



Australian Federation of
Disability Organisations

“Nothing About Us Without Us”

**Submission to the
NDIS Joint Standing Committee
on
Independent Assessments**

April 2021

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- Researcher Michelle Fitts

WESTERN SYDNEY
UNIVERSITY



Institute for Culture
and Society

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- Polio Australia
- National Mental Health Consumer and Carer Forum
- AED Legal Centre
- Autism Aspergers Advocacy Australia (A4)
- NoFASD
- Disability Justice Australia
- Deafness Forum Australia
- Down Syndrome Australia
- DeafBlind Australia

About AFDO

Since 2003, the Australian Federation of Disability Organisations (AFDO), a Disabled Peoples Organisation (DPO) and Disability Representative Organisation (DRO), has been the recognised national peak organisation in the disability sector, along with its disability specific members, representing people with disability. AFDO's mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life.

Our member organisations represent disability specific communities with a total reach of **over 3.8 million Australians**.

AFDO continues to provide a strong, trusted, independent voice for the disability sector on national policy, inquiries, submissions, systemic advocacy and advisory on government initiatives with the Federal and State/Territory governments.

We work to develop a community where people with disability can participate in all aspects of social, economic, political and cultural life. This includes genuine participation in mainstream community life, the development of respectful and valued relationships, social and economic participation, and the opportunity to contribute as valued citizens.

Our vision

That all people with disabilities must be involved equally in all aspects of social, economic, political and cultural life.

Our mission

Using the strength of our membership-based organisations to harness the collective power of uniting people with disability to change society into a community where everyone is equal.

Our strategic objectives

To represent the united voice of our members and people with disability in national initiatives and policy debate.

To enhance the profile, respect and reputation for AFDO through our members.

To build the capacity and sustainability of AFDO and our members.

To foster strong collaboration and engagement between our members and stakeholders.

To enhance AFDO's connection and influence in international disability initiatives, particularly in the Asia Pacific region, through policy, advocacy and engagement.

Our members

Full members:

- Autism Aspergers Advocacy Australia
- Blind Citizens Australia
- Brain Injury Australia
- Deaf Australia
- Deafblind Australia
- Deafness Forum of Australia
- Down Syndrome Australia
- Disability Advocacy Network Australia
- Disability Justice Australia
- Disability Resources Centre
- Enhanced Lifestyles
- National Mental Health Consumer and Carer Forum (NMHCCF)
- People with Disability WA
- People with Disabilities ACT
- Polio Australia
- Physical Disability Australia
- Women with Disabilities Victoria
- Women with Disabilities ACT

Associate members:

- AED Legal Centre
- All Means All
- Aspergers Victoria
- Disability Advocacy and Complaints Service of South Australia (DACSSA)
- Disability Law Queensland
- Leadership Plus
- National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD)
- YDAS – Youth Disability Advocacy Service



Introduction: “Nothing About Us Without Us”

We appreciate and thank the Joint Standing Committee for allowing us the opportunity to outline our concerns over the proposed implementation of Independent Assessments and changes to the NDIS.

The Australian Federation of Disability Organisations (AFDO) and our Members would also like to acknowledge Minister Reynolds as the new Minister for the NDIS. We believe that Minister Reynolds has a unique opportunity to reset the strained relationship between the senior management of the NDIA with people with disability, their families communities and the organisations that represent them with the senior management of the National Disability Insurance Agency.

We want to state that our commitment and support of the NDIS is unequivocal and that we all wish to work collaboratively and provide our expertise and deep knowledge of the NDIS to develop improvements

We are deeply concerned about:

1. The lack of consultation and co-design with people with disability, their families, communities and the organisations that represent them regarding Independent Assessments and changes proposed to the NDIS
2. How the functional assessments will be carried out
3. How the assessments will be used to determine participant plans and funding
4. The impact of these assessments and the availability of support for participants

“The proposed introduction of IA represents a totally top-down approach to planning. It begins with a participant’s impairments, rather than their goals and aspirations.

It puts people in boxes before they have had a chance to outline what they would like to achieve or the ways in which they hope their lives change. It could mean that aspirations like leaving home or increased independence will need to be traded off against essential supports or that funding to support these activities will be lost if not used.

*It is also unclear how environmental factors, such as **sustainable informal supports** (not informal supports) will be included in IA. This is counter to everything that people with disability and their families and carers hoped for in the creation of the NDIS and fundamentally undermines the principles on which it was founded.”¹*

¹ Professor Bruce Bonyhady - The Melbourne Disability Institute. Submission to the NDIS Joint Standing Committee Inquiry into Independent Assessments “An Analysis of the NDIA’s proposed approach to Independent Assessments” February 2021

We fully endorse the following Submissions and Issues Papers:

- **The Public Interest Advocacy Centre**

Submission to Joint Standing Committee on the NDIS Inquiry into Independent Assessment March 2021

- **The Victorian Council of Social Services**

Issues Paper: NDIS access, eligibility and independent assessments Submission to the Joint Standing Committee on the NDIS Inquiry into Independent Assessments March 2021

- **The Melbourne Disability Institute – Professor Bruce Bonyhady**

An Analysis of the NDIA's proposed approach to Independent Assessments

- **The Commonwealth Ombudsman**

Inquiry into Independent Assessments February 2021

- **NoFASD**

Survey results: Community concerns about compulsory assessments March 2021

Recommendations

We maintain and continue to endorse the wider sector recommendations on this issue;

