



Support Coordination

MJD Foundation Submission to the National Disability Insurance Agency

September 2020

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Submission Purpose

In August 2020, the National Disability Insurance Agency (NDIA) released the "*Discussion Paper – Support Coordination – External Consultation*".

The purpose of this submission is to respond to the questions raised in this paper.



Background

The MJD Foundation (MJDF) works in partnership with Aboriginal¹ Australians, their families and communities living with Machado-Joseph Disease (MJD) and other closely associated ataxias in remote and very remote communities, and urban centres across the Northern Territory and in Far North Queensland. Its clients include people with MJD who are NDIS participants, people with MJD who are non-NDIS participants, children at risk of having MJD and family carers.

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

People living with long-term, degenerative, neurological conditions such as Machado-Joseph Disease (MJD), experience highly complex, cumulative needs. For people living with MJD and other neurodegenerative conditions, supports are required for up to twenty years, transitioning through the mild, moderate and severe phases of the disease. Specifically, in the Aboriginal & Torres Strait Islander context, these needs may be exacerbated by remote, underserved, impoverished environments. Communication and mobility capacity are incrementally reduced by MJD, ultimately resulting in complete dependence and there are currently no technologies or medications to remedy this.

Themes

The MJDF's unique experience provides several frameworks or themes in which government policy and its implementation can be analysed and critiqued.

<p>Degenerative - MJD is a slow progressing, degenerative neurological condition. As participants progress through the stages of MJD (mild, moderate, severe), their support needs increase, and their capacity to independently manage those supports diminishes.</p>

<p>Genetic condition - MJD is a genetic/hereditary condition. Therefore, there are often family members living with the condition across multiple generations. This compromises the 'informal supports' relied upon by NDIA.</p>

<p>High complexity - MJD is a highly complex condition resulting in a significant and complex NDIS/Primary Health mainstream interface. A high level of knowledge and expertise is required of individuals working with participants living with MJD.</p>
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<p>ATSI - Social and educational disadvantage, in combination with language and cultural differences make engagement with both mainstream and disability support providers complex for Aboriginal & Torres Strait Islanders living with a disability, especially those from remote communities.</p>
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<p>Remote Service Delivery - In the remote & very remote context there are extensive barriers and challenges leading to a thin market due to: a lack of staff accommodation; challenges with attracting and retaining staff; lack of accessible infrastructure (including transport); lack of services; unreliable/expensive fly-in-fly-out community trips (community closures, 'sorry business' etc).</p>
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Responses to questions raised in the Support Coordination are discussed using one or more of the above themes.

¹ The MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander in recognition that Aboriginal people are the original inhabitants of Arnhem Land. Aboriginal and Torres Strait Islander is referred to in the National context. No disrespect is intended to our Torres Strait Islander families and communities. The MJDF acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.

Responses

Inclusion of support coordination in plans

1. What factors should be considered when determining if, when and for how long support coordination should be funded in an NDIS participant's plan?

This response does not cover existing factors that NDIA planners generally consider when determining the level of support coordination.

More consideration and emphasis should be placed on the following factors, all of which commulatively increase the number of support coordination hours required in a plan:

Degenerative nature of disability

Support coordination requirements for NDIS participants living with MJD and other neurodegenerative conditions cannot be confined to initial, or time limited assistance, resulting in a tension with the NDIS principles of individual capacity development, and maximising informal supports. Whilst there are currently 63% of participants with a disability type "other neurological"², for neurodegenerative conditions, this percentage should be even higher.

While there is no doubt that an orientation to increasing independence, knowledge and skills and autonomy for participants should be a desired outcome of the NDIS, the MJD Foundation (MJDF) has over a decade of experience and data from meeting client needs, indicating that people living with MJD will require ongoing and *increasing* support coordination as the condition progresses – rather than a diminution. Factors contributing to this (and outlined below) include: the genetic/hereditary nature of MJD and reduced informal care capacity; culture and environment; and the interrelationship between primary health and disability needs consequent the condition.

