

Independent Assessments

MJD Foundation Submission to the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme

March 2021

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Submission Purpose

The purpose of this submission is to highlight the problematic issues with Independent Assessments (IAs) and, in particular, to outline the expected negative impacts of the introduction of IAs for Aboriginal people living with disability, especially those living with Machado-Joseph disease and from remote and very remote communities.

This submission is advocating for:

1. The proposed rollout of IAs to halt with no enabling changes being made to the National Disability Insurance Scheme (NDIS) legislation. As it currently stands the proposed implementation of the IAs in remote communities will prove totally impractical and discriminatory. Major adjustments will be necessary to the way in which IAs are implemented and utilised to determine access and devise budgets under the NDIS. An independent review of the IA pilots should therefore be undertaken, and those review findings fully addressed before any changes to access and planning are proposed.
2. If the above does not occur, the NDIA to provide an exemption from IAs for Aboriginal people with disability from remote Australia.

About the MJD Foundation

The MJD Foundation (MJDF) works in partnership with Aboriginal¹ 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 vast majority of the MJDF's clients live in remote and very remote Aboriginal communities. The MJDF has substantial and unique experience in Aboriginal very remote non-government disability service provision. See Attachment A for further information about MJDF and MJD.

Working with Aboriginal people with disability

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

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

To achieve this client-centred approach the MJDF's engagement model is to always partner non-Aboriginal staff with local Aboriginal staff called MJDF Aboriginal Community Workers (ACW). This model values and respects a 'two-way' approach. The role of the ACW is to reflect family support needs, facilitate and attend MJDF client home, clinical and other visits with relevant non-Aboriginal MJDF staff; interpret at medical, allied health relevant meetings and appointments; educate and

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.

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.

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."*²

This positive feedback from our clients puts MJDF in a good position to recommend ways in which the NDIS should be operating to maximise the benefits for Aboriginal people with disability in remote Australia and, in particular, the disadvantages posed by mandatory IAs.

Terms of Reference

a) the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS

The introduction of IAs is clearly based on a desire to make the NDIS more sustainable by reigning in costs. The main costs to the NDIS are the larger than expected numbers of participants and the larger than expected increases in the funding included in the plans.

Whilst the introduction of IAs is being justified as a means to 'return the NDIS to its original self-help vision'³, as currently proposed, the net impact will serve as an overarching strategy to reduce the number of participants and the amount of funding per plan.

The design of the new process is aimed at standardisation or a "cookie cutter" approach to assessing whether a person is eligible or how much funding they get. The individuality of each person and their goals and aspirations is subjugated to a standard "one size fits all" approach.

The proposed IA process will come at the cost of the choice and control, with participant plan funding being based on the IA alone, being conducted by a person the participant has never met before, and with the IA being non-reviewable. 'Choice and Control' are the very hallmarks of the NDIS for which the Disability sector in Australia has fought so hard.

IAs as proposed will also discriminate against people with disability who do not have the capacity to navigate government systems and advocate for the resources they need. The joint submission by the NDIA and DSS to this Inquiry states that the current process "*has also meant those with greater resources (time, money, the support of family) or a better capacity to understand and navigate the complexities of assembling the information can have an advantage over those with fewer resources or who find the process challenging, confusing and frustrating.*" The new IA process will not mitigate this confusion, challenge or frustration for many participants or prospective participants. If anything, it will increase given the Disability sector's disquiet and misgivings about the proposed

² Report of MJDF Services Assessed by HDAA to the Northern Territory Quality and Safeguarding Framework, 31 March 2017.

³ AFR 18 Feb 21 'Back to Basics Disability Scheme'

process. The nature of the proposed IA process means that those with greater resources, capacity to understand and navigate complexities will have an advantage in the assessment process.

The surprise shown by the disability community at the release of the Functional Capacity Framework in September 2020 shows that the NDIA has not consulted sufficiently with the Disability sector about this significant change to the way functional capability is assessed, and access and funding decisions are made. The NDIA has not been transparent about how IAs will impact on plan funding. Its consultation process has not been about whether IAs should be introduced, but only about how the process might be implemented. The NDIA does not appear to have taken on board any of the concerns expressed by the Disability sector.

