

Proposed Reforms to NDIS Access and Planning Policies

Submission to the National Disability Insurance Agency



About the Australian Autism Alliance

The Australian Autism Alliance (the Alliance) is a coalition of 12 autism organisations around Australia that represent autistic people, their parents and carers, service providers and researchers who aim to realise the potential of autistic Australians. Our substantial national footprint:

- Reaches over 170,000 people through our communication channels
- Employs over 3,000 staff
- Employs, or provides pathways to employment, for over 350 autistic adults
- Contributes to the Australian economy by generating and delivering an estimated \$200m of supports and services
- Builds capacity of the broader community through training and advisory services for over 60,000 people per year
- Covers nearly all of Australia
- Has significant national and international linkages for advocacy, research and service delivery
- Provides direct support to over 30,000 autistic people across the lifespan from early childhood to adulthood
- Operates 230 service outlets across Australia.

About Autism

Autism Spectrum Disorder (or ASD) is a neurodevelopmental condition. Autism is not a disease. People are born autistic. It is a lifelong condition and there is no cure, but the way it affects people may change over time as a person grows and matures. Every autistic person is different.

Autism frequently co-occurs with other conditions including other neurodevelopment conditions (e.g. ADHD, Dyslexia) and Intellectual Disability. There is a high rate of mental ill-health among the autistic population.

Autism and the NDIS

31% of NDIS participants have a primary autism diagnosis and an additional 5% of participants have autism as a secondary disability.¹ In the younger age groups 65% of participants aged 7-14 years and 54% of those aged 15-18 years are autistic.

For further information

The Alliance stands ready to assist the National Disability Insurance Agency (NDIA) to continually improve the NDIS for autistic participants. Alliance Co-Chairs Paul Micallef and Fiona Sharkie can be contacted at chair@australianautismalliance.org.au to discuss this submission.

¹ NDIA, 2019. *Outcomes for participants with ASD*. Available at: <https://data.ndis.gov.au/reports-and-analyses/outcomes-participants-autism-spectrum-disorder>

Summary of recommendations

The way the proposed changes have been developed is highly problematic

1. Halt the appointment of the NDIA's panel of assessors until different approaches have been piloted and comprehensively evaluated, and meaningful co-design with NDIS participants and those that assist them has occurred.
2. Commission a comprehensive evaluation of the second pilot, examining both process and outcomes. The evaluation needs to be conducted independently of the NDIA with results made public.

We have significant concerns about proposed changes to the planning process

3. Abandon the proposal to use functional assessments as the primary determinant of plan budgets.
4. Reflect the intent of the NDIS Act to place participants at the centre of the planning process. Participant goals, aspirations and needs must drive their plan and inform their budgets.

Significant protections are needed if functional assessment proceeds

5. Embed the following protections if the NDIA's functional assessment proposal (which is opposed by the Alliance) proceeds:
6. Allow participants to use their existing clinician/therapist, using the NDIA tools and report format.
7. Require compliance with the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia for functional capacity assessments of autistic people. This includes using assessors that meet the minimum autism training and experience thresholds set out in s.22 of the Guideline.
8. Provide participants with a full version of their functional assessment results, at the same time as they are sent to the NDIA.
9. Provide avenues for review of functional assessments and their access and budget decisions, including to the AAT.
10. Specify minimum experience standards for the assessor workforce that organisations contracted by the NDIA contractors are bound to meet.
11. Allow for exemptions from participating in functional assessments to be granted on the basis of advice from a participant's medical practitioner, including where such assessment might put the person's mental health and wellbeing at risk.

Overview

We have deep concerns about proposed changes to access and planning

Proposed changes to the NDIS access and planning policies, particularly the introduction of functional assessments to determine access and plan budgets constitute the most radical change to the NDIS since its roll out.

A change of such magnitude requires careful design, refinement and implementation, yet the process has been marked by:

- Major policy changes being designed without a supporting evidence-base.
- A lack of consultation on substantial aspects of the policy re-design. Consultation has instead been limited to a narrow range of secondary issues.
- A failure to genuinely consider and respond to real and material concerns raised by the autism and broader disability sector.
- Rushed implementation of proposed changes, with no good reason for the haste.
- Commissioning processes that started ahead of pilots being completed or independently evaluated, and without consultation.

The Australian Autism Alliance (the Alliance) acknowledges the stated objectives behind the introduction of NDIA-commissioned assessments, specifically the intention that consistency and equity should be at the centre of decision making, and that doing so will result in a fairer NDIS. The Alliance does not believe that the proposal, as it currently stands, will achieve these objectives, and may actually exacerbate inequities. We recognise financial sustainability of the Scheme to be a driving factor, but do not believe using functional assessments as a blunt instrument to tighten access to the Scheme and determine individual plan budgets is the way to achieve this.