Capacity of informal supports

The genetic transmission of MJD compromises informal supports. People living with MJD are frequently being cared for by other family members also living with MJD. The most common symptoms – difficulties with balance, co-ordination, and vision are incompatible with providing physical assistance. The pervasive mental health and social and emotional wellbeing deterioration is equally devastating. All of which increase the need for assistance to manage and coordinate necessary supports.

High Complexity of disability

MJD causes multi system deterioration of function, resulting in complex and changing needs across the stages of MJD. These needs are best met in a coordinated, collaborative approach by *both* primary and allied health professionals. It is impossible to cleanly distinguish the health consequences of the disease and those purely resulting in disability. The protein agglutination process that results in lack of voluntary movement, necessitating early and sustained therapeutic intervention, is the same process that causes incontinence, resulting in urinary tract infections and pressure areas, that may necessitate antibiotic and surgical interventions. The process that robs a person with MJD of their ability to speak and swallow, necessitating speech therapy, communication aids and modifications to diet, is the same one that places the person at risk of aspiration pneumonia, and bowel blockage necessitating hospitalisation.

As the disease progresses the distinction becomes increasingly blurred. Best practice care may require lengthy inpatient rehabilitation admissions where the outcomes are directed at remediation

² NDIS Discussion paper – Support Coordination – Aug 2020 (Table 3)

of *both* primary health and disability issues. Crises can and frequently do occur and the resolution of them may require long-term supports. Co-morbidities such as preventable chronic disease are common and likewise cannot be treated in isolation from the disability causing disease. For those living with MJD, the most significant increases in disability and ill-health arise concurrently with decreased ability to advocate for and control their environment and the supports that they need.

Cultural and social considerations

An Aboriginal & Torres Strait Islander context in terms of social and cultural features also necessitates additional support coordination. In the remote context, English is generally not the first language of participants. Social and educational disadvantage, in combination with language and cultural differences make engagement with both mainstream and disability support providers complex for many Aboriginal & Torres Strait Islanders living with a disability, especially those from remote communities.

Location

An overlay of remote and very remote community context in terms of social and environmental features also necessitates additional support coordination. Disability support providers are thin on the ground (or non-existent), mainstream service provision is impoverished, telecommunication substandard, there is minimal transport and associated infrastructure.

In the remote context, due to thin markets, fly-in-fly-out supports are often necessary, which increases the number of Support Coordination hours required due to high costs of Provider Travel.

Case Study – provider travel

Due to the MJDF being unable to secure staff accommodation for support coordinator/allied health professional in Ngukurr (Roper River, NT), we fly-in-fly-out from our Groote Eylandt base every 6-10 weeks. With only 4-5 NDIS participants living in Ngukurr each trip, and the charter and accommodation costs high, the annual cost of the provider travel in 2019/2020 was \$17,000. Shared amongst the participants, and broken down across the items support coordination and therapy, the number of support coordination hours drawn-down to cover the provider travel for the year was approximately **17 hours** per participant.

In the remote context, due to thin markets, coordinating supports with visiting providers (such as therapists) is complex due to travel logistics and collaboration with other organisations in order to pool the visit across as many participants as possible to increase the value for money.

2. Should the current three level structure of support coordination be retained or changed?

Level 3 – Specialist Support Coordination (SCC)

Under principles laid out by the NDIA, specialist support coordination (SSC) is funded only in circumstances to ameliorate high risk and to navigate specific complex support needs. It must be conducted by a qualified and experienced Allied Health Professional. SSC is intended to be time limited and outcomes based, addressing barriers to implementing and utilising NDIS plans and then reduced. It should be distinguished from the level 2 Coordination of Supports related to ongoing needs and assist to manage challenges in the support environment including health, education or justice services.