The evaluation of the voluntary trials of IAs has not shown that there are sufficient numbers of participants in support of this initiative. While some participants may have been pleased with the assessment process, there is no indication what impact the IA has had on the plans of the participants who were assessed, and whether the participant would still be supportive of the initiative once they see the impact on their NDIS plan. The recent instigation of payments for people who agree to partake in the voluntary second trial would seem to indicate that there is not widespread support for the measure.

The current timeline for introduction of IAs is unrealistic because there has not been sufficient time for an independent review of the IA pilots, to fully understand the experiences of people living with disability and assess the outcomes of the pilots. The Disability sector should be given time to digest this information and respond to it. Policy makers should then design a better process to achieve the outcomes of fairness and equity the government says it is seeking, but which will not be achieved with the proposed approach.

Any changes need to allow plenty of time for people with disability, and the Disability Sector generally, to understand what the changes will mean for them.

If the already announced approach proceeds without addressing these concerns, it is inevitable that changes will need to be made to address the legitimate concerns of applicants, participants, their families, carers, and support providers.

b) the impact of similar policies in other jurisdictions and in the provision of other government services

No comments

c) the human and financial resources needed to effectively implement independent assessments

No comments

d) the independence, qualifications, training, expertise and quality assurance of assessors

The NDIA says it will recruit, train and remunerate professional assessors (NDIA appointed assessors) through third parties. An open tender for organisations to undertake this work and employ assessors has been conducted and the successful organisations announced. There is significant concern that the assessors will not be truly independent as they are trained, regulated and paid by the NDIA (albeit through an intermediary).

The perception of independence (or lack thereof) of assessors and therefore the ability to trust them is an important consideration as they have the ability to make decisions that have life-impacting consequences about someone they do not know and only see for a very short time.

APM, Plena Healthcare and HealthStrong have been selected to conduct the voluntary second trial of IAs. APM currently provides Local Area Coordinator services in the Northern Territory, Queensland and Western Australia. The Statement of Works for the tender states that "The NDIA will not issue any Work Orders or referrals for Assessment Services for Participants or Prospective Participants in Local Government Areas in which the Supplier is engaged to deliver LAC and/or ECEI services."⁴ It would appear that APM is therefore not eligible to be an NDIA independent assessor in locations where they hold LAC contracts.

There is also an issue around the use of allied health professionals as assessors. There is currently a significant shortage of allied health professionals working in the disability sector, particularly in remote Australia. Will the use of allied health professionals as assessors mean that there are less of them available to provide therapy supports to participants?

e) the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding

The IA uses generic assessment tools which have not been shown to be able to account for diversity, cultural factors and complex individual circumstances. The Productivity Commission said in its 2011 report "It is important that any tool not unfairly discriminate against people from Indigenous or ethnic communities".⁵

The tools are being used for an additional, different purpose to that for which they were designed. The tools were designed to screen people with disability to indicate how disability has impacted on an individual's daily life. They were not designed as the sole basis for determining funding, yet this is what is being proposed.

Further, there is no transparent information around how the IA tools will be used to calculate a plan budget. The NDIA website says: "Instead of creating a plan that has funding based on individual items or supports, your budget will be closely matched to your functional capacity and the impact of your environment, based on the information in your independent assessment."⁶

The NDIA should be transparent about how the funding will be linked to the IA score. It also needs to explain how it will take into account all the other factors that give context to an individual's disability and life circumstances.

⁴ Attachment 1 - Statement of work, Request for Tender – Independent Assessment Panel, Department of Social Services, paragraph 1.6, p10.

⁵ *Disability Care and Support*, Productivity Commission, July 2011, p317.

⁶ <https://www.ndis.gov.au/about-us/improving-ndis/plan-flexibility-and-budget-planning>

f) the implications of independent assessments for access to and eligibility for the NDIS

No comments

g) the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports

There is a danger that NDIA will rely on the IA report as the sole evidence of the functional capacity of the person with disability. The NDIA considers that the suite of assessment tools will enable equitable decision-making for the majority of people with disability. But it needs to be emphasised that the assessment of functional capacity is only one element in the information needed to decide access to the NDIS and determine the supports needed for a person living with disability to achieve their goals.