1. Immediately cease the roll-out of compulsory assessments as currently planned
2. Undertake a robust and transparent outcome evaluation of the current pilot of the new assessment process. The evaluation must be independent of the NDIA, led by experts and co-designed by people with disability, their families and the organisations that support them
3. Undertake robust, independent and transparent trials of alternative approaches to improving consistency in access and planning – such as allowing a person’s existing health professionals to complete assessments using the same tools
4. Once the trials and evaluations are complete, engage in a meaningful co-design process with people with disability , their families and the organisations that support them to ensure a fair and consistent approach to both access to the scheme and planning and to ensure people with disability receive the support they need

What the Productivity Commission and Tune Report Actually Proposed

Both the Productivity Commission and the Tune Review have set out the principles that frame how Independent Assessments could be undertaken.

- *where possible (and with the individual's permission), the **Scheme should make use of existing medical reports.***
- ***assessments should be portable** across the system — subject to protection of privacy — **so people do not have to repeat information for different providers or government agencies.***
- ***assessments and re-assessments should occur when people join the Scheme, and again at key life stages or when circumstances change.***
- *where an **informal carer** provides substantial care, they **should receive their own assessment if they wish.***
- ***the power to require prospective participants or participants to undertake an assessment be discretionary.***
- ***at least in the short term, the NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments.***
- ***key protections would need to be embedded into the approach, in particular:***
 - ***the right to choose** which NDIA-approved provider to conduct the assessment*
 - ***the right to challenge the results of an independent assessment***
 - *the need for uniform accreditation requirements, **designed and implemented jointly by the NDIA and disability representative organisations***
 - ***the availability of clear, accessible publicly available information about independent assessments.***²

Independent Assessments in other Contexts

Independent Assessment process have been applied in a number of other contexts. In each circumstance this has impacted negatively on people's access to the particular program and the support they received from the program.

Independent Assessments in the Disability Support Pension Space

In 2014/15 the Department of Social Services implemented the following changes to medical evidence assessment:

- From July 2015 individuals applying for the DSP were required to provide all of their medical records. This includes a submission of a medical report from their treating doctor.³

² The Victorian Council of Social Services: Issues Paper: NDIS access, eligibility and independent assessments Submission to the Joint Standing Committee on the NDIS Inquiry into Independent Assessments March 2021

³ Australian Government. (2018). 3.6.2.10 Medical & Other Evidence for DSP, in Guides to Social Policy Law: Social Security Guide. Canberra: Australian Government. Retrieved 05/04/2021 from <http://guides.dss.gov.au/guide-social-security-law/1/1/j/10>

- A two-tiered process to assess medical evidence and to determine if an applicant is eligible has been implemented:
 - In the **first stage**, applicants are required to complete a Job Capacity Assessment (JCA). JCA assessments are conducted by allied health professional (i.e. occupational therapist). The assessment measures an applicant’s level of permanent functional impairment resulting from permanent medical condition(s) and assesses their ability to work based on the medical condition.⁴ If a JCA assessor deems the applicant’s condition(s) to be fully diagnosed, treated and stabilised, then an impairment is rated using the points system in the impairment tables.⁵
 - If the applicant meets the DSP criteria, they move to the **second stage** of the process where a Disability Medical assessment is conducted. The medical evidence provided by the applicant in support of their application is reviewed by a government-contracted doctor to verify whether the evidence demonstrates the medical condition(s) is permanent as defined by DSP qualification, and the level of functional impairment resulting from any permanent medical conditions.

Impacts of the changes

- Research by Soldatic & Fitts (2018) was conducted in four regional centres across three states. The research found that medical practitioners considered the new process, whereby a letter outlining each condition(s), prognosis and treatment is required, as prolonged and inefficient.
- Medical and non-medical professionals accessing the required medical specialists for reports and recommended treatment options resulted in a significant financial obligation and burden for Aboriginal and Torres Strait Islander clients receiving the Newstart Allowance (now replaced by Jobseeker).⁶
- Access to medical treatment and specialists to fulfil the new criteria of “fully treated” was often not available to clients in regional and remote areas.
- This new assessment requirement delayed the process of applying for a DSP as they required extensive time to undertake and gather the required specialist medical evidence.
- Applicants remained on inappropriate lower payments, increasingly their risk of living in poverty and experiencing financial hardship.⁷The Current Pilots for Independent Assessments

⁴ Australian National Audit Office. (2016). Qualifying for the Disability Support Pension. Canberra: Department of Social Services. Retrieved 05/04/2021 from https://www.anao.gov.au/sites/g/files/net5496/f/ANAO_Report_2015-2016_18.pdf.

⁵ Australian Government. (2018). Guides to Social Policy Law: Social Security Guide. Canberra: Australian Government. Retrieved 05/04/2021 from <http://guides.dss.gov.au/guide-social-security-law/1/1/j/10>

⁶ Soldatic, K. & Fitts, M. (2018). ‘At what cost?’ Indigenous Australians’ experiences of applying for disability income support (Disability Support Pension). Penrith, New South Wales: Western Sydney University.

