



# **Submission to Parliamentary Joint Standing Committee on the National Disability Insurance Scheme (NDIS): Inquiry into transitional arrangements for the NDIS**

## **An MJDF Submission to the Joint Standing Committee**

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## Background/Introduction

### Machado Joseph Disease Foundation

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal and Torres Strait Islander people and their families 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 northern Queensland.

### 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 remote or very remote Aboriginal communities<sup>1</sup>. Those who live in urban centres such as Darwin, Alice Springs or Cairns have tended to do so in order to access specialist disability or high level support services as their disease progresses.

These maps show the locations where the MJDF's clients live and where the MJDF provides services.



<sup>1</sup> 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>



## **MJD Foundation Services**

The MJDF conducted a Disability Audit in 2013<sup>2</sup> in selected communities in North East Arnhem land and the NT Gulf region. The Audit analysed the current prevalence across all disability types 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 do not access the range of services they need because the capacity to provide them does not exist at community level. In very remote communities the bulk of the existing services are provided by regional councils and consist of meals on wheels, limited transport and some day respite and personal care. Even these inadequate services are not always available in some communities and are extremely variable both between communities and within communities over time. These limitations are strongly linked to availability of personnel and resources such as vehicles. Out of community respite in urban centres is frequently used as an urgent intervention in stressed care scenarios and is, in fact, de-facto care. High support needs clients require frequent urgent/crisis respite, and preventative provision to low and moderate needs clients is problematic.

Consequently, to improve the quality of life for people with MJD, the MJDF has endeavoured to 'fill the gaps' left by inadequate government services by facilitating and implementing vital treatments and interventions for clients that would otherwise not be available. These services include: occupational therapy, physiotherapy, and speech therapy, the provision of adaptive equipment, social and 'on country' outings, communication (iPad) training, and assistance to access community services. For those who have been relocated to receive care in urban centres 'kin connect' programs allow return visits to home communities.

The MJDF also provides education and research services. 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.

## **MJDF's Way of Working with Client, Family and Community**

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

To achieve this client-centred approach the MJDF's engagement model is to always partner non-Aboriginal staff with local Aboriginal staff called MJDF Aboriginal Community Workers (ACW). The role of the ACW is to reflect family support needs, facilitate and attend MJDF client home, clinical and other visits with relevant non-Aboriginal MJDF staff; interpret at medical, allied health relevant meetings and appointments; educate and mentor non-Aboriginal staff/volunteers about relevant elements of Kinship and Culture; interpret and translate MJDF resources into first language; travel to other communities to talk about MJD and the work of MJDF and plan/attend respite trips as appropriate.

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<sup>2</sup> Disability Audit – NE Arnhem Land NT Gulf – A Snapshot of Indigenous Australian Disability in the Very Remote Communities of: Groote Eylandt Archipelago (Angurugu, Umbukumba, Milyakburra); Galiwin'ku; Ngukurr (including Urapunga) - [http://mjd.org.au/cms/file\\_library/Other/Other\\_592.pdf](http://mjd.org.au/cms/file_library/Other/Other_592.pdf)



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

*“clients, their families and their kin willingly engage with the organisation, and make decisions based on cultural and social needs. Family, extended kin networks, and community members are involved in support delivery. Clients interviewed were open, direct, confident and engaging about their experiences with MJD and how the Foundation was helping them and their families.”<sup>3</sup>*

### **Submission Purpose**

The purpose of this submission is to set out MJDF’s experiences to date in relation to paragraph (b) of the Joint Standing Committee’s terms of reference “the consistency of NDIS plans and delivery of NDIS and other services for people with disabilities across Australia”, having regard to paragraph (v) of the terms of reference “the impact on rural and remote areas, with particular reference to Indigenous communities”.

The submission will therefore cover the experience of MJDF and its clients (Indigenous people with MJD) with the transition to the NDIS, predominantly in very remote communities in the Northern Territory.

## **Planning under the NDIS**

### ***MJDF Experience with Planning***

The MJDF has clients living in supported accommodation in Darwin and in very remote communities across East Arnhem Land. Both these areas started rolling out the NDIS from 1 January 2017.

Clients in supported accommodation in Darwin have severe MJD and experience the highest needs of the clientele of the MJDF, equating to profound core activity restrictions<sup>4</sup>. These clients are largely non-verbal and are unable to move independently. Clients in the very remote communities experience MJD across a wide spectrum of support needs, ranging from preventative early intervention to intensive therapeutic supports and personal care – equating to mild, moderate and severe core activity restrictions<sup>5</sup>.