It is critical to recognise that MJD is slowly progressive condition resulting in highly complex care needs, which at the severe stage are unable to be actioned independently by the affected individuals. Coordinating the appropriate treatments and supports for people with severe MJD is time consuming, technically complex and nuanced, requiring tertiary allied health or primary health qualifications and specialist knowledge of the disease, the cultural requirements of the clients and available services and resources. The MJDF is best positioned to achieve this based on more than a decade of providing specialist assistance to people living with MJD.

The MJDF care model of pairing experienced health practitioners with Aboriginal Community Workers ensures that those living with MJD have access to and are able to plan, navigate and receive the care that they require through responsive and proactive *specialist support coordination*. For the maximum benefits to be available to participants through their NDIS plans this is an ongoing necessity. The recommended specialist support coordination hours for participants living with MJD is described in the 'General' section of this document on page 15.

3. How should support coordination interact with other NDIS supports? For example, local area coordinators, community connectors, liaison officers and recovery coaches?

Especially in the remote/very remote context with thin markets, effective support coordinators should have regular interaction with other NDIS supports in order to understand emerging options for participants to receive supports to meet their goals.

In communities where there are very few support coordinators, there can be significant efficiencies to be made in *joint* support coordination to organise a support to be brought to the community. For example, if there are 15 participants in a remote community that all need a speech or swallowing assessment (across 3 support coordinators), it is significantly more effective to work together on bringing a visiting speech therapist to the community to see all participants. For participants, this also has the benefit of increasing the likelihood of attracting the same therapist who can built rapport with participants.

There is however, currently no incentive for support coordinators to operative in this collaborative manner.

4. How should support coordination interact with and complement existing mainstream services?

Especially in the remote/very remote context with thin markets, effective support coordinators should regularly interact and collaborate with other mainstream supports. Collaboration is a critically important factor for successful remote service delivery, and at an organisational level, establishment of memorandums of understanding to share resources may increase the effectiveness of the support.

There is however, currently no incentive for support coordinators to operate in this collaborative manner.

Case Study – MJDF Memorandum of Understanding with Aboriginal Controlled Primary Health organisation.

Due to an MOU established between our organisations, in the course of MJDF delivering NDIS supports (including support coordination), we are able to sometimes access a seat on a single engine charter, and stay in clinic accommodation. In return, MJDF provides clinical and genetic education to the clinic's primary health professionals about Machado-Joseph Disease. The overall benefit to NDIS participants is a reduction in the amount of provider travel costs we draw down from the participants' plans in that community.

5. What can or should be done to address the level of utilisation of support coordination in plans; and is this any different to general issues of utilisation?

In remote and very remote communities, there has been criticism from the NDIA in circumstances where support coordination utilisation is higher than overall plan utilisation. Comments have been made to MJDF staff around this (including from senior NDIA staff members), with the implication that a high utilisation of support coordination hours and lower overall plan utilisation is a measurement that reflects poorly on the support coordinator.

Due to thin remote markets, the complexity of coordinating and bringing supports to the community significantly increases support coordination hours for participants living in remote/very remote communities.

Case Study – Cancelled therapy visit

The MJDF organised a specialist speech therapist to visit a remote community to do swallowing assessments on 6 of our participants. We also attempted to collaborate with another support coordinator to offer the service to their participants. In total, we spent around 12 hours establishing the referral, organising the travel, and providing preparatory information to the visiting provider. At the last minute, the community was closed due to 'sorry business', and the trip needed to be postponed. Therefore MJDF, as support coordinator drew down 2 hours per participant of support coordination for no outcome for the participants.

Role of support coordination

6. What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

Comments re existing common functions:

Support participants to understand their plans

MJDF self-funded significant work leading up to the transition of the NDIS in educating our clients, preparing 'benchmark plans', and preparing for the planning process. Initially, there was significant resistance from the NDIA on the MJDF attending planning meetings (despite our clients requesting this), and many meetings went ahead with clients who did not understand that they were meeting with NDIA and having a planning meeting. Had the NDIA treated the MJDF with less suspicion and instead been collaborative, many hours of reworking poor plans would have been avoided.