⁷ Soldatic, K. & Fitts, M. (2018). ‘At what cost?’ Indigenous Australians’ experiences of applying for disability income support (Disability Support Pension). Penrith, New South Wales: Western Sydney University.

“The narrow nature of the pilots to date and the absence of detailed evaluation does not provide sufficient evidence to support the sweeping introduction independent assessments.”⁸

Like the Victorian Council of Social Services and Professor Bruce Bonyhady of the Melbourne Disability Institute’s observations of the Pilots, AFDO does not believe that the current two pilots of Independent Assessments provide enough evidence to validate the use of the identified assessment tools or that people with disability from diverse backgrounds with diverse experiences of disability and complex multiple disabilities will fare well under the application of such generic and monoculture assessment tools.

We believe that any planned approach regarding Independent Assessments should require extensive trialling, not piloting and must have a rigorous independent evaluation to receive any form of validation.

AFDO is significantly concerned about how people with disability are being invited or managed into participating in the second of the two pilots. An example being; xx, an NDIS participant and a Chief Executive Officer, was contacted by phone by an employee of an Independent Assessment Company.

This person asked xx to participate in the Pilot by relaying this via their partner and then asked xx to listen to a pre-recorded audio description of the pilot project including consent requirements which had to be agreed to for xx to be engaged in the Pilot. xx has a hearing impairment and is totally deaf; this information is recorded on their NDIS file with a request to communicate via email or text.

The person who called was told by xx partner that he was deaf and couldn’t hear but they still persisted. Xx ultimately requested that they send the information via email for him to review and this eventually occurred. This episode and conduct is a direct breach under the Disability Discrimination Act.

If this was the experience of xx a highly skilled professional, then how are other participants approached? Particularly those who aren’t as life skilled, or who don’t have a strong or skilled circle of support? This further demonstrates the inflexibility and haste with which Independent Assessments are being foisted onto NDIS participants, their families and the organisations that support and advocate for them.

“In line with the updated Participant Engagement Payment Policy, participants taking part in the second independent assessment pilot will be eligible for a reimbursement payment. The reimbursement will be made at a one-off flat rate of \$150 per participant after they have completed an independent assessment.”⁹

We support the principle that people with disability should be remunerated for providing their lived experience perspective when participating in pilot projects, surveys, interviews or focus groups. When people with disability are being offered the \$150 for participation, it

⁸ The Victorian Council of Social Services Issues Paper: NDIS access, eligibility and independent assessments Submission to the Joint Standing Committee on the NDIS Inquiry into Independent Assessments March 2021

⁹ <https://www.ndis.gov.au/participants/independent-assessments/second-independent-assessment-pilot/participants-second-independent-assessment-pilot/after-assessment>Reference see answer to; How much will I be paid?

becomes important that they fully understand that they are consenting to participate in a Pilot for Independent Assessments and have truly given this consent. The experience of xx casts doubt that this has been managed effectively, if at all.

The blunt nature of the use of the IA Tools is evidenced by the experience of Pilot Participants as shown below;

“(The assessor) was a qualified OT. She had experience with a range of disabilities and handled the interview with sensitivity and was agreeably helpful in explaining any question or offered an interpretation if needed. All questions asked required an answer by scale of difficulty between 1-5 for example. Few specific verbal answers. I did point out to her that most people with lifelong disabilities did not like answering questions about their disability or to admit just how disabled they were.”

Person with Polio Participating in the Pilot

We continue to maintain our strong concern that people with disability, their families, the organisations that represent them and the disability sector have not been involved in any real consultation on the proposed biggest changes since the Scheme’s inception. We reject the proposed changes and seek an immediate genuine consultative process to ensure that we all work together to resolve issues with the Scheme in terms of access and equity.

“It is the view of AFDO that NDIS participants and the broader disability community feel they have not been listened to or provided with fair and authentic opportunities to share their thoughts and co-design solutions. The lack of information and limited transparency about proposed NDIS reforms continues to fuel fear and anxiety.”¹⁰

Financial Sustainability of the Scheme

There have been a number of potentially misleading and incorrect statements being made concerning Scheme sustainability as a reason for the introduction of Independent Assessments and proposed significant changes to key elements of the NDIS. There was also a fair degree of “cherry picking” of data concerning average plan packages across different local government areas to further support this and the lack of equity argument.

It is the Federal Government’s role to financially operate the Scheme with co-contributions as agreed from the States and Territories. The Federal Government has the same responsibility for many other support systems and benefits that are in operation for all Australians across multiple departmental areas.

Yet, the NDIS was highlighted as becoming unsustainable in its current form with the message to the sector being heard as, “we need to do these changes or you may not have a Scheme into the future”. This same messaging has not been made with the Aged Pension system, family support payments or other areas, which have increased costs applied periodically under formalised review processes, meaning the cost to government continues to rise.

The Federal Government, at any point in time, manages the requirements of its expenditure across broad portfolios of responsibility.

¹⁰ The Victorian Council of Social Services Issues Paper: NDIS access, eligibility and independent assessments Submission to the Joint Standing Committee on the NDIS Inquiry into Independent Assessments March 2021

The Scheme whilst still approaching full roll out has not been utilising the full amount of its budgeted annual expenditure inclusive of participants plans and there have in fact been a significant under expenditure.

The Scheme provides reasonable and necessary supports for people with serious and significant disability or disabilities that impact on their daily life. Utilising Scheme sustainability as a means to argue changes to the Scheme are urgently required, we view as a completely disingenuous approach.