Planning for clients with MJD is complex, as the disease is multisystem and degenerative. The urban and very remote locations also have vastly differing service provider profiles.

The MJDF is a specialist organisation with cohort specific knowledge. In order to ensure that the range of circumstances and potential support requirements experienced for each client were profiled, the MJDF undertook preparation activities including:

- goal setting with clients using a modified version of the NDIS client planning document, to develop client care plans specifically referencing the change to NDIS;
- development of benchmark plans for each ‘stage’ of MJD in urban supported accommodation

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<sup>3</sup> Report of MJDF Services Assessed by HDAA to the Northern Territory Quality and Safeguarding Framework, 31 March 2017.

<sup>4</sup> Australian Bureau of Statistics, 2009, Disability, Ageing and Carers, Australia: Summary of Findings, 2009, cat.no. 4430.0, Australia

<sup>5</sup> Ibid



and very remote locations. These plans were made available as reference material to the NDIA personnel who engaged with MJDF clients;

- Staff of the MJDF proactively engaged with staff of the NT NDIA office both at the senior management and operational levels to facilitate engagement and support of clients; and
- Upskilling of MJDF Managers of Community Services (MCS) and ACWs regarding the NDIS to ensure that concepts requiring translation were clear.

There was a consistent and clear approach within the MJDF and significant preparation prior to planning beginning. This preparation was absolutely necessary to help clients get the best plans possible. The MJDF did not receive any funding to complete this work. Even if there had been Local Area Coordinators (LACs) in place 6 months before the roll out, they would still not have been able to fulfil this role because they would not have had specific knowledge of the disease nor the existing relationships with the clients, their families and communities.

Despite this preparation by the MJDF, the variable quality of planners has meant that clients of the MJDF have experienced a range of planning outcomes. There has been a marked difference in the quality of plans devised for a client with MJD, dependent on:

- the disability/health specific experience, disease knowledge and approach of the NDIA planner particularly referencing cultural and family orientation. There has been a disconnect evident between the community based, relational and collective decision making process practiced by the MJDF and the deliberative, individualised NDIS model;
- currency of the NDIA planners knowledge of local support services and providers and the service providers intentions regarding providing services under the NDIS. Registration for activities did not always translate into availability of services;
- support available to the client – family and interpreters skilled in explaining NDIS concepts;
- whether the MJDF or local support services known to the client were advised of the planning meeting in advance and were able to be present to support the client;
- willingness of the NDIA to 'rebuild' a plan that was incorrect or inadequate; and
- timing and collaboration for planning activities - clarity about the planning process and the supports offered to participants in these meetings.

Planning for people with disabilities in very remote Aboriginal communities is complex and there are key issues requiring careful consideration for it to be successful. Chief among these is the need for the participants to be well informed about the transition, their options and how this will correlate to 'choice and control'. Unfortunately, the process followed was not always allowed the time, translation and integration into family and community that was needed. It appeared to be driven by a requirement to have a quantum of plans compiled. Staffing appeared to change frequently and there was minimal understanding of the complexities of engaging within these communities viz a viz transport, interpreter, local service and infrastructure availability.

The service provider 'market' is difficult to determine without a presence within community and close consultation with individual managers. The NDS recently reported that up to 54% of registered providers are inactive, with 25%, mostly small NGOs performing 80-90% of the business<sup>6</sup>. It was apparent that at the time of planning the NDIS planners were not aware of the current intentions of the local service providers with regard to provision of services for which they were registered. This resulted in options being put before participants that were not in fact viable. In an already complex space this led to confusion for participants and service providers and a real risk of disengagement.

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<sup>6</sup> NDS Essential Briefing Darwin July 31<sup>st</sup> 2017



Interpreter services alone, while necessary, are insufficient support. Resources and explanatory material in pictorial and first language format was minimal. A specific focus on the needs of the individual is contrary to the family/collective oriented cultural norms and so needs careful introduction. Despite best intentions, plans were developed in some instances without the assistance needed to ensure that all of the information was available.