Support participants to implement supports

In the context of thin markets and the requirement for a high level of knowledge and expertise in delivering supports, the MJDF will often provide additional NDIS supports to participants in addition to support coordination. (See 'conflict of interest' section).

Monitor utilisation of other funded supports in a participant's plan

The MJDF endeavours to thoroughly track the progress of participants' plans as part of our support coordination role. There are significant limitations with the NDIS Provider Portal functionality in regards to reporting/monitoring service bookings and payment requests made by other organisations that we have referred supports to. This results in increased work for MJDF to build budgets 'off system' and track RFSSs to other providers to understand utilisation and progress against the plan.

Support participants to connect with community and mainstream supports

Coordinating the appropriate treatments and supports for people with severe MJD is time consuming, technically complex and nuanced, requiring tertiary allied health or primary health qualifications and specialist knowledge of the disease, the cultural requirements of the clients and available services and resources. The degenerative nature results in significant primary health mainstream interfaces.

Build a participant's capacity for self-direction and independence

As described above, for people living with MJD and other neurodegenerative conditions, as participants transition through the mild, moderate and severe phases of the disease, capacity is eroded. The language the NDIA uses around capacity building should be abandoned for participants living with a degenerative disability as it is not only demoralizing for participants, but is also an unrealistic goal for support coordinators.

Support during crisis – As MJD is degenerative, a participant has constantly changing needs and frequent, complex crises. Additional support coordination hours should routinely be added to cater for this.

Comments re other support coordinator functions:

Quality role

The role of the support coordinator in monitoring the quality of supports provided by other providers is unclear. Certainly, MJDF takes on this role, but it has been questioned by some NDIA staff. In carrying out our support coordinator role, the MJDF will often be in the position to notice quality/training issues with other providers. The MJDF will always work collaboratively with other providers – offering free of charge careworker education. (MJDF sometimes draws down from the participant's NDIS plan, but more often supplement this activity from funding from other sources due to there not be adequate NDIS funding under the 'capacity building' section of the plan).

Case Study – Multiple hospital admissions

A participant living with MJD experienced multiple hospital admissions due to aspiration pneumonia. The MJDF was able to provide careworker education to the SiL provider around the swallowing difficulties (dysphagia) associated with MJD (along with other MJD symptoms), and provide safe swallowing guidelines for staff to follow.

Expert knowledge disability

The MJDF argues that, due to the complexity of MJD and other neurodegenerative conditions, level 3 specialist support coordination hours should be routinely included in plans for participants with moderate and severe MJD. Understanding the disability, and the trajectory of the condition and being able to provide this guidance to other NDIS providers has been critical on countless occasions with our participants.

Case Study – Urinary Tract Infection

A SiL provider was concerned about the sudden functional decline of a participant living with MJD. The SiL provider put this down to the degenerative nature of MJD, and did not think to obtain medical advice. The MJDF was able to meet with the SiL provider and the participant in our role of support coordinator, and recommend the participant was taken to the health clinic with a suspected UTI. The participant did have a UTI, which was treated with antibiotics and the participant's function returned.

Fraud notification to the NDIA

In cases where MJDF has observed questionable practices from another organization, it is not clearly defined what the role of the support coordination should be in reporting this to the NDIA. Additionally, when a report was made, there was no confirmation that the report was being investigated. (MJDF accepts that NDIA cannot necessarily disclose an outcome).

Finding new solutions

Especially in the remote context with thin markets, there could be processes with involve support coordinators to work collaboratively with other support coordinators. Understand the communities in which participants live and the market, and barriers to the market. Innovative ways to build support capacity in remote and very remote communities where there is a thin (or non existent) market.

Interpret/translate supports

In delivering all our supports to NDIS participants (including support coordination), the MJDF partners our Aboriginal and non-Aboriginal staff to work in partnership, to deliver supports and communicate in first language. Whilst a process for Indigenous language interpretation supports is emerging (and is currently a local solution), there is extensive work to do on designing a consistent and comprehensive process supporting the human rights of participants to receive supports in their first language.