Concerns about the way assessments will be carried out

“The current NDIA planning process begins with goals. It then takes account of sustainable informal supports. The final step is the assessment of functional impairments. All three combine to determine reasonable and necessary supports. This process of starting with participants’ goals is absolutely critical to the culture of the NDIS. The focus is, and must continue to be, on what people with disability can do and the support required to exercise their full citizenship - rather than what they cannot do.”¹¹

For too long people with disability have been defined by what they cannot do – a deficit model of disability. The emergence of self-advocacy, the social model of disability and Australia’s contribution to the United Convention on the Rights of People with Disability have helped to reframe how people with disability define themselves. People with disability have begun to demand their place in the life of the community, to exercise their agency and asserting their citizenship rights.

In turn, the community has begun to shift their attitudes regarding what people with disability can achieve and how the community needs to change in order to support this shift in expectations. Wider society began to change its attitudes towards the inclusion of people with disability.

Whilst the use of the functional assessments has a part to play in determining where disability supports might be needed, placing functional assessment as the beginning point of the interaction will be to take people with disability back into the deficit model without any consideration of the person, understanding their goals and aspirations.

People with disability, their families, their communities and the organisations that represent them, know all too well what happens to people with disability under a deficit model of assessment as that is where we all were before the NDIS.

“Under IA, the assessment processes will, inevitably, focus on what people with disability cannot do. It is a deficit-based approach. It will inevitably lead to participants and their advocates identifying every impairment in order to increase the likelihood of a sufficient resource allocation. As a result, it could have the unintended consequence of potentially undermining the sustainability of the scheme. It is also likely to generate inequity, as those who are better educated or more knowledgeable about the underlying assumptions of the questions will be more successful in detailing their impairments in a particular way.”¹²

¹¹ Professor Bruce Bonyhady - The Melbourne Disability Institute. Submission to the NDIS Joint Standing Committee Inquiry into Independent Assessments “An Analysis of the NDIA’s proposed approach to Independent Assessments” February 2021

¹² Professor Bruce Bonyhady - The Melbourne Disability Institute. Submission to the NDIS Joint Standing Committee Inquiry into Independent Assessments “An Analysis of the NDIA’s proposed approach to Independent Assessments” February 2021

AFDO member, NoFASD, reacted with significant concern regarding media statements that people with FASD would no longer be eligible for access to the Scheme. This is in direct opposition to the recommendations from the March 2021 Community Affairs References Committee as submitted in their final report, “Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder”

“Supports for a person with FASD will be necessary over the entire course of their life. Unfortunately, support services in Australia are limited and can be cost prohibitive. Throughout the inquiry, the committee was made aware of the difficulties accessing support through the education system, National Disability Insurance Scheme (NDIS) and social security system. The committee agrees with submitters that FASD must be specifically recognised as a disability by the Australian Government and the social security system. Access to assistance must be urgently improved to help people with FASD and their families to meet the extensive costs of FASD supports. The committee was moved by the challenges faced by parents and carers of children with FASD, pointing to the need for improved access to practical parenting programs, and for carers, more assistance from State and Territory child protection authorities.”¹³.

In their Submission to the Joint Standing Committee, NoFASD provided the views of people with FASD they had collected through a qualitative and quantitative survey, designed to gather information about the predicted impact of independent assessments on individuals and families impacted by Fetal Alcohol Spectrum Disorder (FASD).

“It took years of work with professionals to understand my son and his needs. We finally have things in a reasonably well working state and if someone with no idea about FASD were to sit down and try to assess him in one sitting I’m really concerned he would lose all the support we worked so hard to get in place.”

Survey participants indicated that independent assessments are unlikely to have the ability to accurately capture the needs of people impacted by FASD. Many parents/carers highlighted the complexity of FASD as an inhibiting factor in the effectiveness of independent assessments. For individuals impacted by FASD, cognitive impairments and support needs are complex. People with FASD live with three or more domains of cognitive impairment and these domains are interactive. Looked at in isolation, a moderate impairment in a cognitive domain may not look remarkable, but the domains of impairment experienced by those with FASD impact each other, often with an exacerbating effect. The complexity of these interactions, as well as many other factors, must be understood to provide an accurate assessment of FASD. FASD assessments are conducted by multidisciplinary teams of professionals, each with different skills sets and all with specified training to understand the varying impacts of FASD.

Another example of the complexity of this disability is the fact that individuals with FASD often experience age dysmaturity, where some skills and abilities develop at a faster rate than others. This means that an individual could have communication skills which make them sound like they have the capacity of a 20-year-old, but their

¹³ Community Affairs References Committee “Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder” March 2021

comprehension skills may be at a developmental age of only 6. Respondents indicated that factors like this may adversely impact the assessment, producing inaccurate results and creating barriers to accessing appropriate supports and funding. Many parents reported that their child has “learnt to say the right thing, because they want to please” or “have some skills that hide their true level of need”. In past assessments, these factors have resulted in inaccurate understanding of receptive language issues, cognitive impairments and overall functioning. Many families expressed fear that this will occur in the independent assessments, subsequently affecting eligibility for support and much-needed funding.¹⁴

Deafness Forum of Australia are worried about how Independent Assessments will impact upon people who are deaf who rely on the use of audiograms as a mechanism for eligibility

“The NDIA currently accepts as evidence for eligibility an audiogram or other relevant testing combined with an assessment from a person’s treating audiologist of functional capacity.

