MJD FOUNDATION

MJD Foundation - Disability Service Delivery Model

A review of the MJD Foundation's disability service delivery model: contrast and comparison to traditional disability service models.

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Primary Author: Libby Massey

Contributing Authors: Desireé LaGrappe, Mandy Doherty, Jennifer Cullen, Nadia Lindop

Cover image: Steve (Bakala) Wurramara and Jacob McCue (MJDF), Groote Eylandt
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MJD Foundation Limited
ABN: 65 159 208 867
PO Box 1745,
Nightcliff NT 0814
Ph: 08 8948 0757
www.mjd.org.au

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Executive Summary

The MJD Foundation (MJDF) is a specialist disability support organisation operating across remote North Australia. Providing care to Aboriginal families affected by a genetic, progressive, neurodegenerative condition known as Machado-Joseph disease (MJD), for the past decade, the MJDF has pioneered innovative care and funding models under the direction of Aboriginal families.

This report documents how the MJDF model differs from traditional mainstream disability service delivery. The lack of infrastructure in remote Aboriginal communities has been ignored by successive governments and remains a major barrier to improving service delivery. Despite this, the MJDF has been able to achieve outcomes because it has the engagement of, and ownership by, the Aboriginal families it seeks to serve. The elements of good practice that have been critical to its continued success are explored in detail throughout this report. These include:

- The implementation of a bi-cultural service delivery model referred to as 'two ways'. This has enabled the clients of the MJDF to be the effective drivers of the service, with their needs and priorities reflected in the programs developed and the way that they are implemented. This has enabled the MJDF to deliver genuinely person and family centred supports and tailor its workforce in response.
- The MJDF's nimble and flexible service model has been possible because of a fundraising strategy mostly independent of cyclical government funding that is typically characterised by ties to externally driven outcome measures. A (hard won) and carefully managed interest earning investment base and close sponsor relationships with local Aboriginal Land Councils, the corporate sector (e.g. mining, telecommunications transport, finance), and philanthropic organisations, involving reciprocal sharing of information and resources have all contributed to ensuring the ownership and longevity of the organisation.
- The organisation has tailored and been prepared to adjust its programs over time. Historically deficient disability service provision in remote communities and the decimation of informal family care support caused by the disease affecting several generations concurrently, led to an early focus on advocacy and 'gap filling' basic supports. These included equipment, hands on therapy and facilitating the interface between clients with MJD and the health, housing and community care sector. As relationships have grown with families, genetic services have been prioritised and therapy programs provided 'on country'.
- There is very little precedent to guide the work of the MJDF and therefore the research and education programs play a critical role. Experience has shown that the better informed MJD families are about an activity and its potential impact, the more time they are given to consider issues, the more inclined they are to engage with that activity. It has been critical to develop relationships with families that are robust enough to consider the issues scrupulously and avoid gratuitous concurrence and subsequent disengagement. This has resulted in service models being adapted and recreated. Where there are no protocols and practice guidelines it has been necessary to generate them.
- The advent of the National Disability Insurance Scheme (NDIS) has therefore been viewed by the MJDF as an opportunity to enhance its existing client focus and reflect the Aboriginal worldview, prioritising collective decision-making, relationship and place-based responses. The organisation aligns well with NDIS principles, prioritising intercommunity linkages and building the capacity and knowledge of mainstream organisations about disability, partnering to improve not only physical access but also attitudes.

- The MJDF's workforce comprises Aboriginal people with lived experience of disability and mentors and supports co-researcher capacity, partnering researchers with Aboriginal experts. Peer support and the development of individual capacity are best practice and aligned with the latest research in the international ataxia community.
- Most importantly, as an organisation grown from within the remote community context, the MJDF is committed to remote community capacity development providing long-term sustainable support for its clients and employment and education opportunities for the wider community.

Apart from its application to improving disability service delivery, there are a number of important broader practical and policy lessons that can be drawn from this report. They are particularly relevant for Government agencies, NGOs, the corporate sector and individual practitioners engaging with and developing policies and programs that directly impact on remote Aboriginal communities.

Image: Gayangwa Lalara OAM (MJDF Vice Chairperson/Senior Cultural Advisor)
Photo by: Hugo Sharp

Background / Introduction:

The MJD Foundation (MJDF) was established in 2008, as a community driven response to families overwhelmed by Machado-Joseph disease (MJD) on Groote Eylandt, a remote island located in the Gulf of Carpentaria. Over the past decade, the MJDF's services have expanded to assist families living with Machado-Joseph disease in other remote Aboriginal communities across the Northern Territory (NT) and Far North Queensland.

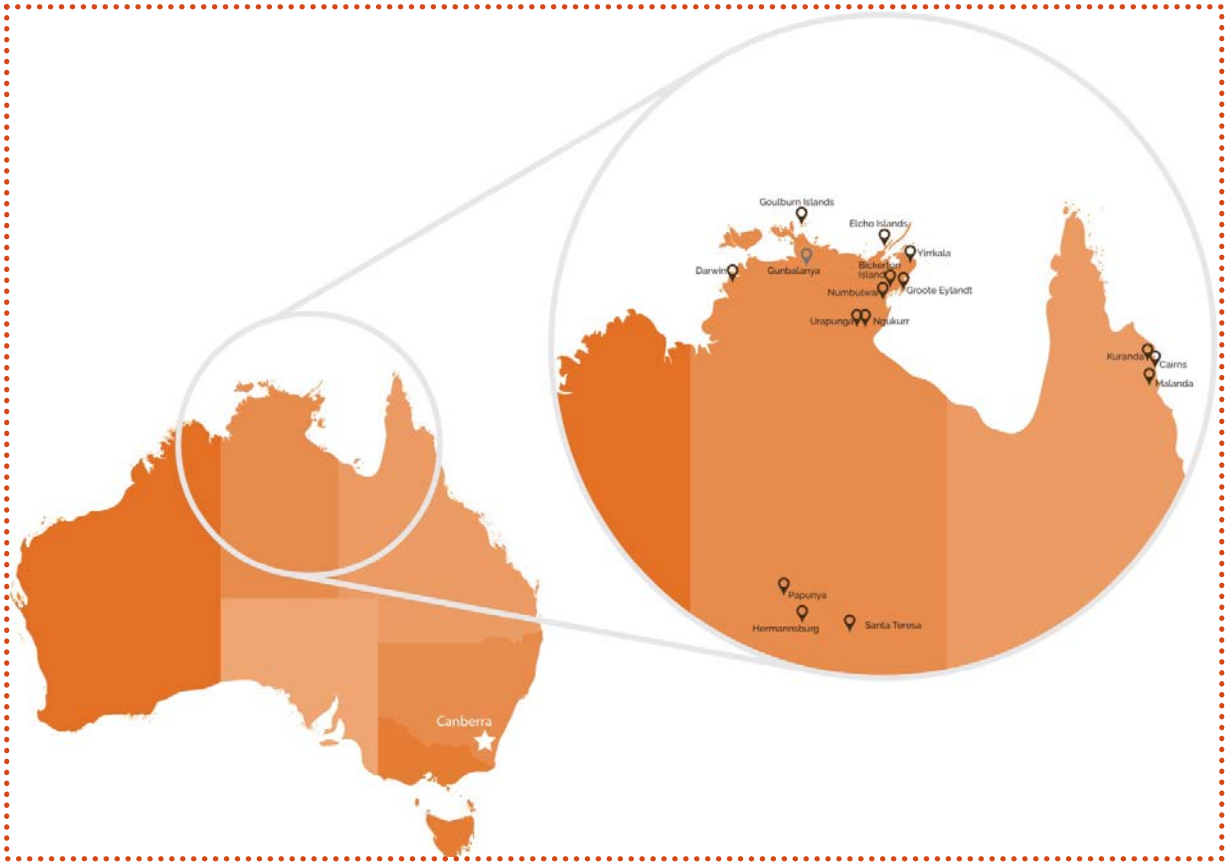

Figure 1 – Locations where the MJDF delivers services to people living with MJD

The MJDF has established a reputation for effectively delivering services in a difficult and complex environment. This report, commissioned by the National Disability Service Agency (NDIA) describes the evolution of the MJDF, identifying the critical issues considered in its development and barriers and facilitators to effective service delivery. It details how the MJDF service delivery model varies from traditional disability service delivery models and how it aligns with good practice for Information, Linkages and Capacity building (ILC) in Aboriginal [i] and remote communities and the ILC activity areas. [ii, 1, 2]

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[i] *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 used 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.*

[ii] *The term 'current good practice' means a practice which, even if not widely used, is recognised by sufficient numbers of practitioners as being based on sound evidence. ILC 'good practice' is practice that increases the independence, social and community participation of people with a disability.*

The MJD Foundation at a glance

The MJDF is different. In contrast to mainstream government and non-government tendered disability services, the organisation evolved to meet the very specific needs created by Machado-Joseph disease (MJD), a highly disabling genetic condition, clustered in small communities in remote northern Australia. Geographical isolation and cultural preference for large, closely tied families, has resulted in disproportionately high numbers of people living with this neurodegenerative condition, also known as Spinocerebellar Ataxia Type 3 (SCA3), in the very remote[iii] communities of north east Arnhem Land.[iv] The disease is currently incurable, creating incrementally increasing levels of disability over many years.[3, v] Ultimately, MJD culminates in complete dependence on others for all activities of daily living, due to profound physical disability and complex medical requirements.[4]

The unprecedented impact of such a high burden of disability in tiny isolated communities has created unsustainable pressure on fragile health and community service infrastructure. From the late 1990's, significant disability and community service gaps were obvious and this, coupled with a paucity of information about the disease within affected communities, resulted in a catastrophic breakdown of care.