Tasks the NDIA says a Support Coordinator should not do:

NDIA sometimes pushes back on hours spent on support coordination with words to the effect of "Support coordination is not case management", yet when pressed for examples of activities that would constitute case management, that should not be support coordination, few planners can articulate any examples. The only clear example that MJDF has received has been around advocacy and program evaluation.

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| 7. Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes? |
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Not from MJDF's perspective. Support coordination should be centred holistically on the person, and targeted support coordination around just one goal may fracture a holistic approach.

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| 8. How could plan management and support coordination be more closely aligned and what would the potential benefits and risks be? |
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Whilst a support coordinator has responsibility for monitoring utilisation of participants' plans, there is limited visibility on the NDIS Provider Portal of service booking details made by other organisations, and the payment requests drawdown against those service bookings. There are often remaining hours left in a service booking that are not visible, and could be freed up for other supports.

In circumstances where the MJDF is both plan manager and support coordinator, we have 100% portal visibility of the utilisation and progress of a plan. This is an accidental benefit of holding both roles, and not one of design by the NDIA (ie an unintended consequence).

It would therefore be beneficial for the support coordinator to have this visibility on the NDIS provider portal. (eg. a report on Service bookings by organisation, with remaining hours available).

Quality of support coordination

9. Should there be minimum qualification requirements or industry accreditation in place for support coordinators? If so, what might be applicable?

NDIS Commission Registration as a provider should be mandatory for support coordinators. This would ensure a level of regulation and present an opportunity to expand the NDIS Practice Standards & Quality Indicators to specifically target support coordination. Support coordination practice standards would be covered in the core modules, but could also be covered specifically as a supplementary module, in the same manner that areas such as: high intensity supports; specialist disability accommodation etc are.

NDIS Commission training similar to the NDIS Worker module should be developed as a training package for all support coordinators to provide a baseline level of consistency and understanding around the role of the support coordinator. Currently, organisations access training and information through a range of varied sources, with a great deal of inconsistent information provided. NDIA staff themselves would also benefit from this, as there is often conflicting advice across different NDIA offices.

Qualifications for Support Coordination levels

L1 and L2 – in theory someone extremely well organised, who has a good relationship with the participant, and understands the options in the community (the market) can perform the role. Therefore, no strict qualifications needed.

L3 should be linked to the complexity of the disability, complex mainstream interfaces (eg clinical knowledge). i.e. Allied health or primary health qualifications.

10. How can the effectiveness of support coordination be measured and demonstrated?

The outcome of a participant achieving their goals is the benchmark that support coordinators should be aiming for. However, a definitive link between goal achievement and quality of support coordination can be problematic especially in a remote/very remote context. Many of the barriers to supporting participants to achieve their goals in remote communities are outside the control of a support coordinator, such as:

- Extreme weather conditions – cyclones, flooding wet seasons and very hot and humid temperatures
- High delivery/freight costs due to inaccessibility
- High staff turnover due to inaccessibility, inadequate staff housing
- 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)
- Differences in the conceptualisation of disability in western medical terms in an Indigenous context
- Lack of staff housing in community
- Issues with attracting and retaining staff
- Lack of accessible housing for people living with disabilities
- Lack of accessible vehicles (community transport) – and long waits for vehicles to be repaired
- Lack of (or season restricted) services (eg tradesmen to install housing mods)
- Unreliable scheduling of community trips for service delivery with possible community closures etc

- 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 (FiFo) out or Drive in Drive out (DiDo) models of service provision.
- Minimal or inconsistent mainstream services (due to same barriers)

The same can be said for linking plan utilisation to quality. Some utilisation levels appear to be increasing as therapy organisations are increasing their FiFo capacity to remote communities, and organisations are bringing participants into urban centres for respite (Short Term Accommodation).