It is not clear if and how an audiogram or other relevant testing will remain a component of the test for eligibility and as an indicator of reduced functional capacity. Because it is unclear, there is concern that the introduction of Independent Assessment will require potential and confirmed participants to self-fund the costs of obtaining an audiogram or other relevant testing reports. The NDIA must not allow these costs to be an impediment to potential participation in the Scheme: it needs to put equitable measures and funding access in place to enable individuals to deal with the costs of these assessments should the process require them.

It is important that the NDIA clarifies if and how it will treat pre-existing hearing acuity assessments as part of the Independent Assessment process. If they are to be disregarded there will be a resultant effect on potential participants’ time, effort and cost. For the most part, before applying to the NDIS, people with hearing impairment have already spent time and funds to ascertain whether they have a hearing loss, the degree of the loss and recommended rehabilitation strategies. They should not have to undergo new testing or be required to explain their circumstances repeatedly in response to different bureaucratic requirements.”

Deafness Forum of Australia

The National Mental Health Consumer and Carer Forum have also stated that the assessment tools used in the Independent Assessment process are not suitable for people with psycho-social impairments.

“In order for people with psychosocial disability to have choice, control and life-long support through the NDIS it is proposed that:

- *The NDIA provide funding for appropriate access and assessments to be undertaken by an allied health professional known to the individual*

¹⁴ NoFASD Survey results: Community concerns about compulsory

- *Assessment tools for use with people with psychosocial disability be co-designed with consumers and carers*
- *More than one support person be involved with any initial or re-assessment process*
- *Instead of requiring a re-assessment for each new plan, the NDIA would accept the reports of the current providers*
- *NDIA should ensure the upskilling of their planners and reviewers including from consumers and carers with lived experience of psychosocial disability from mental health conditions.”*

National Mental Health Consumer and Carer Forum

AFDO are particularly concerned about the down-stream consequences of a “one size fits all” deficit model of assessments as the starting point of a participants NDIS journey.

People with disability simply want their NDIS Plans to work in the first place and need a to be clear about what is reasonable and necessary. However, people with disability, their families, communities and the organisations that support them, are no longer content to just get what they are given. They are capable and used to fighting for what they need and sometimes for what they want. However, with the advent of the NDIS people were hoping for a different relationship with governments and the Australian community. The proposed Independent Assessments and changes to the NDIS takes them back to the space where they started, they are not valued, are a burden and are not entitled to supports.

Not getting the NDIS Plan you need or want, which will increase dramatically under the proposed Independent Assessments and the proposed changes to the NDIS Legislation, will simply mean an increase in plan reviews. It is already apparent that the waiting times for plan reviews are very long. As well, should the internal review process not yield the required outcomes for the participant, then the only pathway for resolution is to make an application to the AAT. Appearing at the AAT places the person with a disability in opposition to the Government and others in the process, with many people with disability, feeling too confronted and scared of undertaking this process.

The onerous and burdensome nature of the NDIS review experience is wearying to people with disability, their families, advocates and organisations that support them.

A one size fits all model of deficit assessments is likely to add to the amount of people seeking a review of their plan and not reduce the number as is the view of the NDIA.

Concerns with how the assessments will be used to determine participant plans and funding

We are further concerned about the shift from discussions about people with disability and their dreams and aspirations to a global budget based on their age and their function level. Our concern extends to the possibility that the NDIA want to deal with categories of disability not people with disability, the individual.

“Some of the questions were very personal, uncomfortable and difficult to answer. I was asked to think about what my life would be like without support. Over and over again, over 20 times, possibly more. I need support to eat, breathe, and to wipe my bum. I don’t want to be forced to think about my life without support. I felt unable to answer your questions. But I had to.

The assessor asked me if I need support to have sex? I do Minister. My hands are paralysed and I can’t touch myself, let alone someone else. I really wasn’t sure how much information to give my assessor so I just looked away, trying to keep myself together.

The assessor also wanted to talk to someone about me without me in the room. He said it could be a family or friend. That felt wrong to me but I agreed to go along with it. But I couldn’t find anyone who knows me well enough who feels comfortable having that conversation without me involved. Everyone I asked has told me that it feels wrong to them. So I’m not the only one that feels this way.”¹⁵

Dr George Taleporos

Given the number of assessment tools that are to form the Independent Assessment it is difficult to understand how they will be weighted and combined. This is particularly important for First Nations people with disability and for people with disability from Culturally and Linguistically Diverse backgrounds.

“A large proportion of the polio cohort who are young enough to be eligible for NDIS support are from culturally and linguistically diverse backgrounds. We would like assurance that assessments will be sensitive not only to any language barriers, but also to cultural needs and priorities.

We are also concerned that many people from CALD backgrounds face particular barriers to accessing the NDIS. Where independent assessments are not culturally-sensitive, where the participant’s own goals and priorities are not central to the process, or where a process of review and appeal is necessitated, we are concerned that people from CALD backgrounds will be further isolated and excluded – or will drop out of the application process altogether.”