The NDIA has acknowledged this to some extent, but it should be emphasised more: “These issues (with generic testing) mean that additional information will need to be gathered and considered carefully to acknowledge the complexity of disability and humanity. This information may include additional personal and environmental factors, individual goals, observations, and parent and caregiver perspectives.”⁷

A noticeable gap in the policy statements is information about how an independent assessment informs a “total reasonable and necessary level of funding”. It is unclear how a functional assessment at a point in time, with no reference to goals nor understanding of the particular disability nor the person, can result in a plan with funding that has any basis in reality.

The NDIA says that the budget will be based on “what the best available information and evidence says will lead to the best outcomes”. The NDIA needs to be transparent about the formula it will use to translate functional assessments into plan funding, including what is the “best available information and evidence” that it is using.

The NDIA describes a scenario where the draft budget is developed based on the functional assessment, that budget is approved by the NDIA delegate, and the plan is then developed which fits that budget. How can a plan be developed without reference to the goals of the participant? The current focus is on the goals and needs of the participant, which require certain supports, which leads to a certain amount of funding needed to meet those goals and needs. The new initiative reverses the current logical approach.

If the funding is only calculated from the functional assessment, how will an adjustment be made, and on what basis, for Aboriginal and Torres Strait Islander participants in remote Australia?

The NDIA states that planning meetings will no longer be about planning nor about funding amounts. It is not even focused on a participant’s goals, but rather how use of mainstream services can be maximised. This seems to be a move away from one of the main aims of the NDIS which is to

⁷ Assessment of Functional Capacity for NDIS – Development and Framework, August 2020, National Disability Insurance Agency, p24.

maximise choice and control for participants. It also appears to focus too heavily on cost shifting between Commonwealth agencies and between governments.

The NDIA also states that the draft budget is the expected cost of providing a reasonable and necessary package of supports for a participant with similar functional capacity, support need and environmental context. This seems to focus on the “mainstream” participant. The policy fails to explain how this will cater for those participants, who are not similar in any of these domains, such as Aboriginal participants with Machado-Joseph disease living in remote Australia.

h) The link between Independent Assessments and plan funding

To our knowledge, none of the IA tools were designed (or subjected to research investigation) to link their scores to funding budgets. The NDIA should disclose its methodology, and any independent research supporting that methodology, around the use of functional assessment tools to calculate funding budgets.

It is clear that the NDIA expects that these assessments will result in a reduction in funding to existing plans. The NDIA’s September 2020 evaluation of the first IA trial used the cost of existing plans as a justification for generic assessments for existing participants: *“plan budgets and payments to participants are increasing well above normal inflation. Payments to participants have increased by 5% per quarter (on average) over the last two years, resulting in payments which are approximately 40% higher in June 2020 compared with two years ago. Further, the longer participants have been in the Scheme, the higher their average payment.”*⁸

These generic assessments should not be used as an excuse to arbitrarily reduce a level of funding that a participant has a reasonable expectation of receiving as a consequence of their disability and their goals.

In remote areas, in particular, where there are few services for people with disability, Aboriginal participants’ plans are often not fully utilized and this has resulted in arbitrary reductions in following years. The use of IAs could be another way by which disability funding is reduced for Aboriginal participants in remote Australia.

The proposed IA changes also refer to plans having a fixed budget and a flexible budget. More clarity is needed around what additional supports will be in the fixed budget. Support coordination is a critical support for Aboriginal participants in remote Australia. Will this be considered part of the fixed budget, and not detract from or reduce the amount available to the participant to achieve his/her goals in the flexible part of the budget?

Similarly, where there are thin markets, the consultation paper says that the fixed budget would include an amount to account for where the NDIA has directly funded services to support participants or where the NDIA has entered into an agreement to deliver a support most efficiently provided by a particular provider. Presumably this amount will not detract from the flexible budget funding so that the participant has maximum choice and control.

⁸ Independent Assessments Pilot Learnings and Ongoing Evaluation Plan, September 2020, National Disability Insurance Agency, pp5-6.

j) the circumstances in which a person may not be required to complete an independent assessment

For the reasons outlined below in relation to term of reference (k), the MJDF argues that there should be an exemption from mandatory IAs for Aboriginal and Torres Strait Islander people with disability from remote Australia.

j) opportunities to review or challenge the outcomes of independent assessments

There is no opportunity for the person living with disability to see the report or to discuss it with the assessor. Rather the only choice being given to the person living with disability is to request a copy of the report from the NDIA. The only opportunity to challenge the report would be to seek a review by the NDIA of a decision it has made on the basis of that report.