With clients located remotely in places such as Elcho Island and Groote Eylandt, there was sometimes inadequate notice of when the NDIA would be visiting those places to talk to clients with MJD about access, and conducting planning meetings (although this improved as time went on due to the MJDF advocating strongly back to the NDIA). Visits were too short, travel plans often poorly executed and planners were often unfamiliar with the community and the local resources and service landscape (e.g. sometimes resulting in plans including support coordination that was not in fact available). In the urban context, there were multiple planners and LACs involved in meetings, few had local or cultural knowledge, and there was contradiction in the explanation of rationales and approaches taken when building plans.

Discussion with NDIA LACs and planners revealed that there had been some sensible consideration given to the specific issues experienced by clients in very remote communities. Additional hours had been approved for 'Coordination of Supports' and respite, referencing the thin provider market, however it appeared that there had been 'maximum allocations' predetermined and ascribed.

NDIA Planners and LACs had minimal understanding of the nature of MJD and the therapeutic services required, opting to provide for therapy assessment and allocation of resources *after* the plan was handed over. Consultation with the allied health professional staff of the MJDF (who have close contact with the client and MJD cohort specific knowledge) and reference to the MJDF benchmark plans at the time the plan was developed would have ensured that the allocations were included and there was no delay to the services commencing. Frequently, at a handover meeting (when MJDF was able to be present) the planner was advised that the proposed plan was incorrect or inadequate for the client given the stage of the disease. This resulted in the NDIA having to revise the plan, sometimes more than once for the same client.

The initial planning meetings attended by MJDF staff gave the overwhelming impression that NDIA planners were only including in plans the supports that clients had previously had under their NT Government support plans. As MJDF services are independent of the NTG services (ie. MJDF has never received funding through the NTG), they were overlooked for inclusion in the plans. There were limited attempts to look at the needs of the clients over the next 12 months, or consider their goals or what supports they would require as the disease progressed.

It is however important to note that where planners were experienced in working in Aboriginal communities and collaborated effectively with the MJDF, vastly different results ensued. There are some excellent planners who worked well with the clients, their families and the MJDF, developed an understanding of the disease, acknowledged the goals of the client, and tried to ensure the plan would work well for the client over the next 12 months. These planners were able to take the time necessary and their communication skills were excellent.

This diversity in the quality of the planner led to varying quality in the plans. The MJDF has clients, at similar stages of the disease, who have vastly different plans according to where they lived, because the planner was different. This may necessitate requests for internal reviews if a request to revise a plan is refused.

The handover of plans has also proven problematic and there has been ineffective and inconsistent communication with multiple NDIA staff sending emails to multiple recipients containing personal details of participants.





This experience shows that Aboriginal and Torres Strait Islander people in remote areas are most at risk of experiencing poor outcomes under the NDIS if they do not have a trusted person to explain the process, to attend the planning meeting with them, and help them navigate the process and implement the plan. Even then, utilisation of all their plan's resources will depend on the availability of service providers in remote areas that are willing and able to undertake the work and that have the trust of the Aboriginal and/or Torres Strait Islander person with disability, their family and community.

It also shows the importance of having planners that understand the NDIS processes, are current in their understanding of service provider intentions, have knowledge of the specific disease, can communicate well with Aboriginal and Torres Strait Islander people and are driven by the need to achieve a quality plan for each person rather than a specific number of approved plans. If all of the planners that worked with MJDF clients had had this approach, it would have saved the NDIA and MJDF time and resources consumed in revising initial plans that were inadequate or incorrect.

Because of the inconsistent quality between planners, it would be sensible to have a process whereby plans can be revised without the need for a formal request for a review. This is occurring in some cases, but should be made more systematic.

For Local Area Coordinators to have an impact on Aboriginal and Torres Strait Islander people in remote areas, they would not only need to be in place at least for 6 months before planning, but also have knowledge of the specific disease they are dealing with, as well as be known by and have the trust of, those people and their families and communities.

Finally, very few planners have particular knowledge of MJD, its symptoms and disease progression. MJDF is well placed, because of its specialist knowledge, to educate planners and the NDIA generally about the disease. It is imperative that this specialist knowledge is taken on board by planners in developing a plan that will address the needs (currently and over the next 12 months) for a person with MJD. Some may argue that there would be a conflict of interest in this because MJDF as a service provider could influence the content of a plan for a person with disability. However, with Aboriginal and Torres Strait Islander people in remote communities, if you do not have the trust and respect of those communities, then they will not engage with you as a service provider. Their consent to the presence of the organisation at planning meetings and their willingness to engage is key. MJDF would not have been able to do the work it has done over the last nine years without the agreement of the families and communities with whom it works.

