24 February 2021

Committee Secretary
Joint Standing Committee on the National Disability Insurance Scheme Independent Assessments
PO Box 6100
Parliament House
Canberra ACT 2600

To whom it may concern

Response to Joint Standing Committee on the NDIS Independent Assessments

Thank you for the opportunity to provide comments relating to introduction of independent assessments in 2021 as part of the NDIS access and planning processes.

Marathon Health is a proud NDIS provider, with a focus on outreaching services to isolated and vulnerable people in Western and Southern NSW and the ACT. We currently support more than 1,000 NDIS participants and have another 431 on waiting lists for our services.

While we believe the proposed process of independent assessments will meet the needs of new NDIS clients in most situations, we anticipate that the proposed process will disadvantage, frustrate and create barriers for participants in rural and remote Australia (particularly Aboriginal and Torres Strait Islander communities); people with psychosocial and complex disabilities; and existing participants who need a plan review due to a change of circumstances.

In the attached submission, we address the following five key issues:

1. Workforce availability
2. Cultural sensitivities and safety
3. Location barriers
4. Complexity challenges
5. Reassessments impacting on continuity of care.

We also outline recommendations for resolving these issues and provide scenarios for the barriers independent assessment will create.

One of the goals under our strategic plan is to support some of the most complex, isolated and vulnerable people in regional and rural NSW on their NDIS journey. We feel strongly about helping create an inclusive Australian society that allows people with disability to fulfil their potential as equal members of the community. We urge the committee to reconsider the barriers this independent assessment process will create for people with a disability and to recognise the unprecedented freedom of choice that people with disability were promised when the NDIS was first established.

Thank you for the opportunity to comment on the NDIS independent assessment process.

Yours sincerely

Justine Summers
Chief Operations Officer

T 1300 402 585
ABN 86 154 318 975

marathonhealth.com.au

Albury **Bathurst** **Canberra** **Dubbo** **Wagga Wagga**

marathon health
Better healthcare, closer to home

NDIS Independent Assessments Submission

February 2021

Independent assessments submission

Introduction

Marathon Health is a not-for-profit, registered charity with a vision of enabling communities to thrive through improved health and wellbeing. We are one of the few health organisations largely based in country Australia with the core purpose to develop and deliver health and wellbeing services in partnership with communities. We are passionate advocates for equal access to quality health services for people, wherever they choose to live.

We deliver a range of high-quality programs that focus on providing supportive care in a person-centred environment. Approximately 55% of our services are focused on mental health, within a recovery-oriented framework. In 2019-20 we supported 992 NDIS participants across 52 communities in Western NSW and the Murrumbidgee, delivering 1,917 services. We helped activate 470 NDIS plans to ensure people had the services they needed through our support coordination services. We have another 431 people on wait lists for our services. We are also partnering with the NDIA to ensure that NDIS participants with exceptionally complex support needs (ECSN) in NSW, the ACT and South Australia are provided with professional, evidence-based supports that help stabilise crisis situations.

We are strongly invested in ensuring the growth of the disability workforce. We hosted Mind the Gap forums in Western NSW when the NDIS started, to bring providers together to understand the environment and learn how to operate cooperatively. Our goal is not to corner the market – but to grow the support available so that people have greater choice in providers and shorter wait time.

Our workforce of 300 includes more than 80 clinicians in speech pathology, occupational therapy, psychology, social work, counselling, dietetics & diabetes education. Our graduate recruitment and student placement programs are strong and represent partnerships with universities across NSW, the ACT and Victoria to develop employment pathways. In 2019-20, we hosted 41 clinical students across all disciplines. To date this calendar year, we have welcomed eight new graduate employees and seven students on clinical placement.

The issues through our eyes

We believe the proposed process of independent assessments will meet the needs of new NDIS clients in most situations. However, we anticipate that the implementation of a panel of healthcare professionals using standardised tools to conduct assessments will disadvantage, frustrate and create barriers for:

- Participants in rural and remote Australia, particularly Aboriginal and Torres Strait Islander communities
- People with psychosocial disabilities
- People with complex disabilities, including communication issues
- Existing participants who need a plan review due to a new life stage or other change of circumstances.

The Tune Review specifically recommended the NDIA not implement a closed or limited panel of providers to undertake functional capacity assessments, yet that is what the NDIA proposes to do. This not only contradicts the Tune Review, but also takes away the unprecedented freedom of choice that people with disability were promised when the NDIS was first established. In our experience, people with disability want the opportunity to choose their own provider. Most have established a relationship with one or more health professionals, who get to know their particular life circumstances, how the disability

Independent assessments submission

impacts their capacity to live the life they choose, and what supports will work best. It takes time to develop those relationships and be able to prepare reports that are appropriate for the NDIS process.