The Tender document Statement of work says that "*Participants and Prospective Participants will have the right to challenge the results of their Assessment if, for whatever reason, they are unsatisfied with the Assessment.*"⁹ This appears to be at odds with the statement by the NDIA that only the NDIA decision and not the assessment is able to be challenged.

Mr Tune, in his report, recommended that a key protection to be included in the use of IAs was "*participants having the right to challenge the results of the functional capacity assessment, including the ability to undertake a second assessment or seek some form of arbitration if, for whatever reason, they are unsatisfied with the assessment.*"¹⁰

The lack of ability to see the assessment report or get a second opinion is a breach of the principles of natural justice. It is depriving people with disability of choice and control.

k) the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds

There are several reasons why the application of IAs is entirely inappropriate for Aboriginal people with disability from remote Australia, especially with a complex disability like MJD.

Trust

Aboriginal people, especially those from remote communities, are more comfortable with people they know. This trust is built up over time. Using an assessor who is unknown to the person with disability will not result in a reliably accurate assessment.

A recent research paper found that a key element of culturally competent communication was trust established between NDIA staff and individuals, families and communities. It suggested

⁹ op. cit., Department of Social Services, paragraph 3.8, p21.

¹⁰ Review of the National Disability Insurance Scheme Act 2013, Removing Red Tape and Implementing the NDIS Participant Service Guarantee, December 2019, David Tune AO PSM, para 4.34b, p66.

that a strategy to promote that trust would be the use of existing providers in assessment processes while managing conflicts of interests.¹¹

The NDIA recognises this in its Functional Capacity Assessment Framework: *"It should also be noted that there are extenuating circumstances where there will be no option but to have an assessor who knows the person they are assessing, particularly in rural, remote and hard to reach populations. In these situations, any risk of sympathy bias is outweighed by the need to complete the assessment process and to do so in a culturally-sensitive manner"*.¹² It remains to be seen whether this statement in the Framework translates into the proposed legislative changes.

For cultural reasons, a family member may speak on behalf of a participant. This will need to be understood by the assessor and factored in to the use of any generic assessment tool.

Engagement and Interpreters

Recent research has highlighted the inadequacy of current engagement practices between the NDIA and Aboriginal and Torres Strait Islander participants in the Northern Territory and Queensland:

*"I was confused that time. They just popped up out of nowhere, I didn't know they were coming. I was surprised and a little bit frightened...When they come I want a straight story from them that I can understand...They missed me with their words they were using. I rang up J..... and asked her who they were. We didn't know. (Participant)."*¹³

The Tender document Statement of Work says that the NDIA will provide training packages to the Supplier, including training: *"for providing Assessment Services to different cultural groups, including Aboriginal and Torres Strait Islander people."*¹⁴ Given that the recent research questions the effectiveness of NDIA's current engagement practices with Aboriginal and Torres Strait Islander Australians with disability in the NT and QLD, it is questionable whether the NDIA's training packages will be adequate.

Mr Tune in his 2019 report said that: *"One of the biggest risks in implementing the new functional capacity assessment process will be disengagement – that is, people with disability refusing to interact with any of the NDIA-approved providers. As with the NDIS as a system more generally, this is a particular risk for Aboriginal and Torres Strait Islanders, those from CALD backgrounds and those with psychosocial disability."*¹⁵

In order for IAs to work in the Aboriginal context, more intensive and extensive local engagement is required, including *"having access not only to an interpreter but the correct interpreter, taking into account kinship and cultural relationships, ... essential to providing culturally appropriate planning processes."*¹⁶

If assessors are to interview Aboriginal applicants/participants in remote Australia, the NDIA will need to provide an interpreter as English is not the first language in many communities. In

¹¹ Culturally competent communication in Indigenous disability assessment, International Journal for Equity and Health, February 2021, Ferdinand, A., & others, p21.

¹² op. cit., NDIA, paragraph 3.6, p27.

¹³ Ferdinand, A., p12.

¹⁴ Op. cit., Department of Social Services, p11.

¹⁵ Op. cit., Tune D., paragraph 4.35, p67.