## Support Coordination under NDIS

### *MJDF Experience with Support Coordination*

The MJDF has concerns about the 'fit' of Support Coordination, as envisioned by the NDIA, with the needs of the MJD cohort and the best practice supports they need. People who have long-term, degenerative, neurological conditions such as Machado Joseph Disease, experience highly complex, increasing needs – these rarely stabilise and certainly never remit. For those in the MJD cohort this is usually occurring in a very remote, impoverished environment, over an unusually extended period. This will create a tension with the idealistic, time limited, capacity development orientation of NDIS support coordination<sup>7</sup>.

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<sup>7</sup> The NDS notes that there have been criticisms of this being an unrealistic goal for some participants. [http://www.disabilityservicesconsulting.com.au/resources/support-coordination-on-the-money?utm\\_source=DSC+Contacts&utm\\_campaign=eb0c744071-EMAIL\\_CAMPAIGN\\_2017\\_02\\_20&utm\\_medium=email&utm\\_term=0\\_153f43591e-eb0c744071-15600351](http://www.disabilityservicesconsulting.com.au/resources/support-coordination-on-the-money?utm_source=DSC+Contacts&utm_campaign=eb0c744071-EMAIL_CAMPAIGN_2017_02_20&utm_medium=email&utm_term=0_153f43591e-eb0c744071-15600351)



While there is no doubt that an orientation to increasing independence and autonomy for clients is very much a desired outcome, there are issues which require specific consideration and safeguarding for people who have MJD. The Support Coordination component for people with moderate and severe MJD will not be able to be confined to initial time limited support. The MJDF has experience and data from meeting client needs spanning 9 years, indicating that the needs of this cohort will require Levels 2 and 3 Support Coordination as the disease progresses (and not 'time limited').

The MJDF is registered for Support Coordination and has commenced this role for several clients in the last 8 weeks. Experiences of Support Coordination by the MJDF are therefore still limited, however there are several live issues. These relate to the structure of the support coordination role as well as the mechanics of managing the supports required. The issues are that:

- the NDIA does not appear to have a clear picture of the actual Support Coordination options available in communities, which is likely to be one of several negative consequences of accreditation and registration processes running concurrently. This has led to requests for services for Support Coordination being fielded by organisations who are not registered or not available/willing to do the role;
- there is no defined structure for addressing support coordination needs or best practice guidelines provided by the NDIA. The MJDF has developed a Support Coordination procedure that actively encourages collaboration with other registered support providers which is essential in the very remote/thin market environment;
- the Portal is missing functionality to allow a Support Coordinator to see the overall client plan including all service bookings, payment requests for all support providers and funding remaining in the plan. To remedy this the NDIA NT has agreed to provide monthly remittances to Support Coordinator organisations and require them to track this in a spreadsheet. This is a convoluted inefficient mechanism that will place undue pressure on smaller agencies; and
- transitional arrangements have been implemented inconsistently. For clients of the MJDF this has meant that important supports such as continence aids, thickeners and supplements, are affected. The MJDF has funded these gaps on some occasions, however it is unclear that this will be reimbursed.

## **Remote communities and the NDIS**

### ***MJDF Experience in Remote Australia***

There are extensive barriers to service delivery in remote Australia which must be taken into account when considering how best to deliver services, especially for Aboriginal and Torres Strait Islander clients residing in remote communities.

Some of the characteristics of delivering supports in very remote locations include:

- Extreme weather conditions – cyclones, flooding, wet seasons and very hot and humid temperatures;
- High delivery/freight costs due to remoteness;
- High staff turnover due to remoteness, inadequate staff housing, dry communities, burnout;
- Culturally oriented community issues – closure for respect, gender matching for workforce/clients, family based decision making (and the fact that these are not adequately catered for in funding services); and
- Differences in the conceptualisation of disability in western medical terms in an Indigenous context.





These characteristics lead to many barriers, which in turn directly affect the 'market' in remote (and very remote) locations and significantly increase the unit costs:

- Lack of staff housing in community – with sharing being common;
- Lack of accessible housing for people living with disabilities;
- Lack of accessible vehicles (community transport) – and typically long wait times for vehicles to be repaired;
- Lack of other services (eg tradesmen to install housing modifications);
- Lack of accessible community infrastructure – due to weather extremes (lack of drainage, kerbs, gutters, graded access, street lighting, sealed roads);
- Limited housing and facilities makes provision of services in-situ in some communities problematic, necessitating Fly In Fly Out (FIFO) or Drive In Drive Out (DIDO) models of service provision; and
- Minimal or poor quality mainstream services (due to same barriers).