At the time the MJDF was established in 2008, access to preventative, therapeutic and allied health interventions in remote north Australia was minimal and substandard. Resource impoverishment translated to a service delivery model adopted by local service providers, the NT Department of Health (Aged & Disability service - now Office of Disability) and others, which was limited to essential services inundated with high caseloads and a prioritisation of clients with the highest needs. People with MJD were dying early in their communities of largely preventable complications[vi] or, when care needs became too great, sent away to residential facilities in urban centres such as Darwin or Gove. It was also increasingly clear more people and younger generations were becoming affected. In some families three generations were manifesting the disease concurrently, with carers also experiencing early symptoms. This created growing anxiety at a community level and an ethos of 'shame and blame' evolved, further reducing quality of life, as people struggled to understand and contextualise the disease's devastating impact.

Working together with families to address needs in this context has required close communication, courage and innovation. In its journey to meet service need gaps and tailor supports, the MJDF has learnt it is fundamental to listen carefully to families and direct its endeavours accordingly.

Consequently, the MJDF provides genetic education and counselling alongside more traditional disability supports, interventional therapeutic activities and research. Carers are prioritised alongside clients and the organisation places a premium on conducting all activities within the cultural expectations and norms of local communities. At its core, the MJDF seeks to partner with families and build local capacity. In this sense, it breaks from traditional disability service models (which are based on individual care only), providing a lifelong and mixed mode family-oriented service which honours a relationship based wholistic approach that aligns with Aboriginal community expectations and mores.

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iii MJDF defines geographical remoteness using the Australia Standard Geographical Classification – remoteness Area (ASGC – RA) developed by the Australian Bureau of Statistics. The MJDF also utilises the NDIS rural/remote Modified Monash Model (MMM) which further breaks down the ASGC RA categories to represent variation in population size in rural and remotes areas.http://www.health.gov.au/internet/main/publishing.nsf/content/modified-monash-model

iv There are currently 101 Aboriginal Australians known to the MJDF who are symptomatic and over 650 people believed to be at risk of MJD (MJDF, 2018); SCA3/MJD is the most common dominant ataxia worldwide with large populations in the Portuguese Azores, Brazil, Israel and elsewhere.

v Mean survival time after symptom onset is 21.8 years.

vi Bowel obstruction, aspiration pneumonia, urinary sepsis, infected pressure injuries, etc.

Before the MJDF, Our beginnings – Grass roots and needs driven

A history of families

It is important to understand the nature of Machado-Joseph Disease, initial government responses and the challenges of establishing the MJDF, to understand how its model of service delivery developed.

During the late 1960's and 70's, a family on Groote Eylandt began to experience a mysterious illness referred to by local Anindilyakwa[vii] people as 'drunken walking sickness'. Those affected were sometimes called 'bird people' and their weakness attributed to being 'cursed' -believed to be the result of a broken cultural law. Elsewhere it was referred to as 'Groote Eylandt Syndrome'.[5]

Sporadic investigations by medical professionals over the next two decades were unable to identify the cause of the illness, despite increasing numbers of people affected and other cases identified in communities on the mainland. Clinically, the condition was noted to mainly affect adults and be of a neurological nature, typified by muscle weakness and resulted in a broad based ataxic gait and difficulties with speaking, swallowing and vision.[5]

Early theories linked it to the manganese mine on the island [5,6] and it was not until 1996 that the genetic nature of the disease was confirmed,[7,8] and other families identified in nearby Yirrkala. Subsequently known as Machado-Joseph disease or Spinocerebellar Ataxia type 3 (SCA3), introduction of the gene into the Aboriginal families was initially thought to have been through historical trepang trade between the Macassan people of Indonesia[viii] and north east Arnhem Land.[8] Later research published in 2012 supported an Asian origin and this work is ongoing to determine a more accurate estimation.[9,10]

Community and government responses – independent funding model

By the early 2000's, the numbers of affected people on Groote Eylandt and at Yirrkala had increased and cases had also been confirmed at nearby Galiwin'ku on Elcho Island and at Numbulwar on the mainland. The NT Department of Health funded Anglicare NT, a faith-based community service agency, to develop a report detailing the impact of the disease[11] and local care guidelines were developed describing the extent of interventions needed. Despite this, the NT Department of Health and Community Services was unable to dedicate ongoing funding. Preventable chronic disease mitigation strategies dominated health care resource allocation, with minimal disability specific funding allocated territory wide. A systemic reluctance to resource a cohort specific issue was reinforced by lack of visibility of the issue within a centralised primary health care dominated system. Any minimal supports provided were generally funded from Federal Aged Care funding and only available for those over 50 years old.

The issue continued to generate local support, however, and despite some resistance from the NT Government, was tabled as an genda item by the Anindilyakwa Land Council (ALC) in the Regional Partnership Agreement (RPA) negotiations for Groote Eylandt in 2007.[ix] The RPA provided the political tool which lead to the Federal Government allocating $100,000 of funding (which was matched by the Anindilyakwa Land Council) to investigate Machado-Joseph disease on Groote Eylandt, establishing the MJD Foundation in May 2008. The Anindilyakwa Land Council (ALC) donated a further $1 million to launch the MJDF's research program in 2009. Initial consultations with families established the urgent need for ongoing, sustained support in addition to research.

[vii] *The Anindilyakwa people are the traditional owners of Groote Eylandt who have occupied the archipelago for over 8,000 years (Anindilyakwa Land Council, 2018) [accessed from https://www.anindilyakwa.com.au/culture/anthropology]*

[viii] *With connections to the Portuguese families with MJD.*

[ix] *Devised in 2004, The Regional Partnership Agreement platform was designed to provide a mechanism for establishing a uniform Commonwealth Government investment strategy across a region with respect to Indigenous Affairs. intended to provide a coordinated response to priorities identified for the region, thus eliminating duplication or gaps. Regional Partnership Agreements (RPAs) formed part of the Commonwealth Government's then arrangements for Indigenous Affairs and service delivery. Where States and Territories have agreed, RPAs also included State and Territory investment. The terms of RPAs complied with the 'Framework Principles for Government Service Delivery' agreed by the Council of Australian Government in June 2004.*

To appropriately address the complex, often intimate, needs of people living with MJD, it was determined targeted support services, developed and closely directed by Aboriginal people, were needed. Accordingly, an application was made to the Aboriginals Benefit Account (ABA)[x] to secure stable, dedicated funding for the MJDF. The ABA (and the then Federal Minister for Indigenous Affairs) concurred and provided the MJDF with an initial grant of $1.6 million in 2009, with a further significant grant of $6 million grant in 2010. Conditions of the $6 million grant stipulated the funding be invested in perpetuity and the investment earnings channelled to the ongoing activities of the MJDF.

Education, research, advocacy, equipment provision and improved community services were the initial focuses of the MJDF. The organisation employed a small workforce of allied health professionals and Aboriginal community workers on Groote Eylandt, conducted preliminary sleep research and contracted the University of Sydney's Anzac Research Institute to establish a zebrafish model of MJD at the Brain and Mind Centre.[xi]

In 2012, increased demand for MJDF services for Groote Eylandters living with MJD was supported through a five-year grant from Groote Eylandt Bickerton Island Enterprises (GEBIE). At this time, it was apparent that similar support for MJD families at Elcho Island, Ngukurr and its surrounding communities, Oenpelli and several Central Australian communities was also required. This led to an application for a funding variation to increase the $6 million invested funds provided by the ABA. The ABA Advisory Committee approved this in May 2013 and the incumbent Minister for Indigenous Affairs approved the grant. A change of government shortly afterwards, however, delayed the handover of funds to the MJDF and a lengthy legal battle ensued, which was finally decided in the MJDF's favour in March 2017.

Until the legal outcome was decided, the Federal Government endowed the MJDF the equivalent of lost investment earnings by way of tied grants. An important donation of an additional $1million was provided by the ALC in late 2015 strengthening the research program.