¹⁶ op. cit., Ferdinand A. & others, p23.

remote Aboriginal communities it is impractical to expect the correct interpreter to be NAATI-qualified. NDIA should not insist on this qualification in the interests of fairness and equity.

Availability of assessments in remote Australia

In remote Aboriginal communities there is not the infrastructure nor sufficient professionals to be able to administer the assessment in the participant's home environment. David Tune reflected this in his report, saying *"it may not always be possible to source an appropriate provider, or there may be particular individual circumstances where it is more appropriate for non-NDIA approved providers to undertake the assessments."*¹⁷

The NDIA's Functional Capacity Assessment Framework also recognises this: *"Assessment tools that require highly specialized qualifications (such as psychologist or medical specialist qualifications) will not be practical on a national scale especially in geographically isolated areas."*¹⁸

An additional factor is that functional assessments need to be face to face to allow for an optimal interaction between an assessor and an Aboriginal person (or in fact any person) with disability. The Statement of Work related to the tender for the panel of assessors, specifically countenances that assessors can get approval from the NDIA to conduct assessments on-line: *"where distance to a rural town or remote community would make face-to-face Assessment Services impractical"*.¹⁹

This conflicts with the NDIA's Functional Capacity Assessment Framework which acknowledges *"the need to complete the assessment process and to do so in a culturally-sensitive manner"*,²⁰ and the NDIA website which says a participant has a choice *"to have your assessment done at a place that suits you or by video call if you have an appropriate internet connection and device"*.²¹ This prospect of the NDIA having contracted IAs to include Telehealth IAs would be disastrous for people living with disability.

Suitability of Assessment Process

The tender documents specify the time that assessors should spend in undertaking observation and administering the assessment tools (20 minutes) and writing a report (estimated 2-3 hours in total, not including travel). This is not an adequate time to allow for careful consideration of the individual circumstances of applicants/participants, particularly in remote Aboriginal communities where established trusting relationships, cross-cultural communication and language are key factors that determine the quality of engagement.

In order for Aboriginal people with MJD to have the choice and control which is the underlying tenet of the NDIS, applicants/participants need to have their needs, within their cultural context and cultural roles, incorporated into the process. *"In order for assessment and planning needs to be undertaken in a culturally-appropriate and holistic manner, it should incorporate Indigenous perspectives of health and disability, cultural practice (such as storytelling) and familial and communal roles of caring."*²²

¹⁷ op. cit., Tune D., paragraph 4.38., p67.

¹⁸ op. cit., NDIA, paragraph 3.7, p28.

¹⁹ op. cit., DSS, paragraph 1.6, p9.

²⁰ op. cit., NDIA, para 3.6, p27.

²¹ ndia.gov.au/participants/independent-assessments/independent-assessment-process

²² op. cit., Ferdinand A. & others, page 24.

The complexity of the disease, cultural background, goals and family circumstances all need to be taken into account to give the full picture of the support needs of an Aboriginal applicant/participant in remote Australia. It is highly doubtful that the proposed assessment process could lead to this result.

Lack of Culturally Valid Assessment Tools

There is no indication that the assessment tools chosen are validated for Aboriginal and Torres Strait Islander peoples. The Productivity Commission acknowledged this issue in its 2011 report: "*The Commission considers that the NDIS should only use a tool to assess the needs of particular groups where its reliability and validity have been established for that group.*"²³

The World Health Organisation's International Classification of Functioning, Disability and Health (ICF) was developed to represent a compromise between medical and social models of disability, and it is understood that ancestral connectivity and community collectivity are relevant facets of experiencing disability in Indigenous contexts which are not recognized by the ICF. Research shows that the centrality of family is also not recognized in the ICF.²⁴

Until there are ICF tests which are useful and appropriate for Aboriginal and Torres Strait Islander people with disability, the NDIA should use reports from the applicant/participant's known therapists and/or medical specialists.

1) the appropriateness of independent assessments for people with particular disability types, including psychosocial disability

Machado-Joseph Disease is a complex disability. The NDIA acknowledges this by allocating participants with this disability to the complex pathway. A set of standardised questions over a short time period would be grossly inadequate to accurately reflect the functional capacity of a person with MJD which can vary at different times of the day due to their ataxia and the impacts of fatigue.