It may seem logical for an organisation to endeavour to make organisational changes to better structure itself to achieve efficiencies and reduce costs, however efficiencies that may be achievable in an urban setting, may not be possible in a remote and very remote setting, and especially for a charitable organisation targeting a specific/unique client cohort. For example, a basic barrier of 'lack of staff housing' or a small number of clients in a very remote community may completely prohibit an organisation from being able to employ staff with the optimal mix of skills for its workforce, resulting in highly qualified workers performing tasks that attract a lower financial unit price.

The MJDF has been operating successfully for 9 years in very remote Australia. It has achieved excellent outcomes for its clients by sourcing funding from a range of entities; Indigenous, corporate, philanthropic and government. This diversity in funding has enabled the MJDF to be innovative in the services that it provides to its clients and flexible and responsive to their needs (rather than constrained by some funding agreements which are often short term and provide the funding so late in the financial year that there is little room for flexibility).

Collaboration with other service providers in the region is also critical in thin markets where service providers need to be flexible in how services are provided.

The lack of adequate transport and infrastructure facilities in very remote communities is a huge deterrent to improving markets in these places. Service providers would be more likely to locate themselves in remote areas if there is adequate staff housing, roads and other services to enable their staff to reside there for any length of time.

Experience has shown that cross government collaboration to improve outcomes in Aboriginal and Torres Strait Islander communities in remote Australia has generally not been successful. Similarly, reliance on mainstream service providers to be more inclusive of Aboriginal and Torres Strait Islander people with disabilities in remote areas has not so far proved achievable.

The way forward is to build on established community organisations that have a successful track record in delivering services and who have existing good relationships with families and communities in the remote areas. Collaboration and not control should be the focus.



## Cost of providing services in remote areas

### *MJDF Experience with NDIS Pricing of Supports*

The MJDF notes the inadequacy of NDIA prices for supports in remote and very remote areas of Australia, given the barriers that exist and the realities of delivering services in these areas.

In preparation for the rollout of the NDIS in the NT, the MJDF conducted an internal Unit Costing using the National Costing and Pricing Framework for Disability Services.<sup>8</sup> The aim was to calculate the unit cost of providing MJDF services in the pre-NDIS landscape, to understand its cost drivers, and to reveal the actual cost of delivering services and the additional costs in very remote areas. MJDF understands that there is currently minimal benchmarked data available from services operating successfully in the field.

The Unit Costing exercise<sup>9</sup> was undertaken over an eight (8) week period in mid 2016. The resulting report was subject to an independent review by Deloitte Access Economics to verify the method used, the calculations and the assumptions made.

#### **Unit costs**

The results of the costing exercise showed that the NDIS unit pricing for the supports that the MJDF expects to deliver under the NDIS are significantly lower than MJDF's unit costs. The Darwin unit cost for an MJDF Manager, Community Services is \$130/hour and for an Aboriginal Community Worker it is \$90/hour. The most common supports that MJDF expects to deliver range from \$40.92/hour to \$92.27/hour (the only exception being Therapy assessments at \$175.57/hour).

#### **Workforce realities**

The NDIS pricing uses a use-value market based method and assigns a range of unit prices to NDIS support items. The values assigned to these supports are largely based on the skill/qualifications required of the individual delivering the support. However, the NDIS has made the erroneous assumption that it is possible for an organisation working in remote Australia to sustain a structured workforce with these levels of skills.

Firstly, the NDIS has assumed that there is a critical mass of participants in the very remote community to support a workforce that comprises the range of skills/qualifications. That for the range of different skill levels (representing salaries), there are enough total support hours required in the community to enable an organisation to sustainably employ this range of skills.

The reality is much different. The MJDF employs Health Professionals (due to the extremely complex nature of MJD) in the lead roles responsible for client supports in each community (Manager, Community Services). The MJDF also partners that individual with Aboriginal Community Workers.

However, the critical mass is not present to employ a range of more junior roles, as the MJDF provides cohort specific supports. So, the Manager, Community Services is often delivering the support (e.g. Therapy Assessment which attracts \$175.57/hour), yet they are also delivering other supports that attract a much lower price (eg. such as Assistance to access community at \$46.58/hour).