Demonstration by support coordinators of attempts they have made to support innovative programs which meet a gap in provision of 'in community' regular core supports to remote/very remote participants could be measured/supported/incentivized by the NDIA.

11. Are there emerging examples of good practice and innovation in support coordination?

Collaboration between support coordination organisations to address thin markets and pool funds. eg. When this does not occur in remote communities MJDF has seen two (2) organisations send a speech therapist to visit few people, where it could have been coordinated and more efficient to have one (1) visiting therapist.

Individuals' ability to make decisions, is often at odds with collective decision making within Aboriginal communities. Collective decision making with families alongside the support coordinator to design group programs that package NDIS supports across participants is an example of an innovative approach with one resultant program being delivered across the MJDF and another NDIS provider. See: <https://www.youtube.com/watch?v=ki047Gw0z-k&feature=youtu.be>

Workforce planning/organisation around the support coordination tasks. In most cases the MJDF support coordinator is delivering multiple supports at the same time: For example: support coordination, assist domestic activities, accessing community, therapy etc

More sophisticated program design – a holistic approach to family engagement by cross program funded engagement. eg a 4 hour engagement with family funded by 2 hours NDIS participant support coordination, 1 hour Young carer program, 1 hour primary health (genetics education).

12. Are the levels and relativities in the NDIA price limits across different services including support coordination working effectively in the interests of participants and a sustainable, innovative market?

Support coordination pricing should not be reduced. The MJDF is already unable to cover our support coordination costs solely from NDIS plan drawdowns.

13. Should support coordination pricing be determined, at least in part, based on progression of participant goals and outcomes, and how might this work?

Achieving goals for a participant should always be the benchmark, however pricing should be determined by the level of qualification, skills and experienced required by a support coordinator to support participants to achieve their goals (not withstanding the barriers that may be in place – and out of the control of the support coordinator).

Building capacity for decision making

14. How can a support coordinator assist a participant to make informed decisions and choices and choices about their disability supports? What are the challenges?

The MJDF approaches service delivery using 'Our Way', which in practical terms, pairs an Aboriginal community worker and a non-Aboriginal allied or primary health 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 MJDF affected families. Many of MJDF's ACWs are also people living with MJD (or are their carers) which has assisted in mitigating the 'shame' that may be felt by people with MJD when seeking NDIS supports.

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 over individual decision making. Understanding these firmly held beliefs and working together to enable the interactions necessary to provide supports is imperative.

The MJDF's 'our 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.

15. How does a support coordinator build a participant's independence rather than reliance? Should support coordination pricing be determined, at least in part, based on building a participant's capacity for decision making to become more independent?

While there is no doubt that an orientation to increasing independence, knowledge and skills and autonomy for participants should be a desired outcome of the NDIS, the MJDF has over a decade of experience and data from meeting client needs, indicating that people living with MJD will require ongoing and *increasing* support coordination as the disease progresses and their capacity declines.

Support coordination pricing should not be linked to increased capacity and independence for a condition that is neurodegenerative.

16. How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role? What are the appropriate parameters of the personal advocacy role and the support coordination role?

In the first instance, a support coordinator is likely to be alerted to an advocacy issue that a participant needs assistance with. There is a fine line between the support coordinator passionately supporting their participant's needs, and taking on the role of advocate.

If the advocacy involves the support coordinator putting pressure on a mainstream provider to deliver a service (eg. A remote housing maintenance modification request to improve access), then the MJDF's view is that this is a reasonable support coordination task. However, if significant follow-up is failing to achieve an outcome for the participant, the MJDF will then refer this situation to a DSS funded advocate.

Advocates funded by DSS are rarely going to know about a man in a remote community with disability who has not been able to get his door fixed and has multiple injuries from running into the hanging door in his wheelchair. The role of the support coordinator in this case is critically important.

Conflict of interest

17. In what circumstances is it more or less appropriate for a participant to receive multiple supports from a single provider?