Polio Australia

For example Ms Jody Barney, a First Nations woman who is deaf. Jody provides cultural safety assessment communication advice to a team of disability support providers and allied health clinicians working with two First Nations people with disability with complex needs, who have experience in the criminal justice system.

This advice, on cultural safety and communication, has helped shape the interaction of disability support providers and the First Nations person with a disability, through the lens of cultural safety, enhance the understanding of cultural safety in providing disability support, convey a message to the family and community about the importance of respecting country, culture, community and family in the context of their family member with a disability.

In the context of one First Nations with FASD this culturally safe assessment and advice has meant that the young woman with FASD has had no contact with police, has avoided

¹⁵ Dr George Taleporos “Open Letter to Minister Roberts March 2021

incarceration, has abstained from drinking and has not been admitted to an emergency department of a hospital with injuries. But cultural safety is not a part of functionality and no assessment tool yet exists for it.

“It is important to note that the NDIS supports many people with disability with complex needs. They would ordinarily be assessed by a multi-disciplinary team working together and observing the participant in multiple settings. Multidisciplinary assessment is now considered best practice in health, accident compensation schemes and other settings, but the paper is silent as to why this best practice approach has not been selected for assessment in the NDIS.”¹⁶

Deafblind Australia (DBA), an AFDO Member Organisation, is highly concerned about the impact of how the Independent Assessments will be used to determine participant plans and funding

“DBA is also deeply concerned about the specific “recognised, standardised tools” that will be used as part of the assessments. Who has endorsed them? Given the specific needs of our community and the lack of consultation with us or other peak groups on the issue, how can the Deafblind community trust that these tools are appropriate and accessible to them? In the current context of information distribution, accessible formats and Auslan translations are provided selectively and sporadically by the NDIA, and are often inaccessible to Auslan users who also have a vision impairment. It is our concern that historical issues of vital information not reaching deafblind people in ways that are accessible and understandable to them is likely to continue and worsen given the lack of consultation undertaken by the NDIA around all aspects of this program.”

DeafBlind Australia

Concerns about the impact of these assessments on the availability of support for participants

Case Study:

MM is a proud Arrente man from Central Australia. MM has an intellectual disability and is detained for the purposes of treatment as a result of a finding of mental impairment and unfitness to plead. MM has significant family and community support. In 2017 MM was declared eligible for the NDIS and his first plan was prepared. MM is now into his third plan. The main theme of MM’s NDIS plan is to provide access to the community and family on country and support his inclusion in the general community.

Over the time of the NDIS plans a community artist who provided MM with one to one support when accessing the community, introduced painting as an activity. MM began to paint independently and over time it emerged that MM was a talented artist. In the last two years MM has painted over fifty paintings and his large works have been valued at \$2,500 by Bindi Mewere Anthurre Artists. As a result of MM engaging in painting he built an independent identity with family and community as

¹⁶ Professor Bruce Bonyhady - The Melbourne Disability Institute. Submission to the NDIS Joint Standing Committee Inquiry into Independent Assessments “An Analysis of the NDIA’s proposed approach to Independent Assessments” February 2021

a 'painting man'. MM began to paint with his aunt when on community. This gave him cultural status and purpose with his family and community and allowed for family and community to communicate with him about his work. This in turn improved his self-esteem and sense of belonging and accomplishment. MM has now painted so many paintings that an exhibition of his works in a Melbourne Gallery will take place in June 2021.

This story goes to the very core of the phrase often linked to the NDIS – that the NDIS is the most comprehensive social revolution since the introduction of Medicare. Indeed this story shows the potential of a person with a disability and what can be achieved through the provision of disability support funded through an NDIS Plan. It is important to remember that people with disability dream bigger than just being able to tie their shoe laces, travel independently on the train or cook their own dinner.

They also dream to express themselves beyond their disability and to become more than their disability. Like all, they want to dance, write, paint, act, have relationships and even have sex – and they need disability support that is reasonable and necessary to help them achieve these goals, these dreams and aspirations.

The NDIS is more than just functionality support and to limit it to that narrow interpretation of what it means to be a citizen of Australia in 2021 is to once again disappoint people with disability about how the community values them.

Independent Assessments and the concurrent proposed changes to the definition of reasonable and necessary supports will significantly impact on MM's ability to continue to employ a community artist who can support his painting. Without this support no one may ever have learned that MM is a talented painter.

“Page 9 notes that language and cultural adjustments are easier to achieve with a small number of assessment tools. This is understandable, but there is a lack of detail about how cultural appropriateness and language translation will be managed. Further, it is not clear whether the tools have been tested in multiple languages and settings, as well as in English. This is particularly important given that the assessment tools ask a lot of nuanced questions. Accurate translation and culturally appropriate processes will be essential to an accurate assessment for all NDIS participants. It is also notable that many of the tools are from other countries and may not translate to Australia, particularly in relation to the importance of environmental factors.”¹⁷

Scheme that is Consistent and Fair

“Your claim that “If you do not agree with an NDIA decision from an independent assessment you can request a review or appeal” shows you simply do not understand that many vulnerable people are simply unable to appeal NDIS decisions because it puts them in legal conflict with the Government. Many of them are not prepared to go there, so your actions to make this an essential step for more NDIS participants is very unfair for the most vulnerable people who you are meant to be helping.”

