

Save the NDIS

A submission in response to Getting the NDIS Back on Track Bill 2024

Never deprive someone of hope; it might be all they have.
H. Jackson Brown, Jr.



Autism Aspergers Advocacy Australia

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Preface

Autism Asperger Advocacy Australia, known as A4, provides this submission hoping to inform and improve the government's approach to the proposed legislation in the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024*.

A4 was created in 2002 as a national grassroots organisation to provide systemic advocacy for Autistic Australians and others affected by autism.

The Department of Social Services recognise A4 as a disability representative organisation (DRO) for autism on its [DRO webpage](#).

A4 is a member of:

- the Australian Federation of Disability Organisations (AFDO),
- the Disability Australian Consortium, and
- the Australian Autism Alliance (the Alliance).

Proud member of



Australian Federation of
Disability Organisations



AUSTRALIAN
Autism Alliance



[A4 Autism Awareness event](#), Parliament House, Canberra, September 2004

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1. Summary

Autism Aspergers Advocacy Australia (A4), who are the Disability Representative Organisation (DRO) for autism that the Department of Social Security lists on [its website](#), strongly opposes the proposed legislation. We give numerous reasons for opposing the proposed changes.

The Government's description of its proposed legislation is inaccurate and misleading. It misrepresents its purpose and likely outcomes of the proposed changes.

The legislation aims to create:

1. A list of unilateral exclusions that will be decided by officials and cannot be challenged - they are protected from external review.
2. An assessment tool without constraint or validation requirement; it is unknown whether a fair and equitable assessment tool exists or is even possible (especially for autistic Australians).
3. Rules and operational guidelines to be decided by the Minister or NDIA officials, and that cannot be challenged/contested by the people whose lives are affected.

The government is unclear about the problems its proposed legislation aims to address. So, the proposed changes cannot be assessed properly against the goals.

The legislation does not solve the problems that the autism sector suspects are meant to be solved. This proposed legislation would allow the NDIS far more scope to impose unreasonable exclusions, continue its detrimental use of inappropriate assessment tools, and enforce more perverse and irrational rules and guidelines on autistic NDIS participants. The proposed changes will not deliver improved outcomes for autistic NDIS participants.

While the NDIS has improved the lives of some autistic Australians, the improvements that have been achieved need to be protected (not annihilated) and further improvements are needed in the lives of more autistic Australians. Government needs to work *with* the autism sector to achieve such outcomes.

A4 is keen for improving the NDIS for autistic people, the most numerous "primary disability type" in the NDIS; but that will depend on processes that deliver agreed strategies, policies, programs, and improved outcomes that are developed and agreed with the whole of the autism sector.

2. Introduction

The NDIS Minister sprang his latest proposed changes to the *NDIS Act 2013* on the disability sector without much notice or consultation.

His approach massively diminished trust in Government and this Minister. The disability sector regards his attempt to make these changes without any meaningful consultation as completely unacceptable. We are left wondering what else he might attempt.

As he said in his second reading speech:

I can only imagine that there will be some anxiety about any talk of changes within the disability sector.

“Some anxiety” is an understatement; the changes he proposed bring massive anxiety, apprehension, and distress to the disability sector, especially autistic NDIS participants and their Informal Supports.

Thankfully, parliament decided to scrutinise his legislation more closely and to consult the disability sector. [The Senate inquiry](#) into the proposed legislation gives the disability sector an extremely limited timeframe to consider the changes; [the bill was introduced](#) on 17/3/2024 and the sector had until 17/5/2024 to make submissions to the Senate inquiry.

Experience demonstrates clearly that the Australian Government does not honestly describe the intent or the outcomes of changes like this to disability legislation. The effects of the previous round of changes to the *NDIS Act 2013* were not what government said would happen. The disability sector must be extremely wary. Government must appreciate that the disability sector cannot trust Government through these processes.

The Minister’s second reading speech does not paint an accurate picture of the proposed changes.

It talks about changes that will:

- “tackle fraud, waste and overcharging” but it is hard to see that it does that - it seems more about limiting/denying essential supports to participants ... and possibly reducing participant numbers.
- make participant’s NDIS plans more flexible but the proposed legislation formally creates “states supports” which is the opposite of flexibility ... and is a mechanism that is already used to excessively reduce plan flexibility. It also aims to control participants’ spending by limiting funding in periods of a participant’s plan ... which decreases flexibility. So, the speech is misleading.
- In respect of “the early intervention pathway is crucial and there will be no changes until that work is done together”, the legislation make substantial changes without any work done together. And allows (apparently promotes) the Minister and the Agency to do the work without any external reference.

He refers to people whose support requests are “languishing in long queues at the Administrative Appeals Tribunal”, claiming to have reduced the numbers but failing to mention that those numbers are again on the increase.

