Physical Disability Australia Ltd
PO Box 345
Toowong QLD 4066.
T | 1800 PDA ORG (1800 732 674)
E | manager@pda.org.au



Friday 12 March 2021

| www.pda.org.au

Mr Martin Hoffman Chief Executive Officer, National Disability Insurance Agency (NDIA) GPO Box 700 CANBERRA ACT 2601

RE: Consultation Paper on the National Disability Insurance Scheme (NDIS)
Access and Eligibility Policy with Independent Assessments

Dear Mr Hoffman

Thank you for putting out a consultation paper on the new NDIS Access and Eligibility Policy<sup>1</sup> and for inviting people with disability and their representative organisations to submit responses to it. What follows is Physical Disability Australia's (PDA's) answers to the questions posed in the paper

We are doing this because we understand the need for a more evidence-based approach for determining who becomes a participant and the benefits they receive, and we wish to contribute to the development of it so that is transparent and fair.

We also understand that a lot of the development of the proposed Access and Eligibility Policy has already been done and the decision to implement Independent Assessments (IAs) has already been made. To this point, PDA would like it noted that we are a signatory to the *Disability sector statement on the Australian Government's planned reforms to the NDIS*<sup>2</sup> that was released on March 11, 2021 and are in broad agreement with its concerns and recommendations.

#### Learning about the NDIS

1. What will people who apply for the NDIS need to know about the IA process? How this information is best provided?

PDA believes an open and honest approach is needed to explain the new Access and Eligibility Policy not just to existing NDIS participants directly, but also to the Australian population as a whole indirectly (through mainstream advertising platforms) so that it is clear that:

- Medical information with regard to participants' specific disability diagnoses will continue to be a significant factor in determining funding levels in the present and future;
- The IA process is being implemented to provide an objective assessment of the functional impact of a person's disability; **and**
- IAs are also being implemented to address threats to the sustainability of the NDIS.

<sup>&</sup>lt;sup>1</sup> <u>https://www.ndis.gov.au/media/2874/dow</u>nload

<sup>&</sup>lt;sup>2</sup> https://everyaustraliancounts.com.au/wp-content/uploads/Statement-of-Concern-NDIS-changes-Full-statement.pdf

In our opinion, the consultation paper lacks candour. It raises the need for uniformity of information with regards to the functional impact of disability, and that the measure will provide greater equity to people with disability who lack the means to get the necessary documents from specialist doctors and allied health professionals... but there is no mention of the other 'benefits' the new access and eligibility policy brings to the NDIA and the Federal Government.

In meetings that are not open to the public, it has been made clear to us and our partner organisations in the disability representative community that the escalating costs of the NDIS are a real source of concern to the Board of Directors, senior management team and government ministers. The term 'unsustainable' has been used and it is clear that stopping the ongoing escalation of costs is of the utmost importance.

PDA understands this and we believe the broader community of people with disability, their families and supporters will understand and accept this too if a commitment is made to lay the fiscal facts before them, and it is acknowledged that IAs are a way to set evidence-based benchmarks for "reasonable and necessary" levels of support.

## **Accessing the NDIS**

2. What should we consider in removing the access lists?

PDA believes removing access lists is problematic due to the overlapping definitions of disabilities and medical conditions and that each person's understanding of what a 'disability' is, and what a 'medical condition' is, is different. For example some people will consider arthritis to be a disability because it is incurable and results in diminished capacity to undertake the activities of daily living over time. Other people will consider arthritis to be a medical condition because it is the effect of an agerelated disease and there are medical and allied health treatment regimes that have some effect on its symptoms. Here an access list can clearly specify whether arthritis, for example, is considered a 'disability' for the purpose of allowing or excluding access to the NDIS, or a 'health condition' for the purpose of referring them to mainstream health services.

PDA feels it is very important for details about an applicant's or participant's disability diagnosis (including details about the expected changes to the degree of impairment over time) to stand in equal importance to the results of an IA when it comes to determining (ongoing) eligibility for participant status and assessing the amount of support that person may need to lead "an ordinary life".

The document linked to in the consultation paper<sup>3</sup> goes into a great deal of detail about the calculations and negotiations that go on between the NDIA and jurisdictional health departments (and other jurisdiction mainstream services) to determine who is responsible for addressing the health and support needs of a person with permanent impairments that adversely impact on their lives, but we fear there will be people left without vital supports if there is no list of conditions that clearly identify 'disabilities' simply because they do not display significant functional impairments at a given point in time.