A broad fundraising model integrating corporate and community cash and in-kind sponsorship, government and philanthropic grants, and donations/bequests provides varied funding sources for the MJDF. Tendering for a combination of Northern Territory, Queensland and Commonwealth Government grants enable educational resource development and the acquisition of some capital and equipment on a case by case basis.

The MJDF developed a nimble and flexible service model because of a fundraising strategy mostly independent of cyclical government funding which is typically characterised by ties to externally driven outcome measures based on the particular government program (usually not based on what outcomes Aboriginal people with MJD want). This flexible model continues to enable the MJDF to deliver genuinely person and family centred supports and tailor its workforce in response. Importantly, the diversified funding structure creates flexibility for the organisation to adapt services and workforce as necessary, and to change program prioritise if families desire this. The supports provided, directly respond to MJDF's clients' and families' expressed requirements - in contrast to those of a predetermined government funding program or those bound by complex organisational culture.

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[x] *The Aboriginals Benefit Account (ABA) is legislated under Part VI of the Aboriginal Land Rights (Northern Territory) Act 1976 (the Land Rights Act) and is a special account for the purposes of the PGPA Act. The ABA receives appropriations based on royalty equivalents, the level of which is determined by the estimated value of the statutory royalties generated from mining on Aboriginal land in the Northern Territory (NT). ABA funds are public money.*

[xi] *The zebrafish research is designed to establish a biological line and test pharmaceutical compounds that may lead to a treatment.*

Remote health and disability services profile

Primary Health Care

Distance and isolation inflate the cost of service provision in remote and very remote locations and the high burden of chronic disease and poor public health profile of Aboriginal and Torres Strait Islander communities has led to a government focus on 'closing the gap' in the primary health sector.[12] Remote community primary health services are frequently overwhelmed by the high volume of patients with chronic illness and characterised by well documented issues relating to recruitment and retention- of both Aboriginal and non-Aboriginal health professionals.[13] Outreach specialist medical services including those required by people who have MJD, such as neurology and genetics[xii] necessitate patient travel to regional centres. There is a strong correlation between these models and low engagement by Aboriginal community members, who place value on place and relationship-based interactions.[14]

The MJD affected families were further disadvantaged because reduced mobility means they lack the physical capacity to seek health services independently, and for those with early and emerging symptoms many were too 'shame'[xiii] to engage. Consequently, the primary health sector was largely blinded to the extent of the issue in many communities. These challenges persist as barriers to health care access.

Community Health Care

Dedicated disability service provision to remote Aboriginal communities across the NT has historicall been very limited. The introduction of existing aged and disability care initiatives only began in the East Arnhem region in a limited manner from the late 1990's. These services were predominantly aged care oriented and funded by the Commonwealth Government. Activities consisted of basic Home and Community Care (HACC) supports such as meals and laundry provision and limited, carer-oriented respite care.[xiv] Access to support for personal care was and remains very limited, with most communities lacking appropriate infrastructure as late as 2013.[15]

xii Prior to 2008 Genetics services were provided by SA Health; from 2008 to 2010 genetic health services were outsourced/contracted to QLD Genetic Health Services. There were no services from 2010-2014. From July 2014 Victorian Clinical Genetic Services are the contract holders

xiii "Shame" is a concept used by Aboriginal English speakers with a broader meaning than the non-Aboriginal use of the word encompassing shyness and extending to profound embarrassment (Leitner & Malcom, 2007)

xiv HACC services usually comprise meals, transport and laundry activities. Carer respite programs were Commonwealth funded and administered by Carers NT for Darwin Urban, Darwin Remote and Katherine regions and Anglicare NT for East Arnhem. Respite was capped at a certain number of days per year.

Allied Health Care

Prior to the National Disability Insurance Scheme (NDIS) roll-out, the NT Department of Health's Aged & Disability Program (now Office of Disability) provided limited allied health services by a remote 'fly in fly out - drive in drive out' (FiFo – DiDo) model. Allowing for distance and limited resources, a 'transdisciplinary' approach was practiced, whereby one discipline assessed and co-ordinated the requirements of all allied health supports required by an individual.[xv] Adaptive equipment was provided from a centralised equipment pool, frequently ensuing very long delays. Home modifications were particularly problematic, requiring co-ordination between the therapists, local community agencies and the NT Department of Housing. Interventional allied health support, beyond home-based exercise programs and residential care, was not available to people with disabilities in the region at all.

In summary, at the time of the establishment of the MJD Foundation in 2008, families with MJD were: unable to access therapeutic/interventional allied health services, or carer support, had no access to consistent genetic or neurological support services.[xvi] Further, there was a demonstrable mismatch between the government disability equipment scheme and the lived circumstances of families, and housing was not fit for purpose.[15] 'Informal care' provided by family members provided the bulk of the high needs care needed by people with MJD and respite options were underfunded, and available out of community only. The genetic nature of the disease increased the likelihood of those same care providers also having the disease, and so an unsustainable vacuum of supports amongst burgeoning needs was created.

xv Occupational therapy or Speech pathology or Physiotherapy or Dietetics, etc.
xvi See xii.

The MJD Foundation Mission

Before 2008, many people with MJD and their families lived with extraordinarily high levels of disability without appropriate infrastructure or assistance. The severe non-ambulant phase of the disease involves complete dependence, incontinence, pressure management, anarthria (inability to produce speech) and dysphagia (difficulty with swallowing).[4] In the MJDF's experience, this phase can last for more than five years. Health care providers, and families alike had very limited information about the disease and how to manage symptoms. This resulted in extreme stress, poor life quality and ill health for both clients and carers.

As its initial task, the MJDF conducted preliminary genealogical work on family pedigrees across the communities. This projected sharply increasing needs- there are now 646 people identified as 'at risk'[xvii] of developing the disease. The MJDF therefore set out to address multiple gaps in service provision and to increase the capacity of people with the disease to interact with services.

The goal was to build local capacity to more sustainably manage the projected needs in collaboration and consultation with families, communities, existing government and non-government service providers and community-based organisations.

The inaugural mission statement of the MJDF reflected a wholistic 'family' orientation to service provision and the urgent need to improve the current circumstances of those with the disease. *To provide a better quality of life for Indigenous Australian sufferers of Machado Joseph Disease in Arnhem Land.*

Over the past decade, as the service provision landscape has changed the mission statement has evolved as is reflected in the MJDF Strategic Plan (2018-2021).[xviii]

The MJD Foundation works in partnership with Aboriginal[xix] Australians, their families and communities living with Machado-Joseph Disease, to provide comprehensive supports and engage in research, providing hope for the future.

[xvii] *In the case of MJD (a 'dominantly' inherited disease), the term 'at risk' is defined as having at least one affected parent or grandparent confirmed to have MJD*

[xviii] *The MJDF Strategic Plan can be accessed here: https://indd.adobe.com/view/a86fd553-4a18-4efe-bc6b-54e31a8b4360*

[xix] *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 used 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.*

Prevalence and modelling

Client Classifications

The MJDF provides wholistic client led services, oriented to supporting families. Aboriginal Australians with Machado Joseph Disease (or closely associated ataxias) are the MJDF's 'Clients'. The MJDF recognises an individual as a client of the MJDF if they meet one or more of the following criteria:

- The individual informs the Director, Community Services or another MJDF staff member or Aboriginal Community worker (ACW) that they are experiencing symptoms, and they are confirmed by the MJDF as being 'at risk'[xx] in terms of their genealogy.
- The MJDF Community Workers or family members identify the individual as evidencing symptoms, and they are confirmed by the MJDF as being 'at risk' in terms of their genealogy.
- A GP or Neurologist performs a neurological assessment (SARA)[xxi] and clinically diagnoses MJD, and the individual is confirmed by the MJDF as being 'at risk' in terms of their genealogy.
- Positive molecular genetic test results are disclosed to the MJDF's staff by the individual, a Departmental agent, or a medical clinic.

In many circumstances, the MJDF will have information indicating an individual has Machado- Joseph disease before the NT/QLD Department of Health or National Disability Insurance Agency (NDIA). It is MJDF policy that this information will not be disclosed to any parties, until the individual has provided their consent and signed a form which allows the MJDF to share their information to specified agencies.

To optimise the services that clients of the MJDF receive, clients are attributed a level of disease severity which equates broadly to their functional capacity. As the disease is progressive, people move through the categories incrementally. People may also be described as **'at risk'** of, or '**monitored'** for, MJD. The MJDF records these classifications by location of the client in Progeny®, a genetic pedigree software.