¹⁷ Professor Bruce Bonyhady - The Melbourne Disability Institute. Submission to the NDIS Joint Standing Committee Inquiry into Independent Assessments “An Analysis of the NDIA's proposed approach to Independent Assessments” February 2021

AFDO does not accept the argument of the former Minister that this process will even out postcode based disparity in plan amounts. The issue is not postcode disparity in the amounts of money in peoples plans, the issue is one of thin markets in anywhere that is not a reasonable sized city. Access to the services needed in a person's plan is a more significant issue for national equity than postcode disparity. Access to services affects groups of people with disability already impacted by dynamics such as geography, social barriers related to age, gender, sexuality, Indigeneity and ethnicity.

The conflation of Independent Assessments and the proposed changes to the NDIS Legislation and the unfairness of both the minds of the general public and people with disability, their families, communities and organisations that advocate and support them, has been sharpened by the united national opposition to them and the fact that no draft legislation has been provided, creating further angst.

The most significant change that will fundamentally alter the equity of the NDIS and result on a widening of disparity will be the proposed changes to "reasonable and necessary". Its links with Independent Assessments are clear; Using functionality as the centrepiece of eligibility instead of life goals and aspirations will categorise participants and disability types, reflecting a medical model of disability. Moving away from the person centred approach to planning on functionality is completely at odds with the Scheme's establishment and values. It appears to be aimed at less people with less money.

Linking functionality to the framing reasonable and necessary with a financial construct based on functionality is totally inequitable and will result in less people being eligible for the Scheme with less access to financial equity of plans. The resultant impact on States and Territories will be a need for them to pick up additional service provision for people that have been denied Scheme entry. We believe that this is the true purpose of Independent Assessments and the proposed changes to the NDIS Legislation.

In addition to being forced to undertake an assessment from a complete stranger, the applicant or participant is not provided with the final report but must specifically request this to be provided from the Assessor. This is not considered best practice or quality customer service and further demeans the person with disability.

"It is not clear why an applicant should not be provided with their full independent assessment results. Provision of the full independent assessment would better fulfil the objects general principles of the NDIS Act, including in enabling people with disability to exercise 'choice and control' in the pursuit of their goals, to ensure people with disability have the same rights to pursue any grievance, and to determine their own best interests in decisions that will affect their lives.

Provision of the full independent assessment empowers applicants in a number of ways, including by:

- *allowing the applicant to ensure the assessor has understood and considered all relevant issues;*
- *ensuring the applicant has all relevant information if they wish to appeal a decision to refuse access. Given the independent assessment forms a*

- crucial part of the access process, and that access decisions are reviewable, it is important that applicants have the full assessment;*
- *allowing the applicant to have the benefit of the functional capacity assessment that has been conducted, to use it as they wish, for instance to provide to other health care providers, service providers, or employers; and*
 - *most importantly, giving applicants information which is about them. This in itself should be sufficient reason for providing the applicant with the full assessment report.*

In any case, we note that applicants would likely have the right to access their full independent assessment under the Privacy Act 1988 (Cth), given the information is personal information. The NDIA should simply provide applicants with their full assessment, rather than requiring them to go through another process.”¹⁸

Downstream consequences of more applications for more plan reviews are an inevitable outcome of the introduction of the proposed Independent Assessments and changes to the NDIS. The internal review process is cumbersome and already takes significant time to obtain a decision. Those concerns are sharpened by two key pieces of evidence – the number of AAT matters that are “settled on the steps of the AAT and the fact that the NDIA do not believe they should take account of AAT precedents in terms of adjustments and changes to policy and process as a result of AAT outcomes.

In 2020 Australian National Audit Office reported on “Decision-making Controls for NDIS Participant Plans”. Recommendation two of that report, to which the NDIA agreed states:

“The National Disability Insurance Agency establishes mechanisms to track and analyse (at the enterprise level) issues arising from review mechanisms to inform continuous improvement in reasonable and necessary decision-making, including:

- a. using outcomes data from internal reviews and AAT reviews, including early resolution outcomes, to inform continuous improvement in reasonable and necessary decision-making; and
- b. implementing metrics for measuring the success of continuous improvement initiatives to enable the Agency to determine whether the initiatives are having the intended impact.

National Disability Insurance Agency response: *Agreed.*”¹⁹

¹⁸ Public Interest Advocacy Centre: Inquiry into Independent Assessments Submission to the Joint Standing Committee March 2021

¹⁹ Australian National Audit Office “Decision-making Controls for NDIS Participant Plans” October 2020 <https://www.anao.gov.au/work/performance-audit/decision-making-controls-ndis-participant-plans>

To ensure equity in the review process and to account for Scheme fairness and consistency we support the observation of the Commonwealth Ombudsman;

“I make one observation about review rights and complaints processes. The NDIA will need to ensure that where participants are assessed as no longer eligible for funded supports based on the outcome of an independent assessment, they have clear information about how to seek a review of the decision and make complaints or provide other feedback. The NDIA should also ensure it has in place clear guidelines for NDIA staff and Partners in the Community about transition to early intervention and/or mainstream services and any conditions and processes relating to re-applying to the NDIS.”