The MJDF regularly provides multiple NDIS supports to our participants based on the following circumstances:

Remote community / thin markets – often there are major gaps in supports in remote communities which MJDF will endeavor to fill to provide our participants with the supports they need to meet their goals. For example, as a general rule, MJDF (in a support coordinator role) refers out personal care, however in some very remote communities, MJDF provides this support as there are no other options.

Family business – the MJDF's 'our way' model reflects the consistently expressed preference of MJD families for developing a relationship with those providing support. The MJDF's employment of Aboriginal Community Workers within affected MJD families to work alongside non-Aboriginal staff is community lead and collectively decided.

High complexity – there is a high level of knowledge, skills, qualifications and experience required to provide adequate supports to participants living with MJD. The MJDF is a cohort specific organization investing heavily in the knowledge of our staff to be able to support our clients.

However, MJD participants living in SDA always have a SiL provider separate to the MJDF, where we always provide the support coordination role.

18. Should the IAC recommendation for the NDIA to enforce an 'independence requirement between intermediary and other funded supports at the participant level' be adopted?

A blanket 'independence requirement' cannot be applied due to the reasons provided in question 17.

However, the MJDF is in favour of separate organisations providing support coordination and SiL supports.

The MJDF is in favour of any organisation that provides support coordination plus other supports needing to demonstrate that more than one worker within the organisation is in regular contact with the participant. ie cannot be the same single worker.

19. What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?

A blanket 'independence requirement' could in fact be catastrophic for participants living with MJD. In remote communities where there are few options, participants may receive even fewer supports. Splitting (for example) MJD support coordination and some high intensity supports may result in lower quality care with organisations without clinical understanding of MJD trajectory.

General

20. What would you identify now as the current critical issues around support coordination?

The NDIS Discussion paper (Support Coordination August 2020) did not address any of the implementation issues within the NDIA in regards to current support coordination policies, standard operating procedures etc. Below are some key issues:

Transparency

On 7th September 2020, Disability Services Consulting (DSC) published the article "*It's all in the timing*".³ Obtained through a freedom of information request, DSC obtained the NDIA Standard Operating Procedure titled "*Include Support Coordination in a Plan*". It defines the low, medium and high level ranges and guideline hours for plan inclusion, however the method used to classify participants into these ranges is redacted. The document further discusses the use of "*Typical Support Packages*" (TSPs).

Without the NDIS rules amended to "*set out the factors the NDIA will consider in funding Support Coordination in a participant's plan*"⁴, how does the NDIA expect to:

- create certainty amongst providers and build a strong vibrant market with increased choice and control for participants by providing certainty to registered providers?
- legitimately undertake this 'external consultation' via the Aug 2020 Discussion paper – Support Coordination?

Consistency

There remain significant and alarming variations between NDIA offices in allocation of Support Coordination hours to participant plans. As the MJDF is cohort specific, we have over a decade of information in providing supports to our clients living with MJD, with an understanding of the differences across urban and remote settings, as well as the trajectory of the condition and the likely crisis points as the condition progresses through the stages of mild, moderate to severe.

Whilst it is true that each individual has unique situations that may also vary their access to informal supports, there are also enough similarities across participants living with MJD – across stages of disease and between urban and remote settings – to provide guidelines for adequate provision of Support Coordination hours. The MJDF has developed 'Benchmark packages' per stage of MJD and per urban/remote locations. These essentially appear to equate to the NDIA's 'Typical Support Packages' of which we have never had any visibility.

Case study

An MJD client living in Far North QLD has consistently received an NDIS package with around 50% of the Support Coordination hours (and 50% total package), compared to participants at the same stage of MJD, with similar informal supports and similar comorbidities. MJDF has exceeded the allocated Support Coordination hours (at our own cost).

³ <https://teamdsc.com.au/resources/its-all-in-the-timing>

⁴ Tune Review



The MJDF has over a decade of experience in providing these supports, and has been providing these supports under the NDIS since 2017. The below table represents a reasonable and necessary guideline, and is in line with NDIS plans that have been in place for participants living with MJD.