The Alliance holds grave concerns that the proposed changes pose a real risk to autistic people who are currently NDIS participants, as well as those seeking to access NDIS supports in the future. These concerns were captured in an earlier [public statement](#) made by the Alliance, and are widely shared among the broader autism community, the disability sector, some LAC Partners and allied health professionals.

Given our deep concerns, we call for the introduction of the functional assessments and their use to determine access and budgets to be immediately halted.

The current pilot on the proposed assessment process needs to be properly evaluated by an independent body and its outcomes robustly measured and understood before these proposals can be considered with a level of authority.

Alternative approaches to improving consistency and equity in access and planning need to be piloted and evaluated.

As the single largest diagnostic group within the NDIS, it is critical that the Scheme remains accessible and responsive to the needs of autistic people.

Feedback on the Proposed Reforms

The way the proposed changes have been developed is highly problematic

The tender process commenced without consultation or an evidence base

The public tender process to select providers to be on the NDIA's panel of assessors was initiated well before information about the scope and scale of the reforms was publicly released or consulted on, and before critical pilots have been completed and evaluated. This undermines confidence in the process and has left the indelible impression that the introduction of the proposed changes is a fait accompli. The public consultation process is being conducted after major changes have already been determined, which undermines the good faith of autistic people and the broader disability community that underpins it.

Consultation with participants and the community has been limited

The Alliance acknowledges that the NDIA has released consultation papers and held forums on proposed changes to access and planning policy. However, the format and focus of the consultation sessions and the questions posed in the published papers have been strictly limited to issues of implementation rather than substantial design. The option for co-design of potential solutions has not been an option.

Alliance members and many autistic people from the communities we support have attended forums held by the NDIA. Most experiences were negative, characterised by frustration and a common feeling that concerns had not been considered or acknowledged and questions remained unanswered.

We are also disappointed to report that in many cases, autistic participants are hearing about these reforms for the first time from Alliance partners. Given the scale of the proposed changes and the impact they will have on autistic participants' lives, a focus by the NDIA to ensure that its key stakeholders are engaged and aware of these reforms is critical.

The proposed reforms are untested, unproven, and unevaluated

The use of functional assessments as the primary determinant of NDIA access decisions and plan budgets is untested, unproven and unevaluated.

In our consultations with expert clinicians and researchers, we have been unable to find an international example where the proposed assessment tools have been used for the purpose of determining a disability support budget. The tools have been designed for screening and assessing functional capacity, not for feeding into an algorithm to determine funding allocations. How the assessment results will be used to do this has not been explained, nor the results of any modelling or testing been made available.

The NDIA's first functional assessments pilot, understandably impacted by the COVID-19 pandemic, was very small scale. The full evaluation has not been released, instead NDIA-generated reports of the pilot's "success" appear to have been based on an online experience survey completed by just 35 NDIS participants.

A second pilot, which is larger in scale, is currently underway. At this point, we understand the planned evaluation is narrow in scope – essentially a process evaluation – and will be conducted by the NDIA itself. It will not answer key questions such as how the assessments will impact plan budgets and whether they will deliver on the objectives of consistency and equity.

A robust and rigorous outcomes evaluation is needed. This needs to be conducted independently of the NDIA, and its results published in the public domain.

Recommendations:

- 1. Halt the appointment of the NDIA’s panel of assessors until different approaches have been piloted and comprehensively evaluated, and meaningful co-design with NDIS participants and those that assist them has occurred.**
- 2. Commission a comprehensive evaluation of the second pilot, examining both process and outcomes. The evaluation needs to be conducted independently of the NDIA with results made public.**

We have significant concerns about the design of functional assessments

The proposed reforms will not address systemic inequities

The Alliance agrees that inequities of outcomes based on the socio-economic status of participants needs to be addressed. Use of functional assessments as a blunt tool to determine access and plan budgets will not achieve this. Indeed, it may well exacerbate inequities.

While there will be an equal process in theory, it will not generate equity in outcomes. Those who can eloquently describe their functional capacity challenges will do better than those who are unwilling or unable to describe the challenges they face in their daily lives. People with low social capital, low education; distrust of government; or low English proficiency are at higher risk of receiving assessment results that do not accurately reflect their circumstances. Those who understand the process may have the perverse incentive to show their ‘worst self’ in order to have a greater level of impairment recorded and attract higher funding.

While the NDIA has indicated that a participant can ask their treating health professional to attend the assessment, there is no funding to cover this. This option will therefore only be available to those who can afford to pay, which raises equity issues.

High consequence assessments conducted by a stranger will not work well for autistic people

Autism is multifaceted, nuanced and highly variable in how it affects the functional capacity of each autistic person, in each situation. It will be very challenging, even for the most skilled assessor, to build a comprehensive and accurate picture of the needs and circumstances of an autistic person they are meeting for the first time, and in a very short window (average of 2.5-3 hours, including report writing).