Review of client categories is conducted at least annually, in a process where the clinical staff of the MJDF collaboratively attribute both a clinical disease categorisation and a perceived level of support need. Social work and community services staff of the MJDF support the identification of the perceived level of support need. This process is led by the Manager of Community Services (MCS) for the person being considered. Where disease status changes markedly between annual reviews, client status may be altered pending assessment by the MCS and consultation with the Director of Community Services.

[xx] *At risk of having MJD means they have a parent, grandparent or great-grandparent with MJD.*
[xxi] *SARA – Scale for the Assessment and Rating of Ataxia.*

Clinical MJD

People may be diagnosed either through a molecular blood test, or a neurological assessment (SARA rating with increases over a period of time) combined with being 'at risk'.

Progression of MJD can be assessed and managed in three stages, mild, moderate and severe:

- Mild: (duration approximately 10 years) little or no assistance required for mobility.
- Moderate: (duration approximately 5 to 7 years) requires a mobility aid.
- Severe: ambulant (duration approximately 3 to 5 years).
- *Severe: wheelchair dependent (duration approximately 3-5 years).

* It is worth noting that many clients of the MJDF have been very reluctant to use wheelchairs despite significant safety risks, regular falls and dependence on 1-2-person assistance to ambulate. Among other factors, this is attributed to previously described phenomena such as 'shame' that some people may associate with using wheelchairs and other mobility aids within their community. Whilst clients at this severe stage of disease have been prescribed a wheelchair by a qualified allied health professional and its use encouraged for safety, these clients remain 'ambulant' until such time that wheelchair use is accepted by them and their family. These individuals self-manage their mobility restrictions by limiting distances they attempt to walk, very intense dependence on carer support and other techniques they have adopted. While the person might otherwise be described as wheelchair dependent given their profound disability, a wheelchair may not be in use.

This individual practice by many MJDF clients has necessitated the division of two-sub categories under severe: severe - wheelchair dependent and severe – ambulant. The MJDF recognises this is not the standard clinical practice; however, the categorisation ensures the degree of disability and high support needs are appropriately captured for those persons who are 'wheelchair users.'

Monitored

Indicates the person has either self-reported emerging symptoms to the MJDF or family members have raised concerns with the MJDF. These people have had no neurological assessment or SARA rating and no molecular blood test.

At Risk

At risk of having MJD – indicates the person has a parent, grandparent or great grandparent with MJD. A further category of clients have a pre-symptomatic positive diagnosis of MJD (i.e.molecular confirmation before onset of symptoms). These cases are currently very rare in the NT.
The following table shows current known prevalence
Figure 2: Aboriginal MJD Prevalence in Australia (MJDF, 2018)

Location	Symptomatic or +'ve test	Monitored ^	At risk *
Groote Eylandt	12	13	186
Yirrkala	3	14	112
Elcho Island	11	12	121
Ngukurr	5	10	95
Central Australia	5	3	97
Numbulwar	1	2	4
Oenpelli	3	1	8
Nth Qld	5	1	23
S. Australia	1	0	0
Total	46	56	646
MJD	101		

Service Need Requirements

In addition to the classification of disease, the MJDF also considers the quantum of service needs required by each client annually. This may not correlate directly with their disease severity, but factors in the formal and informal supports available, comorbidities, family circumstances and social & emotional wellbeing (SEWB) needs.

Examples of service need classification (not exhaustive)

- **Low** - living independently or with family. Initiates low levels of engagement with the MJDF. The person tends to make contact with MJDF when something is needed. Usually ambulant.
- **Medium** - living independently or with family. Functional, clinical and or social and emotional needs require regular engagement with the MJDF and moderate engagement with other support services.
- **High** – experiencing high support needs clinically, functionally or for social and emotional wellbeing. Engaging at a high level with MJDF. Usually also engaging with other support services at a high level. MJDF providing significant coordination of supports across support services and other mainstream providers.

Image: MJDF vehicle, Numbulwar Photo by: Nick Kenny

MJDF Service model

Culture, Communication and 'Two way' working

Culture

To deliver bio-medical health services effectively in a non-dominant culture, it is critical to prioritise and value the cultural and social issues that may be barriers to people accessing the service and recognise where facilitators to engagement present, e.g. promoting the oral use of the people's first language.[16] Inherent in this, is the recognition of different world views and preferred practices including moiety divisions and relationship structures. When fully explored, what may have been regarded as 'non-compliance' or disinterest can be recontextualised. The patient who 'lurks' around a corner in a health centre is not rude – simply unable to enter a space occupied by a person to whom he or she is in an avoidance relationship. Those who do not turn up for repeat treatments or therapies or fail to come to the door when a visiting health professional visits, may not be permitted to receive treatment of that nature from someone of the opposite gender. The confidentiality and privacy that is integral to western sensibility, may result in suspicion and anxiety for those who prioritise collective decision making and visibility. Understanding these firmly held beliefs and working together to enable the interactions necessary to treat disease and disability is imperative. Awareness allows approaches to dealing with differences to be incorporated into the practical components of service delivery. This is sometimes referred to as cultural safety or security and its importance in health care and service delivery increasingly recognised at the state, territory and national levels.[17] Learning the ways culture impacts on disability care support is key to the MJDF's ability to engage effectively with its clients.

The MJDF considers the whole person and the context in which they are living their lives. Therefore, assistance to navigate the social determinants of health are tackled in conjunction with traditional disability supports. Considerations such as access to reliable transport, food security, and domestic and family violence (DFV), are major barriers to MJDF's clients' access to the bio-medical health and disability services they require to manage their health and so are dealt with in a holistic manner. This is achieved by supporting the client's access to the services as a first step and then building in skill development as a means to consolidate capacity development.

This approach builds individual capacity as the client is assisted to learn new skills from their interactions with the MJDF's 'two-way team' and the inclusive education program implemented. They are also able to make decisions about their lives from a position of improved baseline wellbeing. This differs from traditional disability models which typically have a more narrow interpretation of the role they play and where the distinction between the silos of health and disability service delivery are more delineated.

Image: 'On Country' Physiotherapy session Photo by: Kate Pope (MJDF)

Communication

Language and health literacy remain significantly underestimated barriers in health and disability care in the remote Aboriginal context.[16] The majority of health and disability care information both written and spoken is provided at an English level that is not commensurate with that utilised by people in communities[xxii,16] Providing written information in people's first language is also not always useful unless they are literate in that language. The use of audio-visual materials does not completely ameliorate this issue as pictorial literacy varies across cultures and images must be considered carefully to ensure taboos related to death and gender are not violated.

Secondary to disease and disability pathology, speech complications endured by people living with MJD compound the language and health literacy barriers. People with MJD experience a prolonged period of dysarthria (difficulty forming speech sounds), which eventuates in complete loss of speech (anarthria). These individuals are reliant upon augmentative and alternative forms of communication (AAC), such as sign language or an alphabet board (for those with some English literacy), and skilled, patient communication partners to relay their message. Matters are further complicated by hearing loss endemic in remote Aboriginal communities; up to 60% adults and 85% of children.[18]

Working with community experts to devise alternative methods of sharing information has been critical to the MJDF's ability to engage with families. This is particularly pertinent as the MJDF provides support to families from more than five distinct language groups, each with specific requirements.. This approach builds individual and community capacity to understand what is involved in the disability, treatment and those options that are available to enable choice to be exercised. In contrast, traditional disability models assume a certain level of literacy in the English language and do not provide practical, useful options to communicate with those who do not have that literacy.Patient care models are often time limited so that sufficient time is not taken to sit with the person with disability and make sure they understand what is happening and why.

Workforce

Local community members are best equipped to assist in navigating the cultural and communication issues discussed above. To achieve this, the MJDF has adopted a 'two way' working model.
In practical terms, this effectively pairs an Aboriginal community worker and a non-Aboriginal health or community service professional. In contrast to other organisations, the MJDF does not utilise an 'open' recruitment strategy when employing Aboriginal community workers. Rather, in response to a need to respect moiety divisions and avoidance relationship structures, the Aboriginal Community Workers (ACW) are derived from within the affected families. Many of MJDF's ACWs are also people living with MJD which has assisted in mitigating the 'shame' that may be felt by people with MJD when seeking assistance.

The MJDF's 'two way' model also reflects the consistently expressed preference of MJD families for developing a relationship with those providing support. The arrangement allows for dual mentoring and sharing of information, ensuring the balance of power in interactions is more even. Capacity in individuals and local community is also enhanced as culture, language and relationships are taught alongside health and disability information. Administrative arrangements for workers are also designed to be informal and responsive to community, family, financial and cultural needs.

This differs from traditional models where workers are employed to suit the organisation and its structures rather than those that are acceptable to clients. Rarely are workers drawn from the community and encouraged to share decision-making within the organisation.

