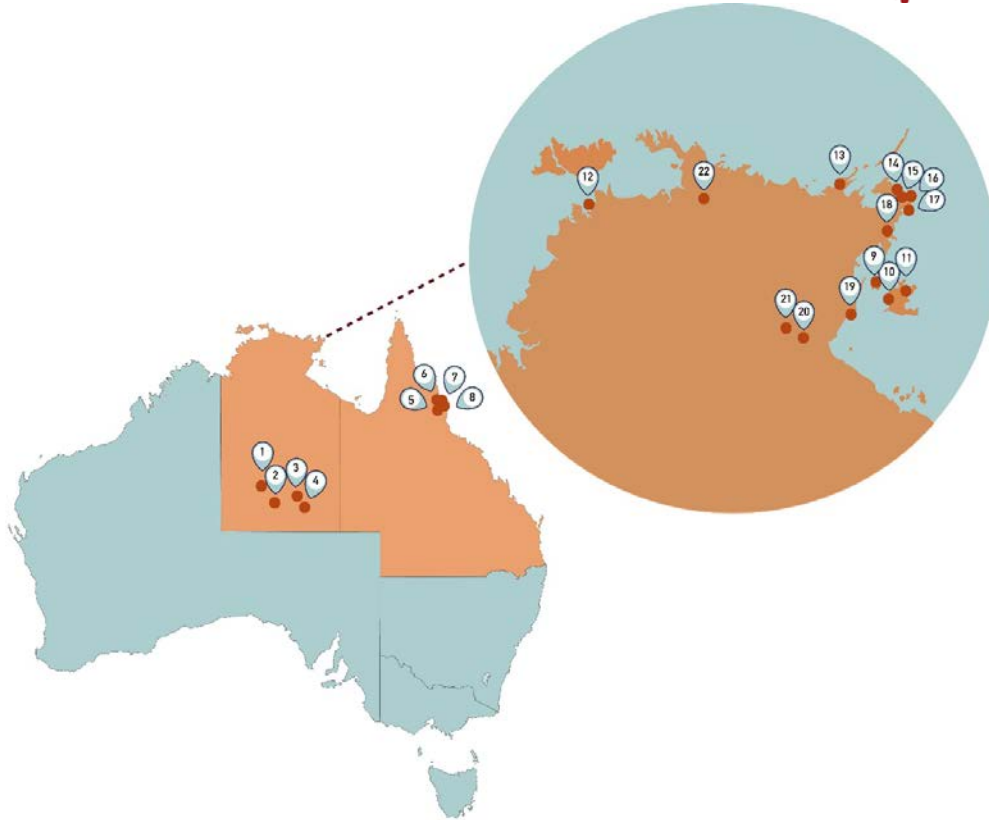
³ MJDF defines remote and very remote as follows:

Remote – ASGC-RA rating of R4 <http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator>

Very Remote – ASGC-RA rating of R5 <http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator>

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>



- | | | | | |
|--|---|--|--|---|
| <p>Central Australia</p> <ul style="list-style-type: none"> 1. Papunya 2. Ntaria (Hermannsburg) 3. Mparntwe (Alice Springs) 4. Ltyentye Apurte (Santa Teresa) | <p>Far North Queensland</p> <ul style="list-style-type: none"> 5. Atherton 6. Kowrowa 7. Ngoonbi (Kuranda) 8. Gimuy (Cairns) | <p>Groote Archipelago</p> <ul style="list-style-type: none"> 9. Milyakburra 10. Angurugu 11. Umbakumba <p>Darwin</p> <ul style="list-style-type: none"> 12. Darwin | <p>East Arnhem Land</p> <ul style="list-style-type: none"> 13. Galiwin'ku (Elcho Island) 14. Birrijiimi (Wallaby Beach) 15. Gungayara (Ski Beach) 16. Nhulunbuy (Gove) 17. Yirrkala 18. Birany Birany | <p>South East Arnhem Land</p> <ul style="list-style-type: none"> 19. Numbulwar 20. Ngukurr 21. Urapunga <p>West Arnhem Land</p> <ul style="list-style-type: none"> 22. Gunbalanya (Dempeli) |
|--|---|--|--|---|



MJD Foundation Supports/Services

The MJDF conducted a Disability Audit in 2013⁴ 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.

⁴ 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) - http://mjd.org.au/cms/file_library/Other/Other_592.pdf