Complaints are up. Service guarantees are unrealised.

He says:

We've established the Inklings pilot with the Telethon Kids Institute in Western Australia to help families of children who are showing early signs of autism with evidence based interventions.

Early intervention is one of the key principles of the NDIS, and the world-leading Inklings program takes us from a 'wait and see' approach to an 'identify and act' approach.

This exaggerates the nature of the Inklings pilot since it hopes to deliver evidence of better outcomes for children considered at risk of later getting an autism diagnosis. The NDIS should never have considered a ‘wait and see’ approach for autistic children or children who are regarded as possibly autistic; that shows how hopelessly inadequate the NDIS’s understanding of autism has always been. The current approach does little to address the problem that many autistic children are first labelled with Developmental Delay (29 of the *NDIS Act 2013*) or Global Developmental Delay (DSM-5), which delays significantly their ASD diagnosis and subsequent/consequent access to appropriate supports for their ASD.

He says:

But early intervention is crucial for a life with less reliance on supports later on and the chance for a child to flourish.

However, the changes do nothing to abolish the NDIS’s cruel approach to autistic children whose clinicians advise need substantial supports: see <https://a4.org.au/index.php/node/2567>.

Just as the government disrespects and distrusts people with disability, their Informal Supports, and advocates, the sector must further distrust the Minister and the Australian Government.

The disability sector cannot take Government and politicians at their word on these matters. Too many politicians are more influenced by media commentators who regard the NDIS as a waste of money than the Australian community more generally who regard the NDIS as a crucial improvement to our nation.

3. Issues

3.1. Sector consultation

The introduction of this legislation was an exercise in how not to do it.

The Minister introduced this legislation with no discernible consultation with the autism sector, ... and it appears with very little of the wider disability sector. Even former Minister Reynold's previous failed attempt to create so-called Independent Assessments was handled better.

It is not clear what the new legislation aims to do. Or even why it's necessary. It looks like the "new framework" is a smokescreen for having an assessment tool (s32L(2), s32L(8)) and lists of allowed and disallowed supports. The second reading speech is misleading and not at all helpful.

The proposed legislation aims to make a number of significant changes. But Government did not consult with the disability sector about the changes ... about the purpose of the changes (that is the problem(s) the Government is trying to solve or the challenges that they want to address) or whether the proposed legislative changes are likely to achieve agreed outcomes.

The issues are far too important to be even attempted without fully consulting the disability sector.

3.2. Understanding the problem

It is not clear from the material the Government has provided what the problem is (or problems are) that the Government is trying to solve. It seems to us that they are tackling the wrong problems.

In his 2nd reading speech, the Minister says:

the NDIS, as we all know, is not working quite the way it should and is not working consistently and well enough for many people.

It would help if Government were clear about what data they regard as supporting this claim. The problem cannot be solved, the challenge cannot be met, unless we all know and agree on the nature and extent of the problem/challenge.

The NDIS's many problems include:

- The NDIS's culture ... in part reflected in rising numbers of complaints and AAT review requests.
- The inability to improve many aspects of its performance, achieve much of its Participant Service Guarantees or meet its legal obligations such as FoI deadlines).
- Its failure to explain properly its full role in the social and financial well-being of the nation.
- A lack of data, data analysis and research effort to better inform policy and program development.

- Dependence on and adherence to the original Productivity Commission estimates and predictions ... that were simply wrong in some areas and desperately need revision.
- Its inadequate understanding of autism and how best to support autistic Australians who need the NDIS.

The problem is not NDIS inability to create rules and guidelines, lists that document its preferences, or restrict flexibility through stated supports in NDIS Plans for participants. Clearly, the NDIS can already do these things; it has done them before. The problem is instead that the NDIA lacks the culture, expertise, capability, and intent to develop and implement good (informed and well considered) policy and programs that achieve outcomes agreed with the disability sector¹. The proposed legislation does not address this key problem.

The lack of a credible continuous improvement program in the NDIS is a major concern. Data collection seems more focused on reporting unbelievably positive outcomes rather than on improving the NDIS for participants (and Informal Supports).