We worry that participants we are working with will not feel that their circumstances have been fully understood because the assessors won't know the person, or appreciate the environment they live in of their culture. Things are likely to be missed and judgements may be made that do not reflect the true circumstances, especially if the day the assessor comes to visit is not reflective of most days the person experiences.

It is also difficult to agree that independent assessments will be the solution for the financial inequality issues that currently exist in the access process, because our participants will still face out-of-pocket expenses related to a diagnosis and having a medical specialist confirm that their disability is likely to be permanent and impact on their daily functioning.

Following are the key issues we have concerns about and associated recommendations:

- Workforce availability
- Cultural sensitivities and safety
- Location barriers
- Complexity challenges
- Reassessments impacting on continuity of care.

Workforce availability

In our experience, finding experienced allied health clinicians who have worked with people with disabilities and have access to appropriate clinical supervision, to administer these independent assessments will be the most significant challenge in rural and remote communities. The criteria for people to be on the panel of independent assessors is quite challenging. Assessments are also not generally the type of work experienced clinicians want to undertake, so this puts the quality of the process at risk.

We anticipate that organisations delivering assessments as part of the panel will need to draw a clinical workforce away from existing areas of need, including sensitive industries such as aged care, early childhood early intervention and allied health clinicians already delivering NDIS services – some of whom may not be experienced in working with people with disability, particularly psychosocial participants. While this might boost the number of people engaging with the NDIS, it will cause a delay in people activating plans and receiving life-changing supports. This will impact further on waiting lists in rural and remote areas, which are already in the hundreds, with waiting times of more than a year.

As an organisation committed to the development of the industry, we do not want to lose staff or have to compete for new graduate employees. We regularly host students on clinical placements and have a strong graduate recruitment focus as part of our commitment to growing the industry for the benefit of all people with disability. We have partnerships with universities across NSW, the ACT and Victoria to develop employment pathways and have hosted 48 students on clinical placement in the past 18 months. A similar approach will be required by the NDIA to grow the workforce needed if independent assessments are to be an integral part of the NDIS in the future.

Our recommendation

The NDIA needs to develop a strong disability employment pathway strategy so that it can grow its own allied health workforce and avoid moving people out of other sensitive industries and causing a backlog in the delivery of NDIS.

Independent assessments submission

Cultural sensitivities

Of the 523,200 Aboriginal and Torres Strait Islander people living in private households in 2015, almost one-quarter (23.9%) reported living with disability and 7.3% (38,100) had a severe or profound disability, meaning they sometimes or always needed help with daily activities related to self-care, mobility or communication (ABS 2017).

AIWH data shows that when compared with non-Indigenous Australians, Indigenous Australians are 1.8 times as likely to have disability and yet only 6.2% (22,749) of all NDIS participants identified as Indigenous at 31 March 2020. Although it has now reached 400,000 people with disability, the current NDIS system has not yet achieved the volume of Aboriginal and Torres Strait Islander people that was initially expected.

With Aboriginal and Torres Strait Islander people with disability already at a disadvantage culturally, the independent assessment process is likely to be another barrier to them accessing the support they need. People with disability are the experts in their own support needs. Building relationships with GPs and other medical and allied health professionals and developing a productive, shared understanding of their individual needs can take time and requires a mutual commitment to building trust. In rural and remote Indigenous communities, those health professionals also need a high level of cultural awareness and recognition to ensure people will engage in the process.

We are concerned that people who are unfamiliar with working in rural and remote areas, particularly those who have not worked in Indigenous communities, will be expected to assess Aboriginal and Torres Strait Islander people needing access to the NDIS – if those people don't give up on accessing the system completely.

In the ECSN program we are facilitating a Community of Practice (CoP) for support coordinators delivering services into Anangu Pitjantjatjara Yankunytjatjara (APY) Lands in South Australia, the Northern Territory and Western Australia. The APY Lands Support Coordination CoP has identified significant concerns in relation to independent assessments, primarily revolving around the complexity of Indigenous and very remote communities. With the paucity of providers currently delivering supports into APY Lands, there is little likelihood that the NDIA will find a service able to enter APY Lands in the first instance and then undertake quite complex assessments. This is likely to further disadvantage many of the participants living in APY Lands and may cause some NDIS participants to lose access to the scheme.