[xxii] *Many Aboriginal people are multi-lingual, but do not speak English as a first language. In general, English is only used during occasional interactions with non-Aboriginal people.*

Service Delivery

Traditional disability support organisations have been bound by block funded grant conditions and were consequently limited in the responses they could provide to support clients.
The MJDF has been able to develop its own agenda based around client need because of flexible funding, a defined cohort and minimal other service providers operating in the domain. This has led to completely client led, responsive services. Over the past decade, the focus has evolved while maintaining a basic orientation to delivering improvements to peoples' quality of life. Adjustments have occurred in response to changing client knowledge and expectations, legislation, government review, the service provider landscape and organisational resources.Service Evolution

The initial services prioritised by the MJDF were: *Advocacy, Improving Services, Equipment, Education and Research*. These reflected the most significant and pressing gaps experienced by people with MJD and their families at the time.

Advocacy

People who have MJD and their families are entitled to the full extent of government disability supports available Unfortunately, poor funding, staffing and infrastructure constrains delivery of these services in remote communities and results in significant unmet needs.[15] Barriers to both clients and family carers in attempting to report unmet needs have included a lack of awareness of their human rights, 'shame',[xxiii, 19] and communication and mobility restrictions.

Aboriginal people living with a disability rarely seek support independently.[20] As a first step to address this barrier, the MJDF trained and employed local Aboriginal Community Workers (ACW) in the most affected communities, to work alongside non-Aboriginal allied health professionals. MJDF ACWs are cultural and language experts in their own communities and uniquely well placed in terms of kinship to elicit intimate information appropriately.[xxiv, 21] Learning about the needs of families 'from the inside' is invaluable to target advocacy. As family experts, the ACWs also play a vital role in developing the family pedigrees. The pedigrees record the numbers of people at risk of the disease, past deaths, current clients and those with emerging symptoms. They are a powerful tool, which inform the current and future likely impact of MJD and should advise future Government policy.

MJDF's engagement with various government and non-government service providers has therefore been informed by timely and accurate reflection of current service mismatch, both of existing and anticipated future client needs. This has frequently required diplomacy. Difficult working conditions in remote communities, in addition to previous low levels of consumer feedback, meant providers were strained and sensitive to perceptions of criticism about their services. Navigating this space and developing collaborative and collegiate relationships, while simultaneously advocating for improvement, required the MJDF to tread carefully and contribute to practical solutions

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xxiii "Shame" is a concept used by Aboriginal English speakers with a broader meaning than the non-Aboriginal use of the word encompassing shyness and extending to profound embarrassment. (Leitner & Malcom, 2007)
xxiv See 'workforce' section p14 regarding recruitment of ACW.

Improving Services

Early work by the MJDF focused on filling the gaps in service provision. Along with the ACWs, professional care workers and volunteers have been recruited to provide weekend personal care for clients with severe disability and to facilitate community access, including transport. In the early years, employing a community based Occupational Therapist allowed the first 'hands on' therapeutic interventions in the MJDF's 'Staying stronger for longer' therapy program on Groote Eylandt. 'Staying stronger for Longer' formalises therapeutic components, such as hydrotherapy, by utilising a 'therapy by stealth' model. In this model, physical, social, mental and emotional health gains are facilitated by participation in informal, or opportunistic, activities provided in everyday living- such as collecting firewood, hunting and cooking, moving furniture or carrying groceries. The approach enabled people to conceptualise and find practical value in therapeutic activities. Variations of this are also conducted in other locations by the visiting MJDF staff.

For each family group, the MJDF now employs a Manager of Community Services (MCS) who has tertiary qualifications in allied health, nursing, community services or disability. The MCSs work alongside ACWs to identify and meet client and family needs.

Responding to recently emerging research proving early uptake of robust physical activity is protective for function,[22] physical activity programs have recently been escalated. The programs are delivered using some mainstream methods and also 'on country' in family groups. This is in keeping with people's desire to be able to connect with each other, their land and culture. Where possible, the programs also include speech therapy. 'On country' is a therapeutic delivery mode that is wholistic and enthusiastically embraced. A 'communication group' has been established in Darwin in collaboration with the NT Office of Disability. The group is run by speech pathologists and is working toward developing verbal and non-verbal communication skills, use of technology and literacy to support people's needs as they lose speech.

The interface between clients with MJD and the health, housing and community care sector can be compromised by multiple issues. Communication problems arising from either the physical consequences of the disease or English proficiency are common. Physical attendance at appointments can also be difficult to achieve independently, or not prioritised due to transport problems, competing priorities or a failure to understand the importance of the issue in relation to the disease process. These issues can be magnified for clients familiar with a remote community lifestyle who move into town. No suitable service exists with the ability to tackle these issues and so the MJDF has designed a Family Support Worker (FSW) role. The FSWs work with the MCS and ACWs in the team to assist with these interfaces. A priority for this program is capacity building, assisting families to develop appropriate skills and knowledge and improving social & emotional wellbeing. This is especially important to consider dealing with degenerative genetic conditions such as MJD, as it acknowledges the inexorable decline of capacity of those with the disease (and often their carers). It entails building skills and resilience for the family unit and relationships with service providers for the management of the ongoing supports that will be needed.

The prioritisation of embedding Social and Emotional Wellbeing (SEWB) improvements into all MJDF activities is reflective of very high rates of depressive illness, known to be common for people with MJD and their carers.[23] SEWB support activities have been developed in response to feedback from the ACWs. Early programs, such as iPad filming and editing workshops, enabled people with MJD to access employment that accommodated increasing disability and facilitated continued inclusion within community.

The skills learnt have also enabled continued participation in cultural activities – now as filmmaker rather than performer. Intensive work documenting issues and finding strengths was facilitated by conducting separate 'men's and women's' camps. The information shared in these gatherings has been a guide to adapting and developing additional programs. Increasingly, the MJDF's Kin-Connect program provides vital cultural and family reconnection for those people with MJD who have had to move to residential care facilities in urban locations and the 'Holiday of a Lifetime' opportunities enable people for whom so much has been robbed to experience unique holidays of their own design.

Accessible transport for people with disability in remote communities was often simply not available,[15] so the MJDF secured (through grants, sponsorship or NT Government Fleet gifts) and modified vehicles and employed and trained appropriate family members as drivers/community workers. All the MJDF's vehicle fleet are modified with either wheelchair lifts (providing full wheelchair accessibility) or passenger seat turneys that enable the passenger seat to swivel out of the vehicle (providing improved accessibility). This has allowed families to access health, community and cultural activities together, reducing the isolation that results from physical disability, and improving the safety of their carers.

Genetic services have further been prioritised by the MJDF as another key area for improvement. Such services have been inconsistently provided in the NT. In response, the MJDF has supported and enhanced the NT Department of Health clinical genetic services (education, counselling and diagnostics) by funding and mentoring clinical genetics service visits to communities. The area is complex and the potential for cultural misunderstanding and disengagement is high. It is vital that the services are delivered in the context of established relationships within the communities. This is work that has no precedent in Australia and a model is developing iteratively in close consultation with ACWs. The ACWs mentor the genetic counsellor about culture, language and relationship structures that may impact on understanding and they assist to develop concepts used in educational resources.

Mr S

Early work (2010) with men from the MJD families on Groote Eylandt revealed a strong need to retain important familial and cultural roles whilst confronted by physical deterioration. For those men who were wheelchair dependent, an inability to perform the physical aspects of their roles resulted in an intense grief attributed to this loss.

In fact, it was noted that 'slow dancing' – subtle missteps in the complex rhythmic clapping, singing and dancing required in ceremony were early memorable indications that they were affected. A non-Aboriginal MJDF filmmaker who recorded a men's camp developed a strong relationship with several of the men and offered to teach them simple filming and editing using iPads. As a consequence of the 'two way' approach employed in these interactions the MJDF was able to respond to the men's need and procured the necessary equipment through a collaboration with the Telstra Foundation, along with support from the Groote Eylandt Country Women's Association and NT Library.

One of these men has maintained a strong interest in filmmaking. He has since been engaged by several independent filmmakers on the island to film, produce and edit local productions. He has also made the transition as actor and director (www.bakalathefilm.com and the Telstra Foundation's short promo https://vimeo.com/134169789) . Most importantly, he is now the official filmmaker for cultural ceremonies. The opportunity affords him a new respect for his ability to share these important occasions.

Equipment

The provision and maintenance of equipment in remote Aboriginal communities is complicated by isolation, climate and freight distribution. The MJDF has had an active equipment provision program from the beginning. Apart from an initial catch up phase, for clients who did not have basic needs such as beds and bathing, showering and toilet aids, most of the equipment provided has been outside of the scope of the NT Department of Health/Disability Equipment Program (DEP).[xxv] Where there were safety and care concerns - because of the lag time from prescription to delivery of government issued equipment, the MJDF has provided alternatives expediently; however, equipment provision for purchases eligible under government funded schemes has not been preferred policy.