Key Vulnerabilities of Independent Assessments

1. Independent Assessments won't advance the good practice of using a multi-disciplinary assessment model
2. Independent Assessment fail to situate function in environments outside the home
3. Taking a set of facts and drawing conclusions without context will leave Independent Assessment vulnerable to superficiality
4. Independent Assessments may be legal but they will not be legitimate
5. Independent Assessments don't measure potential

AFDO notes the recommendations from the Commonwealth Ombudsman specifically on these issues:

“In implementing compulsory independent assessments, the NDIA should ensure the following:

1. *Participants, carers and other stakeholders are provided with clear, consistent and accessible information:*
 - *regarding the independent assessment process, including opportunities for internal and external review and complaints mechanisms, and*
 - *about when additional independent assessments can be requested, including clear guidance on the Independent Assessment Framework and how it applies to individual assessments, so that it is clear when assessments do not comply with that framework.*
2. *The information about independent assessment processes contained in the NDIA's.*
3. *operational guidelines, standard operating procedures and practice guidelines is complete, and up to date and accessible.*

4. *NDIA decision makers are provided with comprehensive training about exemptions from an independent assessment and prospective participants are given clear reasons when a decision is made not to grant an exemption.*
5. *There is ongoing consultation about the changes, and the opportunity to refine processes based on complaints and other feedback where appropriate.*
6. *Further consultation and engagement with Aboriginal and Torres Strait Islander and CALD participants and prospective participants, carers and representative groups be undertaken to ensure culturally appropriate methods of assessment are used.”²⁰*

We also note and support the recommendations for an alternative approach from Professor Bruce Bonyhady at the Melbourne Disability Institute and the former Chair of the NDIA;

“An alternative fair way forward

Against this background, it will be necessary for the NDIA to totally rethink IA; to start again, based on strong, transparent and accessible evidence and co-design. The key elements of an alternative approach which would ensure that assessments are valid, equitable and consistent, make the NDIS sustainable and align with the UNCPRD and the original vision of the NDIS are:

- *An assessment process which is genuinely co-designed with people with disability, their families, carers and representative organisations and which has strong evidence for its validity. This must include transparent testing and feedback on any questionnaires to understand strengths and weaknesses. There must also be opportunities to include expert reports as part of assessments, especially when these reports have been gathered from experts who have known the participant for many years (as highlighted in the Ray v NDIS case).*
- *The assessment process must start with the goals of the participant and so be individual 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. This implies a balancing of ‘top-down’ and ‘bottom-up’ planning. This will also ensure that goals are considered first rather than squeezed into a pre-determined funding level based on functional impairments alone.*
- *Then any planned new approach will require extensive trialling, not piloting. It will need to be based on a whole of population study and include control groups. It is notable that when the NDIS was initially trialled in 2013, the minimum size for the trial was considered to be at least 10,000 participants. In the end 30,000 was chosen as the final figure. Any testing would need to include the full range of environmental factors, including ensuring the full range of geographic locations from metropolitan to very remote.*

²⁰ Commonwealth Ombudsman “Inquiry into Independent Assessments” February 2021

- *Once a valid, equitable and consistent assessment process has been evaluated, the evidence for its effectiveness must be made available in accessible formats to people with disability their families and carers, so there is an evidence base on which confidence and trust can be rebuilt.*
- *Assessments should then be undertaken by multi-disciplinary teams and, if needed, in multiple settings. Setting short, arbitrary limits on assessment times is a false economy. It will only lead to needless reviews and appeals, cause avoidable stress and fear amongst participants and their families and contribute to increasing inequity. Specifically, administrative efficiency should be designed to underpin the accurate determination of both eligibility and reasonable and necessary supports - not compromise these foundational aims. Then, when assessments are scaled up, implementation science should be used to ensure that the assessment tools and processes are used with high fidelity and so are reliable and lead to consistent results.*
- *Funding should then be allowed to be used very flexibly by participants, with a minimum number of fixed categories, as envisaged as part of IA.*
- *Even with all of these careful steps it is inevitable that further lessons will need to be learned. Continuous evaluation must therefore 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. It must include lived experience of disability, implying co-designed evaluation, as well as co-design in the development of new assessment processes.*
- *Internal reviews and successful AAT claims should be seen as opportunities to learn and improve and all aspects of the implementation of the NDIS should be reviewable. The current practice of settling meritorious AAT appeals “on the steps of the AAT” must cease.*
- *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), so there is no longer a “cliff” at the edge of the NDIS. This is a key foundation for the NDIS and would lead to greater equity between NDIS participants and those not eligible for support. In the absence of this investment in Tier 2, all assessment processes (not just IA) will fail to meet their essential objectives, even if they are well designed and implemented. Failure to invest in Tier 2 will also continue to place on going pressure on 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.”²¹*

²¹ Professor Bruce Bonyhady - The Melbourne Disability Institute. Submission to the NDIS Joint Standing Committee Inquiry into Independent Assessments “An Analysis of the NDIA’s proposed approach to Independent Assessments” February 2021

Conclusion

As a result of the failure by the Government to produce new draft NDIS legislation we believe that the twin issues of Independent Assessments and proposed changes to the NDIS legislation have become the same issue.

The current spate of media articles seem to point to a Government strategy that aims to fundamentally change the National Disability Insurance Scheme, reduce access, reduce plan values and continually ensure that existing participants have to continually prove their disability.

It remains of significant concern that Independent Assessment and proposed changes to the NDIS Legislation will fundamentally alter the equity and fairness of the NDIS and signals to people with disability that they are not of value.