We also have concerns about the skill set of people undertaking independent assessments in any Indigenous communities where people with complex chronic health conditions are located. Assessors need to have enough subject matter expertise to navigate the issue around chronic health related needs versus permanent disability and where the two intersect and impact on functional capacity.

We ensure all our frontline staff receive cultural safety training and, when working with Indigenous people, our clinicians know the importance of individualising the tools and language they use to suit the setting and fit the context. It is likely that independent assessors working in rural and remote Indigenous communities will need to link with known, trusted and respected key workers and use their links to reach people needing an assessment for the NDIS.

Our recommendations

i. That the NDIA consider excluding people living in remote Aboriginal and Torres Strait Communities from the need to undertake independent assessments, in a similar fashion to the exemptions from mutual obligation requirements that apply for Centrelink participants living in some very remote areas.

Independent assessments submission

ii. That independent assessors work with rural and regional planners who have established relationships, are respected, and understand the cultural nuances around working with people and communities in rural and remote communities.

Location barriers

It is widely anticipated—and feared—across the disability industry that that panel of approved providers will comprise a few large, possibly multinational, companies. It is likely that panel members will be largely based in major centres, meaning there will be a need for significant travel to reach people in rural and remote areas – and travel comes at a cost.

If members of the assessment panel are not based in rural areas; they may be unable or unwilling to travel or the costs may be prohibitive. This will mean they are unable to offer people in rural and remote locations the same access to services as people who live in major centres. This will simply be another barrier to people who already have access issues.

Virtual assessments will dilute the quality of outcomes and put people in rural and remote areas at a higher disadvantage of gaining approval to participate in the NDIS. Some of the participants we work with would also struggle to connect to a telehealth session. Research suggests that for many people with disabilities, the only way to make telehealth successful is to use a local support person to navigate the technology and help the person express their needs and wants. Other people in our region live in remote areas where internet access is poor, while we have found that most children can only concentrate in front of a screen for up to 30 minutes. These participants are unsuitable for a telehealth assessment – they need a familiar, comfortable environment where they can demonstrate their everyday needs.

Our recommendations

i. That face-to-face assessments be the priority, with telehealth assessments used as a last resort.
ii. That video assessments be used if a telehealth assessment is unavoidable.
iii. That evidence and/or advice provided by a treating professional who a person with a disability in a rural or remote area already engages with be accepted as part of the independent assessment process.

Complexity challenges

It is difficult to agree that a standardised assessment tool will accurately capture the wildly diverse needs of people with all kinds of disability. In 2018, almost one-quarter (23.2%) of all people with disability reported a mental or behavioural disorder as their main condition (ABS), up from 21.5% in 2015. In 2017, the NDIA estimated that by full roll-out of the NDIS (estimated to be 2019-20), 13.9% of NDIS participants (64,000) would have a primary psychosocial disability requiring support. At June 2019, that figure had reached 9.1% (27,975 people).

In our experience, people with psychosocial issues face huge challenges in accessing the NDIS already and this is partly contributing to the lower than anticipated take-up rate. We support the view of Occupational Therapy Australia and mental health consumer groups that the measurement tools proposed are not appropriate for psychosocial assessments. The fact that highly vulnerable people will be assessed by complete strangers, rather than the health professional they have come to know and trust is of significant concern.

Other people with reduced cognitive abilities would need questions to be rephrased so they can understand what is being asked. We also work wit people who would give a false picture of their circumstances and overstate their ability, in the faith they are giving the “correct” answer or what they think the assessor want to hear.

Independent assessments submission

The short time frame allowed for independent assessments under the NDIA's proposal is another significant obstacle for people with complex conditions. It is difficult to assess the episodic and fluctuating nature of mental illness in the context of a one-off engagement that lasts for approximately three hours and has as little as 20 minutes of clinical observation. This timeframe also tends to result in an assessor selecting an inappropriate task to observe. This type of decision requires clinical skill and time for the participant to identify a suitable functional task.

One size does not fit all. This process does not allow enough time for anyone to get to know a participant, appreciate their lifestyle, environment and aspirations and to really understand their needs. And while a person may perform the assessment tasks competently in their home environment, to gain a true appreciation of how they manage in all of the environments they interact with, as assessor will need a considerably longer period of time to undertake an assessment.