Attending a high stress, high consequence assessment with an unknown therapist who has undetermined expertise in autism will also be incredibly challenging for autistic people and their families.

Through consultation with Alliance partners and members of the autistic community we have identified the following substantial concerns:

- Stigma, shame and pride can result in autistic people masking and overstate their capacity to function, risking inaccurate assessment outcomes.
- Autistic people and their families have expressed despair about the indignity of having to explain their personal challenges and deficits to a stranger repeatedly.

- Significant anxiety and fear is presenting as a real barrier to participation. Some have not been able to complete the assessment. Under the proposed changes this would mean they would be treated as withdrawing their access request.
- Disturbingly some have reported a heightened risk of self-harm such is the anxiety that this proposal provokes.
- Heightened impacts have been reported by those with a history of trauma, abuse or violence.
- Significant burdens on autistic parents who will have to attend their own assessment, as well as their child's assessment.
- Requirements for a third party to speak privately to the assessor undermines the agency and dignity of the person with disability.

Scarce public resources will be wasted on repeat assessments

Many prospective or current NDIS participants will have pre-existing functional assessments, but will likely still need to undergo the NDIA functional assessment process. For example, a person recently diagnosed as autistic will have undergone a comprehensive functional capacity assessment (consistent with the Australian Government endorsed National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia) using many of the same tools proposed by the NDIA.

While the NDIA have indicated that pre-existing assessments will form part of the overall 'evidence' it is unclear how much weight they will be given. Requiring repeat assessments (despite earlier ones often being funded by Medicare or other public means) represents wasted resources that could be applied elsewhere to provide better outcomes. It also creates the potential for inconsistent results, which under the proposed reforms could not be adequately addressed through review or grievance processes.

We also question the logic of subjecting participants to frequent functional assessments throughout their time in the Scheme, when their planners and treating practitioners are better placed to keep the NDIA informed of key changes to capacity.

Assessments will be undertaken by clinicians with insufficient autism experience

The 'disability agnostic' assessment approach being proposed by the NDIA brings with it a real risk that assessors will not have specialist training or experience in autism. The National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia recommends (in Section 4.2) that therapists and clinicians conducting functional assessments have a detailed understanding of *and* experience in assessing autism.

If the assessor lacks autism proficiency, there is a danger that the assessment tools they choose and the way they use them will be problematic. Their expert judgment (or lack thereof) about which tools to use and how to use them is material to the assessment outcomes.

We are also concerned that the assessor workforce will be largely comprised of junior clinicians. While assessors will need to hold the appropriate professional qualifications and be registered with the Australian Health Practitioner Registration Agency (except in the case of speech pathologists, for whom the only point of accountability is their professional association), organisations delivering assessment services will likely hire relatively inexperienced, less expensive therapists, in order to maximise their returns.

Perverse incentives may lead to cost cutting in the assessment process

Each independent assessment will be funded by the NDIA on a unit, rather than a time basis. This creates an incentive for assessment providers and their workforce to focus on efficiency at the expense of quality and accuracy.

Companies awarded the NDIA assessment contract may devolve the delivery of assessments to sub-contractors. This raises considerable red flags about quality assurance, oversight of practice and a further tangling of both the lines of responsibility and the contractual incentives that will be driving the assessor workforce.

Thin markets will be exacerbated by diverting therapists into NDIA assessments

NDIA tender rules prevent contractors from undertaking assessments in local government areas where they are providing Local Area Coordination, Early Childhood Intervention or Support Provision services for the NDIS. We do not dispute this effort to manage conflicts of interest.

Allied health workforce shortages are well understood. We are concerned that a direct consequence of introducing this new administrative layer of assessors to the NDIS will be diversion of critical allied health workforce resources away from delivering supports to people with disability.

Reducing the pool of qualified therapists available to support people with disability will exacerbate thin markets already experienced in remote, rural, regional and outer-metro areas, and for cohorts who find it particularly challenging to secure a therapist. Such policy failure is both foreseeable and avoidable.

NDIA-commissioned assessments are not independent

Motivations to cut scheme costs, and the centrality of NDIA-commissioned assessments in determining scheme access and plan budgets creates a clear conflict of interest for the Agency and their contractors.

There is no proper oversight of the proposed assessment process

The Alliance is deeply troubled by the proposal that people will not be given a copy of the full assessment report unless they specifically apply to see it, and that assessments will not be reviewable by the Administrative Appeals Tribunal, despite the significant impact they will have on access and plan budget decisions.

This represents a fundamental disempowerment of participants and a disregard for natural justice. It creates a dangerous imbalance in the relationship between participants and the NDIA.