For example, infants with Down Syndrome, may meet many developmental milestones before they reach school age and so an IA may not identify current

<sup>&</sup>lt;sup>3</sup> Applied Principles and Levels of Support (<a href="https://www.coag.gov.au/sites/default/files/communique/">https://www.coag.gov.au/sites/default/files/communique/</a> NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf)

functional impairments and as a result of these, it is foreseeable that an NDIA Planner/delegate without detailed knowledge of the likely prognosis of Down Syndrome nor the efficacy of early intervention therapy, may deem such an infant ineligible for participant status. This would be a great injustice because it is well known that the condition is highly likely to have significant developmental and functional implications as the infant ages though school years into adulthood.

Having access lists that clearly identify conditions that are known by health professionals and the broader community to be medical conditions would significantly ameliorate this risk.

For older applicants, Multiple Sclerosis, is an example of an impairment identified in List B (Permanent conditions for which functional capacity are [sic] variable and further assessment of functional capacity is generally required<sup>4</sup>), as a disability likely to make an applicant eligible for access to the NDIS, but in it's early stages, a person with MS may have no significant functional impairment and, under the new policy, may be denied participant status at that point. As with an infant with Down Syndrome, such a person may benefit significantly from early interventional therapy and thereby save the NDIS significant money in years to come.

3. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?

The simplest way to clarify evidence requirements from health professionals about the nature of a person's disability is to provide relevant existing and would-be participants with a form for those health professionals to complete: diagnosis; prognosis; likely functional impact; etc. This is something that should be fairly simple to create with reference to the eligibility criteria set down in the *NDIS Act*.

To support affected existing and would-be participants with limited financial means, the NDIA could offer to have these forms completed in an Independent Medical Examination (IME) organised by the NDIA. Many employers currently use the IME process to similarly gather information and medical advice regarding employees' injuries and capacity to fulfil the occupational requirements of their roles.

In making this recommendation however, we recommend more care be taken to identify understanding and empathetic health practitioners than those typical retained by many employers and workers' compensation insurers.

4. How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

The blurriness over what conditions constitutes a 'disability' that renders someone eligible for the NDIS is something that needs to be addressed with clear legislation and plain English policy statements. PDA does not think this can be done without adding a schedule with a list of conditions to the *NDIS Act* that will certify 'disability' if they are accompanied by clearly measurable or predictable loss of functional capacity.

<sup>&</sup>lt;sup>4</sup> https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-b-permanent-conditions-which-functional-capacity-are-variable-and-further-assessment-functional-capacity-generally-required

The NDIS Act needs to acknowledge, and the NDIA also needs to understand, that many "chronic and acute" health conditions will cause disability if and when health treatment fails to ameliorate them.

Diabetes Miletus, for example is a condition that many people (and the NDIA) understand to be a chronic health condition rather than a disability. However, if the disease, which affects blood circulation results in the amputation of a foot, or blindness, then it needs to be understood as a disability from that point forward. As such, it is the NDIA's best interest to explain this in general terms and make it clear what constitutes a disability from their perspective.

# **Undertaking an Independent Assessment**

5. What are the traits and skills that you most want in an assessor?

Independent assessors should have an appropriate allied health qualification and familiarity with the circumstances of a broad range of disabilities and the impacts they have on a person's life. They should also be assessed personally themselves for empathy and an ability to understand and document what is being communicated to them.

6. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

Holding the IA in a participant's home is usually the best option as this provides an opportunity for an assessor to clearly understand the circumstances of the participant and what his or her needs might be (especially with regards to home modifications). However, it needs to be born in mind that many people with disability live in situations that are less than ideal and not of their own choosing. Assessors need to be aware of this and have the flexibility to organise to meet participants elsewhere as required. When this is done a supplementary assessment of the participants' need for Specialist Disability Accommodation (SDA) or capacity building supports to enable them to identify and secure a personal housing solution, should be conducted in addition to the standard assessment(s).

7. How can we ensure IAs are delivered in a way that considers and promotes cultural safety and inclusion?

As with all matters related to cultural appropriateness and inclusion, the way to ensure IAs are culturally inclusive is to specifically recruit Allied Health practitioners who are skilled at interacting with people from culturally and linguistically diverse (CALD) backgrounds.