The length of time for an assessment could also be an issue for an applicant/participant who has MJD. It is a neuro-degenerative disease. Applicants with the disease may find it too tiring to concentrate for that length of time. Even stretching the assessment over 2 or 3 days may be expecting too much. Depending on whether an assessment is done first thing in the morning when the participant is fresher, or later in the day when he/she is more fatigued, the assessment will have different outcomes.

²³ op. cit., Productivity Commission, p318.

²⁴ Op. cit., Ferdinand A. & others, page 25.

m) any other related matters

The MJDF agrees with the conclusion of Professor Bruce Bonyhady in his submission on the NDIA consultation papers, that the NDIA needs to re-think the whole IA process. If it is to proceed it needs:

- an assessment process that is genuinely co-designed with the disability sector and which has strong evidence for its validity, allowing the inclusion of expert reports as part of assessments.
- The assessment process must start with the goals of the participant while also allowing for environmental factors, including sustainable informal supports. It should include an expected range (not a single point estimate) of funding for reasonable and necessary supports, based on individual functional impairments.
- Any planned new approach should have extensive trialling, not piloting. Any testing would need to include ensuring the full range of geographic locations from metropolitan to very remote.
- Once a valid, equitable and consistent assessment process has been evaluated, the evidence for its effectiveness must be made available to the disability sector.
- Assessments should be undertaken by multi-disciplinary teams and, if needed, in multiple settings. The assessment tools and processes must be reliable and lead to accurate and consistent results.
- Continuous evaluation must be a feature of the implementation of any new assessment processes. This should be independent of the Agency and any NDIA partner implementing the new assessment processes.
- There must also be sufficient investment in what the Productivity Commission in its Inquiry into Disability Care and Support described as Tier 2 (people with disability not eligible for the NDIS), to support scheme sustainability.
- The duties and responsibilities of Local Area Coordinators should be aligned with the original intent, with a primary focus on building trusted relationships, assistance with service navigation and service development.²⁵

²⁵ An Analysis of the NDIA's Proposed Approach to Independent Assessments, Professor Bruce Bonyhady AM, Melbourne Disability Institute, February 2021, p15-16.

Conclusion

The MJDF is concerned about the discriminatory impact of generic testing of the functional capacity of Aboriginal people living with disability for the purposes of access and funding decisions under the NDIS, particularly for those who are from remote communities.

The concerns outlined above are legitimate and arise from past experience of Aboriginal people and those who deliver disability services to them in remote and very remote areas. It is imperative that these concerns are addressed before IAs are rolled out across Aboriginal communities in remote Australia.

Recommendations

To address some of these concerns and support Aboriginal people with disability over the course of their lives, the MJDF recommends that the NDIA accepts the need for an exemption for Aboriginal and Torres Strait Islander applicants/participants who come from remote Australia, from mandatory IAs.

Failing that, major adjustments need to be made to the scheme for Aboriginal and Torres Strait Islander applicants/participants in remote Australia. In those circumstances, the MJDF recommends that:

1. any assessment tool used must be validated for use with Aboriginal people with disability;
2. the assessment tools must be administered by professionals that the Aboriginal applicant/participant knows and trusts;
3. family members can be present and are able to assist the applicant/participant as needed;
4. interpreters (to be paid for by the NDIA) must be used in the application of the assessment tools where English is not the first language of the applicant/participant;
5. the assessor's report must be provided to the applicant/participant before the planning meeting;
6. participants have the right to challenge the results of the functional capacity assessment if they are unsatisfied with it;
7. the NDIA must consider any other allied health professional reports provided by the applicant/participant and not rely solely on the standard functional assessment;
8. the NDIA must publish detailed information about how it calculates a funding package based on the functional assessment; and
9. the NDIA must consult with Aboriginal people with disability and organisations that provide disability services to them before implementing these changes, allowing enough time for Aboriginal participants to be informed about and understand the changes before they are implemented.

Appendix A – Consultation

MJD Foundation

Since its inception in 2008, the MJD Foundation (MJDF) has been working in partnership with Aboriginal²⁶ 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 communities²⁷. 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.

²⁶ 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.

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



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. Birritjimi (Wallaby Beach) 15. Gungyangara (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 (Oenpetli)
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