Not what the Tune Review recommended

Forcing participants to use NDIA appointed assessors contradicts the Tune Review which explicitly states:

NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments.

We also have significant concerns about proposed changes to the planning process

Participant rights and voice are being disregarded

Proposals for draft plans and budgets to be developed *without* participant input are alarming. They undermine participant voice and agency. Perversely, these changes will move the Scheme further along the trajectory of being a welfarised model that is all about residual funded supports rather than an empowerment/rights model that is about participation.

Section 31 (a) and (b) of the *NDIS Act (2013) Clth* provides that the preparation of a plan should (so far as reasonably practicable) be individualised and directed by the participant. Yet proposed changes would mean that participants have a draft plan and draft plan budget developed on their behalf *before* they are given the opportunity to outline their goals and aspirations and without reference to their identified support needs. The ability of either the participant or their planner to substantially alter the budget or content of their plan appears to be strictly limited (even more so that the current Typical Support Package range). Far from directing their own plan, participants will be forced to “shoehorn” their goals, aspirations and needs into a plan and budget pre-built by a “Personalised Budget Tool”, which will focus on deficits and impairment.

Participants need to be elevated to the centre of the planning process. We need to strengthen rather diminish the opportunity for the participant to drive their plan, with the overriding aim being to meet their goals and aspirations with opportunities and supports.

Functional assessment tools are not designed to be converted into a plan budget

The proposal conflates functional capacity with support needs, which are not the same thing. The results of functional assessments should not be the determining factor in plan budgets. Function assessment tools do not give the full picture of the person’s needs, and have not been designed to do so. Nor were these tools designed to determine a level of funding for support.

Recommendations:

- 3. Abandon the proposal to use functional assessments as the primary determinant of plan budgets.**
- 4. Reflect the intent of the NDIS Act to place participants at the centre of the planning process. Participant goals, aspirations and needs must drive their plan and inform their budgets.**

Significant protections are needed if functional assessments proceed

The Alliance does not support the NDIA proposed model for assessments as it currently stands. If a version of it proceeds, there are a range of conditions and protections that must be put in place. For autistic people these include:

- **Allowing participants to use their existing clinician/therapist.** The assessment would be funded by the NDIA and be delivered using the tools and format required. We are mindful that the NDIA is concerned about 'sympathy bias,' but believe that it can be managed and controlled for if bias exists. Oversight via the Australian National Audit Office and leveraging of professional standards governing clinicians/practitioners would hold assessors accountable.
- A requirement that functional assessments for autistic people are conducted in accordance with the government-endorsed **National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia.**

The Guideline requires that **assessors be skilled and experienced in working with autistic people.**

- Allowance for **exemptions from participating in functional assessments to be granted on the basis of advice from a participant's medical practitioner,** including where such assessment might put the person's mental health and wellbeing at risk.

We consider it appropriate that the lens of risk and safety is applied to avoid psychological harm and trauma for participants and their families who cannot safely undergo an independent assessment at the hands of a stranger.

- Provide avenues for **review of functional assessments and their access and budget decisions,** including to the AAT. Natural justice and procedural fairness dictate that participants receive a copy of their report at the same time the NDIA do, and that they have access to independent review.
- A **minimum experience requirement for the assessor workforce** must be set out by the NDIA in its contractual arrangements with assessment providers.

Inspiration can be drawn from Victoria's Transport Accident Commission which requires that assessors demonstrate a minimum of five years clinical experience; a minimum of eight hours each week of direct clinical care experience, either currently or over a 12-month period; and for retired clinicians, evidence of currency of clinical knowledge through ongoing academic studies.

The NDIA estimates that the volume of assessments by disability types will see 28% of referrals to assessors in 2020-21 being for autistic participants, rising to 33% of referrals in 2022-23. With autism representing the largest single diagnostic cohort within the NDIS, it is essential that any organisation delivering assessments, and their staff and sub-contractors, can demonstrate experience and training in working with autistic people.

Recommendation:

- 5. Embed the following protections if the NDIA's functional assessment proposal (which is opposed by the Alliance) proceeds:**
- **Allow participants to use their existing clinician/therapist, using the NDIA tools and report format.**
 - **Require compliance with the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia for functional capacity assessments of autistic people. This includes using assessors that meet the minimum autism training and experience thresholds set out in s.22 of the Guideline.**
 - **Provide participants with a full version of their functional assessment results, at the same time as they are sent to the NDIA**
 - **Provide avenues for review of functional assessments and their access and budget decisions, including to the AAT.**
 - **Specify mandatory minimum experience standards for the assessor workforce**
 - **Allow for exemptions from participating in functional assessments to be granted on the basis of advice from a participant's medical practitioner, particularly where such assessment might put the person's mental health and wellbeing at risk.**