Household products targeted to facilitate care (and reduce caregiver burden) have also been purchased – such as washing machines and dryers to manage incontinence, or air conditioners which assist in the management of thermoregulatory problems that occur in MJD. Innovative, non-standard equipment options have also been trialled, such as beach wheelchairs.

Common use, community based, equipment has been an important MJDF initiative to build overall community capacity. The purchase and installation of aircraft wheelchair lifts (DPL)[xxvi] and specialised aisle wheelchairs for Groote Eylandt, Elcho Island, Nhulunbuy and Darwin has enabled all people in the region who use wheelchairs (or have mobility restrictions) to access the Regular Passenger Transport (RPT) routes operated by commercial airlines. This has been a valuable cost saving alternative to relying on expensive chartered flights for both individuals and government funded services, such as the Patient Assisted Travel Scheme (PATS) and respite agencies. A solar powered swimming pool hoist and hydrotherapy equipment has been installed on Groote Eylandt, enabling access to the public swimming pool and hydrotherapy. Likewise, a corporate grant has facilitated a trial of the use and efficacy of Apple iPads to meet communication and SEWB needs. The trial has morphed into a research project assessing the complex communication needs of people with MJD. The MJDF's business model is an important element enhancing the equipment program. It enables cost effective delivery and innovation of the equipment program and has secured corporate sponsorship of barge freight from Darwin to remote coastal/island communities.

Education

The MJDF has gradually developed a robust education program delivering targeted information about MJD to doctors, health and care professionals through in-services, conference presentations, community sessions, and through peer reviewed journal publications and by supporting and enhancing the genetic education and counselling services provided by the NT Department of Health.[xxvii]

Resources are continually being developed in response to issues experienced and include: Medical Protocols (evidenced based best practice guidelines and literature reviews) focused on MJD symptom management. Provided in three forms, these are tailored to cater to health professionals, careworkers and families. Carers' education resources outline common issues and strategies for managing the care requirements of people with all stages of MJD and are designed to be used by both family carers and professional carers. The MJDF has also produced audio-visual teaching resources documenting clinical management of MJD, the preferred method for engagement with families ('Proper Way') and genetic education.[xxviii]

[xxv] *Previously Territory Mobility and Equipment Scheme (TiMES) now Disability Equipment Program (DEP) necessary equipment is provided free of charge after means testing *MJD clients receive the Disability Support Pension (DSP) and were eligible for all levels and contributions waived.*

[xxvi] *The Disabled Passenger Lift (DPL) is manufactured by AMSGSE (Tasmania): http://www.amsgse.com.au/*

[xxvii] *Prior to 2008 Genetics services were provided by SA Health; from 2008 to 2010 genetic health services were outsourced/contracted to QLD Genetic Health Services. There were no services from 2010-2014. From July 2014 Victorian Clinical Genetic Services are the contract holders.*

[xxviii] *All MJDF resources are available at: http://mjd.org.au/19-resources.html*

Research

Community leaders on Groote Eylandt have been very clear about the importance of research. The generous resources that the ALC has provided have been firmly targeted to engage the best researchers in the world to work towards treatments that will slow the progression of the disease and assist management of symptoms. The flexibility allowed by the untied funding has enabled problems with sleep, communication, continence, and mobility to be early priorities. The MJDF has also hosted an international research conference in 2015 which was attended by researchers from all over the world. This provided an invaluable opportunity to grow collaborations and determine the best areas in which to direct future research activities.

Consolidation

As the numbers of people experiencing MJD have grown, service priorities have changed as the organisation maturd and its resources were consolidated. The early focus on gap filling has been tempered by the gradual implementation of tailored services by the MJDF and some external reviews, such as the NT Government disability equipment program revamp.[xxix] The advent of the NDIS created both opportunities and challenges that required thoughtful consideration and close consultation with MJD families. A recent MJDF organisational review has cemented a new organisational structure, reflective of an established service provider in the region. Moving forward, there will be an even better capacity to deliver tailored services 'two-ways' and enhance the research program to prioritise Aboriginal co-researcher development.

The current core MJDF services have been streamlined. The equipment program was consolidated within the renamed 'community services' program and an increasing nexus is evident between the research and education programs. Each of the *Research, Education, Community Services and* Advocacy programs are underpinned by a strong commitment to appropriate governance and measurable key performance indicators and these are detailed in the new MJDF strategic plan (2018-2021).[xxx]

Utilising a combination of resources drawn from NDIS plans and pre-existing resources, clients of the MJDF and their families in remote communities are now able to access occupational therapy, physiotherapy, and speech therapy at home and on country, at a minimum every 6 week or weekly for 2 locations. As the NDIS rolls out and assistive technology is incorporated into plans, there is evidence that provision of adaptive equipment is occurring in a more timely manner.

[xxix] *Gatter Review (2009) "Review of the NT TIMES Scheme and SEAT Service"*
[xxx] *The MJDF Strategic Plan can be accessed here: https://indd.adobe.com/view/a86fd553-4a18-4efe-bc6b-54e31a8b4360*

Disability Services delivered differently

Client led service delivery

Excellent and consistent advice and oversight by senior Aboriginal community members in the MJDF's community of origin (Groote Eylandt) set the pattern for engagement in other communities. The services have been developed and delivered in direct response to conversations with families. 'We should ask them' has been the familiar response by our ACWs to ideas and initiatives that are contemplated. We have learnt that far from being non-compliant or unreceptive to interventions, clients and families alike have been open, engaged and keen to try new things. It has been critical not to assume anything. Working across different family groups, programs have been tailored to maximise engagement based on local preferences and cultural rules.

The disability specific expertise of the professional staff, an attention to research initiatives that may be helpful and taking time to work through questions, challenges and delays have been the cornerstones of maximising engagement by clients with the activities of the MJDF. Being prepared to step outside the scope of traditional disability care and analyse and respond to the 'pain points' experienced by families has required courage. There are also additional risks associated with this model and the MJDF is governed by a Board of Directors with dedicated Risk and Finance Subcommittees who analyse and advise regarding organisational risk. There have been occasions where questions have been raised about the 'model' the MJDF has implemented. It is not unusual for the activities we conduct to take longer, cost more and to involve many more people than 'the client'.

Over time, we have learnt to reflect regularly and adapt programs to ensure that people are best positioned to engage with them. We have also learnt that there are some compromises that cannot be made. Travel to assist clients living remotely for example is expensive; plans can and do change at short notice. Central to decisions about managing resources in this context has been a commitment to 'do what we say we will do' and adjust capacity accordingly.

The resulting service model is a hybrid – not purely disability not community service nor health, but an amalgam based on client centred strengthening of families and developing capacity.

The MJDF therapy programs are illustrative of this approach. People who have MJD can be independent for longer, the earlier and the more robustly they engage with physical activity.[22] The degree of independent function a person with disability can achieve is correlated with their own physical and social and emotional wellbeing, and that of their carers'.[24]

The starting point for the 'Staying stronger for longer' program was an opportunity to implement therapeutic activities in a Western bio-medical oriented framework. The intention was to introduce activities such as hydrotherapy and hand therapy to assist in the prevention of disabling contractures and provide opportunities to work on the components of safe transferring. Facilitating the delivery of this with ACWs and families involved several iterations. Over time, this included tailoring sessions for gender and avoidance relationships, determining appropriate swimming attire and introducing individual night time sessions. Factors such as weather and cultural obligations led to a block orientation for structuring therapy, rather than the original regular weekly sessions. Ultimately, it evolved into the 'on country' program. In this iteration, the western bio-medical interventions are modified to incorporate culturally important activities such as fishing and bush food collection in homelands. Transfers in and out of 4WD vehicles, sand walking and calling out to family on the beach all translated into important therapeutic results, with functional implications that are readily understood and prioritised.

Research and Education

There is very little precedent to guide the work of the MJDF. A constant finding over the past decade has been that the better informed people are about an activity and its potential impact, the more time they are given to consider issues, the more inclined they are to engage with that activity. It has been critical to develop relationships with families that are robust enough to consider the issues scrupulously and avoid gratuitous concurrence and subsequent disengagement.[25] This has resulted in service models being adapted and recreated. Where there are no protocols and practice guidelines it has been necessary to generate them. Many of the initial research initiatives conducted have concerned the value that MJDF families place on interventions – 'what is important to them' - and prompts engagement.

Image: Kaitleen Garrawurra Photo by: Nick Kenny (MJDF)

Outcomes and demonstration of efficacy

Engagement through involvement leads to ownership.

The quality and safeguards framework assessment conducted prior to support provider accreditation with the NDIS made it unequivocally clear that the model the MJDF implements works.