As PDA understands the situation, the people who carry out the IAs will be employees of companies who win tenders to undertake the work. However we do not know if CALD expertise is an essential selection criteria for successful tenderers. If it is not, we recommend it be made so.

If the NDIA is unable to find tenderers with CALD expertise, then it may need to consider directly employing a pool of allied health professionals with CALD expertise as a means to ensure inclusivity. This, of course, will mean the assessments are not 'independent' *per se*, but we believe the 'independence' of the assessors is less important than their capacity to interact with participants in culturally appropriate ways.

The NDIA should also ensure that the Allied Health professionals who carry out IAs also have access to the funds required to use interpreters where (would-be) participants prefer to use languages other than English (including Auslan).

### **Exemptions**

8. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

PDA believes that people who can not understand the assessment process, are noncommunicative, who have clearly identifiable intense support needs that are justified by medical reports from relevant specialist health practitioners should be exempted from the need to undergo an independent assessment.

We learnt in a recent meeting that it is proposed a diagnosis of Motor Neurone Disease would trigger an exemption from the general IA process because the disease progresses promptly, with escalating serious functional impairments leading to a person's death within a relatively short timeframe. PDA recommends other disabilities be granted similar exemptions where the prognosis is clear and resultant functional impact is, regrettably, clear and assured.

We also believe that participants such as these should be given long term packages of support that forgo the need for regular reviews. PDA is aware that the families of participants with profoundly significantly disabilities are anxious about the prospect of having to 'prove' their loved one has ongoing needs to a changing panoply of gate-keepers on a regular basis.

### **Quality assurance**

9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

PDA believes the best way to monitor the quality of IAs is to recruit and employ a panel of expert assessors to randomly audit the work of IA contractors to ensure assessments are being conducted to a high standard and that the reports created properly summarise the evidence gathered. To accomplish this, it will be necessary for some assessment interactions to be observed and/or recorded.

We also believe quality assurance needs to incorporate feedback from assessment subjects; those that become and remain NDIS participants, and those that do not get access or lose it. To ensure valid and accurate feedback reports are done, PDA would recommend this work be outsourced to a reputable tertiary education institution and not be done by NDIA staff nor a for-profit consultancy firm. In recent times PDA has been alarmed at the (lack of) quality of some outsourced research documents commissioned by government departments.

# Communications and accessibility of information

10. How should we provide the assessment results to the person applying for the NDIS?

To begin with, assessment results should be provided to subjects as a matter of course, without the need for them to be requested.

The assessment results should be provided in 'writing<sup>5</sup>' in the languages of the assessment subjects' choice. Where the subjects are not readers, then assessment

<sup>&</sup>lt;sup>5</sup> If the assessment subject is a member of the Deaf community, the NDIA should consider making assessment results available in Auslan through a video recording.

results should be provided verbally, via telephone, video-conference, or in-person meetings with an invitation to the subject to include a support person of their choice.

To facilitate the provision of results in this manner, PDA recommends that the NDIA produce an assessment result proforma template that explains in plain language what each element of the IA conducted seeks to determine and how the subject's score was assessed. The proforma should also detail what each range of assessment scores means in terms of entry into the scheme and likely impact in budgeting calculations.

We also think it is important for IA subjects to be given the opportunity to discuss their assessment results with an appropriate expert so their concerns can be noted and any misunderstandings they have resolved.

#### In Conclusion

PDA hopes the answers we have given to the consultation paper's questions are clear and receive your favourable consideration.

Yours Sincerely,

Liz Reid

President and Director (NT)

Physical Disability Australia Physic

Simon Burchill Manager

Burlill

Physical Disability Australia

#### **About Us**

Physical Disability Australia (PDA) is a national peak membership-based representative organisation run by people with physical disability for people with physical disability. PDA was founded 21 years ago and we have over 1,000 members from all Australian States and Territories. Our purpose is to:

- Remove barriers through systematic advocacy to all levels of government to enable every Australian living with a physical disability opportunities to realise their full potential;
- Proactively embrace and promote difference and diversity for an inclusive society; and
- Actively promote of the rights, responsibilities, issues and participation of Australians with physical disability.