MJD Stage	Urban	Remote
Mild	L2 – Support Coordination - 72	L2 – Support Coordination - 108
Moderate	L2 – Support Coordination - 90	L2 – Support Coordination - 130
Severe	L2 – Support Coordination - 108 L3 – Specialist Support Coordination - 30	L2 – Support Coordination - 156 L3 – Specialist Support Coordination - 45

Certainty

With a lack of transparency and consistency in allocating Support Coordination hours, there is a lack of confidence for organisations to build a business case to build capacity and offer more supports in remote communities.

NDIA messaging

There are inconsistent messages from the NDIA across different offices, with NDIS Providers still sometimes being treated with suspicion and mistrust. Some planners welcome MJD knowledge, education and benchmarks, others treat us poorly.

NDIS Provider Portal visibility

As a Support Coordinator, it is not possible (unless we are also the Plan Manager) to view Service bookings/payment requests (left over funding). MJDF is often left out of pocket at the end of a plan, and are unable to accurately monitor utilisation of other funded supports in a participant's plan.

21. What are the priority actions the NDIA might take to grow an innovative and effective support coordination market in the interests of participants?

Provide **transparency** around the policies, standard operating procedures used to determine support coordination hours.

Develop '**Typical Support Packages**' in collaboration with cohort specific, expert organisations.

Specifically, for participants living with a degenerative condition, **abandon the messaging around capacity building**, as it is not only demoralising for participants living with a degenerative condition, but does not represent the reality of a degenerative condition which is eroding capacity.

Routinely fund Level 3 Specialist Support Coordination for participants with complex degenerative conditions.

Modify the **NDIS Provider Portal** to enhance functionality to enable support coordinators to have visibility (with participant consent) to service bookings and payment requests from other organisations.

Work with DSS to target the funding of software tools/apps to compel support coordinators to increase their collaboration. For example, therapist bookings, shared resources (eg remote single



engine charters).

Consider incentives for support coordinators who attempt to design solutions to fill gaps in core supports which are delivered face to face and in remote communities.



Appendix A – MJD Foundation

MJD Foundation

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal⁵ Australians, their families and communities living with Machado-Joseph Disease (MJD) in a growing number of remote and very remote communities and urban centres across the Northern Territory (NT) and in Far North Queensland (QLD).

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

Machado-Joseph Disease

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

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

The vast majority of the MJDF's clients live in very remote Aboriginal communities⁶. Those who live in urban centres such as Darwin, Alice Springs or Cairns have tended to do so in order to access specialist disability or high level support services as their disease progresses.

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

⁵ The MJDF uses the term Aboriginal in preference to Aboriginal and Torres Strait Islander in recognition that Aboriginal people are the original inhabitants of Arnhem Land. Aboriginal and Torres Strait Islander is referred to in the National context. No disrespect is intended to our Torres Strait Islander families and communities. The MJDF acknowledges the inclusion of Torres Strait Islanders who may be affected by MJD.



Central Australia 1. Papunya 2. Ntaria (Hermannsburg) 3. Mparntwe (Alice Springs) 4. Ltyentye Apurte (Santa Teresa)	Far North Queensland 5. Atherton 6. Kowrowa 7. Ngoonbi (Kuranda) 8. Gimuy (Cairns)	Groote Archipelago 9. Milyakburra 10. Angurugu 11. Umbakumba Darwin 12. Darwin	East Arnhem Land 13. Galiwin'ku (Elcho Island) 14. Birrijiimi (Wallaby Beach) 15. Gungyanga (Ski Beach) 16. Nhulunbuy (Gove) 17. Yirrkala 18. Birany Birany	South East Arnhem Land 19. Numbulwar 20. Ngukurr 21. Urapunga West Arnhem Land 22. Gunbalanya (Dempeli)
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