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<sup>8</sup> The National Costing & Pricing Framework for Disability Services was commissioned by National Disability Services (October 2-14), and developed by Curtin University.

<sup>9</sup> [http://mjd.org.au/cms/file\\_library/Other/Other\\_953.pdf](http://mjd.org.au/cms/file_library/Other/Other_953.pdf)



Secondly, the NDIS has overlooked a range of barriers that exist in employing staff in very remote communities. It is often extremely difficult to secure very remote community staff housing, and this becomes a barrier to being able to employ a range of staff.

#### **Remote loading**

The MJDF calculated very remote load percentage (VRLP) was 25.3% which is equal to the NDIS' new rate of 25% adopted on 1<sup>st</sup> July 2017. The conclusion here is that the NDIS has accurate financial figures representing the costs of delivering supports in very remote communities. However, as per the point above, this does not necessarily consider the other barriers to delivering services in very remote communities (such as the example provided of a lack of staff accommodation).

#### **NDIS volume of supports vs MJDF supports**

In addition to the NDIS unit price being insufficient to cover just 1 hour of service, it is yet to be determined whether the number of hours MJDF spends on a support with a client will be comparable with their NDIS plan (e.g. MJDF may spend 8 hours providing therapy, where the NDIS plan only approves 1 hour of therapy).

In contrast to stable disabling conditions, MJD is a complex, multi-system, degenerative disease requiring regular review and intensive supports in order for independence and health to be optimised. The use of informal and less skilled support services is limited by the complexity of the disease extending to real risk of harm (aspirations, pressure wounds, accidental injury and depressive illness) if managed inadequately. Often family members who are carers also have a genetic predisposition to MJD.

Once MJDF has secure a clearer picture of the number of approved hours allocated in clients' NDIS plans, this will provide an additional instructive comparison between NDIS projected costs and the realities faced by MJDF.



## Conclusions and recommendations

Apart from the Barkly trial site, the NDIS has commenced rolling out in the NT since 1 January 2017 to people with disability in Darwin supported accommodation and in the East Arnhem region. From 1 July 2017 the NDIS has commenced the roll out in the Darwin remote region, Katherine and in Alice Springs supported accommodation.

### Planning

The MJDF's experience with the NDIS since 1 January 2017 shows that the planning process has not been well managed or executed:

- NDIA planners have been inconsistent in levels of knowledge, understanding and communication;
- plans have mostly been based on previous inadequate support plans created and funded under the NT Government (ignoring other non NTG funded supports), and have had to be revised several times;
- there has been little information provided to MJD clients by the NDIA about the NDIS. In its absence, the MJDF has had to fund the provision of information to its staff so they could pass that information to its clients;
- NDIA planners have not communicated well with the MJDF so that visits to remote communities can be coordinated where neither has a permanent presence; and
- MJD is not well understood by NDIA staff. Revised plans are often inadequate in terms of therapy, respite, support coordination, transport and resource supplements. The MJDF will be taking this up with NDIA separately.

Whether this is due to the speed of the roll out, the lack of transparency from the NT Government around transferring existing clients to the NDIS, the difficulty in retaining staff in remote Australia or a combination of these and other factors is hard to say.

### Support Coordination

Support coordination is not operating as well as it should be for clients with MJD. There is also little assistance provided by the NDIA to guide support coordinators in their role. The MJDF is developing its own processes and templates as it goes. It is inefficient for each organisation to have to do this.

### Remote Australia

Remote service provision in Aboriginal and Torres Strait Islander communities needs a different approach to urban and regional areas. Governments should ensure adequate transport and infrastructure and work with communities and established organisations, rather than impose restraints on innovation and flexibility.

### Costs

The costs (and other barriers) of delivering services in very remote Australia is not accurately reflected in the NDIS price guide. The realities of service provision need to be better acknowledged by the NDIA.

### Recommendations

1. In relation to support coordination, the NDIA should revise its planning guidelines and price guide to acknowledge that in some diseases, 'time limited' Support Coordination is unrealistic.
2. The NDIA should recognise the key role played by Support Coordinators and provide greater guidance about the role.
3. In remote areas, the NDIS should be encouraging better service provision by governments, and more collaboration with and between service providers.
4. The NDIA, Commonwealth and State/Territory governments should recognise the full implications arising from existing endemic market failure in remote communities and develop



specifically targeted initiatives aimed at addressing current shortfalls in infrastructure and transport, and work in partnership with locally based organisations in addressing these.

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