"MJDF adopts a holistic person-centred or family-centred approach that puts the needs of the client firmly at the centre of the process and is based on their views and wishes. MJDF staff discovers and act on what is important to a person. For them it is a process of patient continual listening and learning, focusing on what is important now to the person and what is important for their future. Actions are taken in alliance with the person, their family and their community. The outcome is a strengths-based practice which emphasises people's self- determination and strengths. This practice within this organisation is definitely client led" (NDIS Q&SF Assessment March 2017).

The MJDF is also involved in emerging areas such as genetic education, where standard ethical considerations and protocols are unfamiliar and of questionable relevance.[26] In the biomedical model, this is an arena governed by a priority on protection of the individual's rights and privacy. They are not priorities that sit comfortably with a society based on collective decision making and completely different family structures – where the nuclear family is merely a subset of the whole, and where information is owned by many.

The first step has been to immerse the genetic professionals in the culture and allow time for relationships to develop. Partnering with ACWs provides guidance about how and where people should be approached to discuss family information – and who should be involved. It is delicate and time-consuming work; however, it is critical to ensure people feel comfortable in these interactions and that their perspectives are considered and valued. The full value of the changes that genetic counselling may impart over time has yet to be determined; however, over time more family members have requested consultations and have begun to engage with information about the transmission of the disease within their families, their individual disease status and the risks to them and their children.

MJDF alignment to NDIS activity areas

Many of the activities of the MJDF align well with the NDIS Information Linkages and Capacity (ILC) framework. The framework is consistent with our client centred, lifelong, and mixed mode family-oriented service model. This section demonstrates this by case studies and examples.

NDIS Information, linkages and referrals

The MJDF worked intensively to support the NDIS transition, preparing clients and families for the changes by providing targeted information well in advance of planning meetings, facilitating interviews and assisting with translation and physical communication needs.

As local opportunities to engage with more therapeutic and disability specific services have expanded, the MJDF has prioritised providing easy to understand information about disability services. The aim of this program is to increase their knowledge about and connection to services and facilitate their exercise of choice.

The MJDF also assists clients to access information about mainstream services and interventions that may be of value to clients and their families. The MJDF has collated service directories by location and topic to assist.

Capacity Building for Mainstream Services

Over the course of its history, MJDF staff have engaged with a variety of mainstream services to provide information about MJD to assists our clients' capacity to engage with services and have 'good lives' in community. This has taken many forms. One example of this is illustrated by the upskilling of local police that has been necessary in some locations, because the initial symptoms of the disease mimic alcohol intoxication and clients have been inappropriately targeted. Support to use air travel has been achieved by partnering with and educating local providers. Sessions have included information about communicating with clients, safe transfers and managing mobility equipment. Innovative technology previously unavailable in Australia has also been sourced and donated- such as the aircraft wheelchair lifts (DPL) and aisle wheelchairs.[xxxi] The MJDF also collaborated extensively with the NT Department of Housing during the Commonwealth Government's Strategic Housing and Infrastructure (SIHIP) program. Assistance was provided to model the disability supports needed and to ensure housing design was fit for purpose.

The MJDF education programs continually provide information to a wide audience about the disease, its transmission and its impacts. Health and community service professionals require specific information to assist in decision making when engaging with people who have MJD. So do Federal, State/Territory and Local Government departments, such as the NT Department of Housing and Centrelink. An understanding of the nature of the disease and what requirements it will predicate are essential in policy decision making and about public resource allocation. Accordingly, the MJDF looks for opportunities to improve knowledge, and capacity to assist. Interactive workshops are held regularly, and in-services are also conducted on a case by case basis. Cultural awareness training is an integral component of the education provided and clients regularly assist with providing the training.

The MJDF's previously described ACW recruitment model provides supported, specialised, training for local community members and has been successful at a personal and social level – allowing the individual employees to gain benefit, as well as improve the profile of the disease and the perception of people with disability in the community.

[xxxi] *Vincent Aviation was an inaugural and important sponsor of the MJDF.*

Miss J

Employment opportunities in remote Aboriginal communities are generally sparse, limited in scope and poorly resourced to support mentorship appropriately. Limited infrastructure magnifies this for people who have physical disabilities. 'Right' family relationships (ie kinship connections) and personal experience of the disease, however, are the most critical elements of success for MJDF ACWs. Many of the ACWs employed within the MJDF have MJD and are closely related to other clients. The disease impact on the ACWs and their close relationships adds an element to the workforce administration that requires careful and regular review. Managed well, however, the benefits are substantial. A longstanding employee of the MJDF demonstrates the profound long-term benefit that can be gained from this strategic workforce practice.

Miss J was originally employed by the MJDF when her symptoms were mild. Partnering with the local MCS, the early focus of her work was assisting the delivery of MJDF services to a cohort with severe MJD. Over a period of 7 years she has also developed a strong bio-medical understanding of MJD that is complementary to her Aboriginal understanding of the disease.

Through her role in the MJDF, emerging research about the benefit of sustained physical activity has been enthusiastically received by Miss J. Having personal experience of the benefits, she is a strong advocate for engaging with physical activity within the MJDF. When a new research project commenced to consider the components a physical activity program needs to increase acceptance by Aboriginal people who have MJD and facilitate their engagement, she became a co-researcher. In this role she has developed a range of new research skills, has presented at national conferences and has identified further formal education as a personal and professional development priority. This evolution of the role into less physical tasks allows her to maintain employment, contributing to her own wellbeing, her family and the MJDF body of knowledge even as her disease progresses.

The MJDF has also been the recipient of a Community Inclusion and Capacity Development (CICD) grant from the National Disability Insurance Agency. One of the components involves conducting a feasibility study (2018) to consider the opportunity/viability on Groote Eylandt of establishing an Assistive Technology consortium for specialist allied health services, equipment procurement, and local repair & maintenance. If the concept is feasible and the consortium subsequently commences, this will involve the training and mentoring of local Aboriginal community members. It is envisioned that this could provide local employment opportunities as well as improve the safety of all people with disability by the more efficacious repair and maintenance of their equipment.

Community awareness and capacity building

Supporting Carers

Ensuring carers are supported is integral to the MJDF model. Carers are also regarded as clients by the MJDF. Engagement with the whole family is core work for the MJDF community services team and it provides opportunities to discover issues for carers and work on solutions. Family carers are frequently also either at risk or experiencing early symptoms of MJD. The impact of multiple generations simultaneously affected increases the complexities of the MJDF's work. In addition, some carers are also employed within the MJDF. Strengthening carers requires careful consideration. It is important to remember that people may hold several of these roles simultaneously and to provide support flexibly. For example, it is common for carers to recognise their need for assistance, or a break from care, but carers also want to structure relief 'respite' opportunities together with the client and other family members. In the MJDF model this is legitimised and facilitated by ensuring that there are appropriate alternative external supports brokered. Links are also made with other formal care support structures – such as young carers' programs and supported residential programs.

Mr B

Caring for a loved one who has MJD is physically and emotionally demanding and long-term. The disease progresses over more than 20 years for most people and impacts every body system. The roles that family members previously had in relation to each other are overturned and the disease dominates. Children become carers, husbands do the work of wives and vice versa. In remote Aboriginal communities the lack of other formal, professional care alternatives places a disproportionate burden on family carers. It is frequently impossible to maintain a job and engage socially in the community. For the MJDF, prioritising the needs of family carers is a natural consequence of a holistic model. This extends to the roles that they may desire and be able to take on within the organisation.

Mr B is the carer for his wife who is entering the severe stage of MJD. He has been the community worker/bus driver for the MJDF for 6 years. During this time, his wife has been at his side and they perform the job as a team. This enables him to attend to her as well as earn an income. It provides them both with social connection as they perform transport and community access support for other people with MJD in the community. They are skilled and familiar with the social, health and other issues the other clients confront. This expertise places Mr B and his wife in a good position to advocate and pass on messages relayed to them by the other clients to the clinical team.

The flexibility of the role and the frequent interactions with the skilled staff of the MJDF also means that there are many informal respite and assisted care opportunities built into the role. Like many people living with MJD, Mrs B is currently at the stage where she is clinically ready to use, but resists, a wheelchair. Without a mobility aid, she relies very heavily upon Mr B as this disease and life transition unfolds. The role Mr B plays enables the couple to have more support and visibility in this period from the MJDF allied health team. Consequently, the team are able to assist with modifying transfers and other supports needed. Mr B is a dedicated and committed carer and employee and the couple have a vital connection and role, both for their families and their own situation, through the paid employment role.

Community collaboration

Worldview determines how disease and disability is contextualised[27]. In the remote Aboriginal setting there exists a spectrum of understanding, combining traditional and bio-medical western perspectives. It has been important for the MJDF to work closely with families to establish their own conceptions of MJD and determine how this is best represented in the wider community. The concepts of 'shame' and 'blame' discussed previously in this report are complex and multifactorial and have resulted in isolation and suspicion for the MJD families in some cases. Important local organisations such as Aboriginal land councils and traditional owners' collectives are engaged in order to develop appropriate structures. In the case of the Anindilyakwa Land Council on Groote Eylandt and applications to the ABA this has resulted in significant resource allocation to people with MJD.