The prospect of attending compulsory assessments, with unfamiliar healthcare professionals who are unfamiliar with their circumstances and with limited time to communicate their needs and basic supports, is highly distressing to many NDIS participants. This process will only compound those challenges as they need to build trust and rapport with the people they work with – and that takes time. The specialists and clinicians who deal regularly with people with complex disabilities know and understand their difficulties, their limitations and their aspirations and need to be an integral part of the process.

They would benefit from having a key worker or support person involved in the assessment and to assist the independent assessor.

Our recommendations

i. That the NDIA develop an assessment process that can be administered by suitable key workers for people with complex disability, including cognitive and psychosocial issues—such as locally-based nurses and psychosocial recovery coaches—who have experience working with people with complex disabilities, can build rapport with them and be subcontracted to undertake the task. And that key worker assessments be administered in consultation with a skilled allied health clinician who is a member of the independent assessment panel.
ii. That the NDIA ensure that customer satisfaction benchmarks and service level agreements are put in place for members of the independent assessment panel.
iii. That evidence and/or advice provided by a treating professional who a person with a complex disability already engages with be accepted as part of the independent assessment process.

Reassessments impacting on continuity of care

A client needing a reassessment, due to a new life stage or other change in circumstances, may be on an existing waiting list for support or have existing support arrangements. At Marathon Health, we already have more than 400 people on our waiting list, particularly for speech pathology and occupational therapy, with wait times up to 18 months for occupational therapy. We fear that if there is a delay in the independent assessment process—particularly for reassessments—clients who are already receiving supports will lack continuity of their care, or go for significant periods without support, while others may fall further down the waiting list while they wait for their assessment.

Our recommendation

That evidence and/or advice provided by a treating professional who a person with a disability already engages with be accepted as part of the reassessment process when there is a change in life stage or circumstances.

Independent assessments submission

Client scenarios

To highlight the impact that we believe the current proposal would have on our clients and others with complex disabilities, including communication and psychosocial disabilities, as well as people in rural and remote Australia, we have documented the following scenarios that our clients have already experienced. These client scenarios highlight the barriers that people in rural and remote Australia and people with complex issues can face.

Scenario 1: Unsuitable wheelchairs

We now support two participants at Bourke (a four-hour drive from Dubbo) who were assessed at Dubbo for wheelchairs that did not suit their needs. One was assessed by a clinician while he was in rehabilitation at Dubbo after an amputation. It could only fit into his front door if he lined it up perfectly straight, but after two years it is nearly falling apart because it does not suit the terrain he travels across. These oversights were because his assessment took place remotely.

The second man was also assessed while at Dubbo and prescribed a $38,000 wheelchair that he could not use outside his home, so he chose not to use it at all. He was later assessed by one of our occupational therapists at his home and has now had a second (similarly priced) wheelchair prescribed that he can use both in his local community and inside his home.

There could have been considerable time and financial savings and improvements in both clients' mobility and wellbeing if they had access to an assessment within their usual environment.

Scenario 2: The psychosocial client who tells people he is independent

We support a participant who, due to the impacts of his psychosocial disability, does not acknowledge that he has a mental health diagnosis. He is open in telling people that he can achieve all of his goals without support, including looking after his home and independently managing his living skills. But he could do none of these things before he had an NDIS plan to deliver the support he needs to follow through with his goals. Before the NDIS, he didn't realise when he needed to have a shower, could not maintain an adequate diet and would seclude himself in his home. He now lives independently and is active in his community.

If this participant was reassessed by somebody who didn't know him well and had not developed a trusted relationship with him, he would be unlikely to be honest about the assistance or support he needs to achieve his goals. This could potentially leave him with no assistance at all.

Scenario 3: Retelling stories of trauma can be damaging

We have one participant who has been living with a complex psychosocial disability who has a complicated trauma background and had to retell her traumatic story many times - explaining to strangers how difficult her life has been. Telling others about the things that she has lost in her life has caused additional trauma. She has had to constantly explain why she has lost her independence and feels she has to prove that she cannot lead the same life as others.

She had to visit a different specialist during the NDIS assessment process and was initially declined access because the NDIA deemed that the severe and persistent mental health condition diagnosed by her treating clinical team was not significant enough. After an appeal, and support through the psychosocial access stream at NDIA, she was granted access to the NDIS and it has supported her to live the life she chooses. We expect that asking her to prove her disability to another independent assessor will have a significant impact on her mental wellbeing; reduce her trust in the NDIS; and take away her willingness to continue with the scheme, despite the many benefits it has given her.