At a local level, the MJDF has improved the access to several community buildings on Groote Eylandt and at facilities in other locations by the installation of permanent and temporary ramps. During the SIHIP program, the MJDF advocated for the construction and repair of driveways to new homes that would otherwise have flooded and resulted in the clients being isolated in their new homes. Other activities that have assisted the local community to understand more about people with MJD have been the 'on country' therapy sessions which have frequent guests from the local community and occasionally, corporate sponsors of the MJDF such as senior visiting South32 officials.

Peer Support

Despite being a rare condition, MJD occurs in families and is intergenerational. In fact, one of the challenges in supporting people is that very visibility. Clients and carers alike have witnessed close family members' deterioration over lengthy periods. They are well aware of the disease's trajectory and its prolonged duration. As the MJDF has grown, it has been interesting to see how the need for peer support has eventuated. The MJDF has found that people from different locations are keen to spend time with others who have the disease. This is particularly true for those who come from communities with smaller numbers of people living with the disease. MJDF has facilitated several inter-community visits for the 'Holidays of a Lifetime' program to providing opportunities for engagement with others who share a similar journey.

Individual capacity building

Choice and control is the driver for all the MJDF's activities. In accordance with Aboriginal preferences, choice and control is modified in the MJDF's approach to consider the family and not just the individual's perspective. Clients have directed the delivery of supports to maximise their engagement by requesting group sessions. This has been very successful and most therapeutic activities are structured accordingly. Another important capacity building element has been recruiting people affected by MJD within the ACW and Co-researcher positions. The positive impacts on health and wellbeing for those in appropriately structured and supported employment affect individuals and families alike.

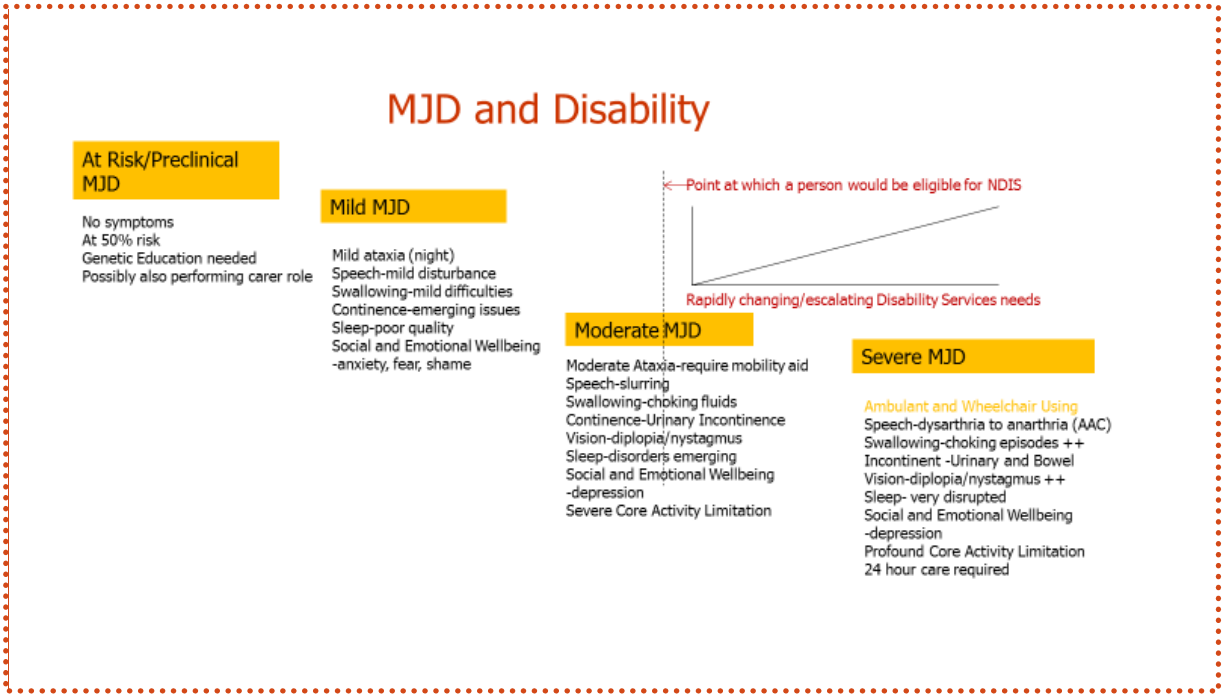
Minimisation of support needs escalation

MJD is a progressive degenerative condition, which eventually results in total incapacitation. Therefore, there are some practical limitations to the ability of clients to achieve total independence.

The MJDF has experience spanning more than a decade supporting people as the disease progresses and has devised a classification process for each of the stages of the disease as outlined below (Fig.3). The supports that are likely to be needed at each stage have been mapped. In preparation for the roll out of the NDIS, these were compiled into 'benchmark plans' which outline the best practice supports.

An individual's journey thorough the disease process is unique. However, there are clear periods during which the person with MJD, and therefore their family, is likely to require an intensification of support. The supports may be related to increasing physical needs or a deterioration of social and emotional wellbeing – or a combination

Figure 3. MJD and NDIS eligibility



Research indicates that early and sustained physical activity and the maintenance of social and emotional wellbeing are key to slowing the impact of the disease[22] and preserving independent function.[28] In the early stages, the mainstream supports that assist to minimise the impact of the disease involve health and wellbeing activities, such as participation in sporting and fitness activities and opportunities to engage in culturally important happenings like ceremony or getting 'on country'. Links to these opportunities are discussed with clients and engagement facilitated by the MJDF team. Likewise, maximising employment options can be an important means of support, enabling structured engagement with the community and mitigating social isolation.

MJDF alignment with Rural and Remote Strategy

Senior staff of the MJDF were privileged to have contributed to the development of the NDIS rural and remote and Aboriginal and Torres Strait Islander strategies. Accordingly, there is genuine alignment with the principles.

Accessibility

The costs of providing services in the remote context have frequently been blamed for the poor level of support provided to people living with disabilities. Ensuring services are accessible entails being located in community. There has been very poor access to therapy and accessible transport in remote communities. The MJDF has focussed on being in communities to develop local capacity. Services are delivered in community, in locations that suit the participants.

Appropriate effective supports and creative approaches

Genuine engagement with clients and families is the first step to developing appropriate effective supports which frequently requires creativity. Responding to clients' expressed needs and tailoring supports to meet those needs is an iterative process and requires a culturally safe construct. Over a decade the MJDF has demonstrated this capacity. The 'two-way' model implemented by the MJDF is derived by Aboriginal people and allows first language support which minimises the potential for misunderstanding and disengagement for cultural mistakes. The approach facilitates genuine engagement. The incarnation of the MJDF therapy program[xxxii] is an example of the way the supports have evolved in consideration of what works to support people best. Research conducted by and in collaboration with the MJDF is likewise initially oriented to finding out how families understand and interact with the research question. Current projects are investigating what is important to them about mobility and communication. These are the cornerstone questions that will guide the development of appropriate and effective supports.

Collaborative partnerships and building remote community capacity

It is especially important in resource impoverished remote Aboriginal communities to enhance existing supports, build capacity and augment additional resources. The MJDF has a history of sharing information and resources and works with a range of local providers, including the local Regional Councils (who tend to provide the majority of the daily personal care supports in NT remote communities), to enable the delivery of the best supports to clients. The ALC and Groote Eylandt and Bickerton Island Enterprises (GEBIE) collaborate with the MJDF to resource ACW supports.

In addition, the fundraising strategy of the MJDF attracts corporate and philanthropic sponsorship of the disability and Aboriginal health domains. The Telstra Foundation's support of the MJDF's communication research and South32's support of the therapy programs exemplifies this.

xxxii Refer 'MJDF Service Model' – Improved Services p17.

MJDF alignment with Aboriginal and Torres Strait Islander Strategy

Proper Way engagement

The MJDF 'two way' model is the practical means by which the MJDF illustrates the principles of the ATSI strategy in its service delivery. It exemplifies 'proper way' engagement. The model demonstrates the power of utilising knowledge and engagement with the culture, language and relationships of clients and their families in delivering disability services.

The MJDF enjoys a very high level of engagement and is committed to continuous improvement. There is much still to learn in this context; however, the building blocks are firmly in place and the exclusively Aboriginal clients of the MJDF are well placed to continue to guide the organisation's work.

Image: Glen Helen Gorge, Central Australia Photo by: Melinda Fajerman (MJDF)

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