3.3. Number of NDIS participants

Most likely, Governments are concerned that there are more Tier 3 NDIS participants than the Productivity Commission predicted, and governments expected. There are several aspects to this:

- The original estimate was wrong. The disability sector expressed concern over this at the outset. The original estimate of 410K, the 450K, was questioned. This was substantially fewer people than the ABS SDAC 2012 estimated had severe or profound disability. There were particular issues around the numbers of autistic NDIS participants expected. The NDIA and government chose to ignore this problem - and continues to do so to this day.
- There is ongoing failure in relation to estimated numbers of autistic NDIS participants. The NDIA persists with its refusal to recognise its initial predictions/estimates of autism numbers were wrong and must be corrected. It keeps reporting the error and never correcting it. And it seems to be blaming the autism sector for the failure when the autism sector advised from the outset that their estimates were wrong.
- There is a growing problem with children with developmental delays (DD & GDD).
- The annihilation of non-NDIS disability supports and the failure to implement NDIS Tiers 1 & 2, as originally conceived, mean that many more people must now rely on the NDIS as the only “disability lifeboat in the ocean they are now adrift in”.

The fact that the NDIS keeps getting its forward estimates wrong suggests that new, possibly evidence-based, approaches to forward estimates are

¹ This is a key lesson learned from Australia’s *Closing the Gap* experiences so far.

needed. Maybe the estimates would be better if they were done in conjunction with disability representatives like some of the DROs.

From the outset, the Productivity Commission, the NDIS and others failed to appreciate that autism diagnoses are growing substantially. The ABS has been reporting for decades growing number of autistic Australians ... very much in line with overseas experiences. This issue needs to be researched and understood rather than ignored or misinterpreted (as is now common practice).

3.4. Children with Disability

One of the issues for the NDIS is that there are far more children who are NDIS participants than were originally expected. This is part of the issue raised above.

As part of the NDIS Review process, the Head of the Melbourne Disability Institute ran around the country asking, “why are there so many children in the NDIS?” He is the one person whose job it is to answer that question.

Of course, it would also be good if the Autism CRC answered the question “why are there so many autistic children”?

Sadly, the simple answer to this question seems to have completely eluded the NDIS Review. The answer is that the original estimates were quite wrong. This problem remains because government officials refuse to update their estimates or understand the available data.

Issues with the development of children were well known when the NDIS was being designed. There were many reports that the numbers of autistic children and children with ADD/ADHD were growing. And descriptions of children with DAMP or other developmental challenges emerged in the research literature.

The architects of the NDIS chose to ignore this information about children.

It seems likely that the creation of Developmental Delay in s9 of the *NDIS Act 2013* has substantially increased the number of children mostly aged 0 to 6 years in the NDIS. The Scheme Actuary now reports that most of these are subsequently diagnosed with Autism Spectrum Disorder (ASD) ... but often too late for best outcome from cost-effective ASD-specific early intervention.

The real purpose of the proposed legislation is to deny many children with autism, intellectual disability and/or developmental delay access to the NDIS and cost-effective early intervention because improving life outcomes for children with disability is considered too expensive. Many children with disabilities, especially autistic children, are considered unworthy of effective early intervention unless it is guaranteed that they will live “normal” lives. It does not matter that many children, through effective early intervention, learn skills that lead to good or improved lives and contribution to the nation - that is not a good enough reason.

The assessment tool (discussed below) is the mechanism that the proposed legislation would use to deny these children the supports that their clinicians advise they need.

The NDIS has an unacceptable record in its interpretation of research and evidence.

Early on, the NDIA developed its initial Early Childhood Early Intervention (ECEI) Approach (Fed 2016) that refers to the ECIA Guidelines. The ECEI Approach relied on a KPMG report² that briefly discussed some research into early intervention for autistic children called *Building Blocks*³. It reported that:

Children in the centre-based program had the largest improved (78.4 after the program compared to 64.4 before the program) followed by the waiting list (74.2 after the program compared to 68.5 before the program), the home-based group had the smallest increase (68.4 after the program compared to 64.4 before the program).

So, by focusing on the waitlist (or *do nothing*) and the home-based groups, the NDIS appears to have concluded (ambiguously) from this research that:

“Nothing is better than the home-based program”

On this basis, the NDIS advises families that “the report highlights the need to match early childhood programs and services to the child’s natural settings”, meaning that home-based programs are considered best (and evidence-based) for young children (most of whom it turns out are autistic). In other words, the NDIA considers the approach with the smallest gains for autistic children to be best practice based on evidence that *doing nothing* got slightly better outcome than the home-based therapy in this instance.

This quality of thinking pervades the NDIA and its approach to early intervention for children with disability. Outcomes like this do not help the sustainability of the Scheme or autistic Australians. The people who developed the ECEI Approach are still involved in the NDIA’s current Childhood Taskforce. This is part of the NDIA’s existing culture.

3.5. Annihilation of Tiers 1 & 2

The NDIS roll-out annihilated other disability services and supports, especially at a state level.

The existing ILC is nothing like the intended Tiers 1 & 2. The inevitable consequence of the absence of Tiers 1 & 2 is that people with disability are

² KPMG, *Reviewing the evidence on the effectiveness of early childhood intervention* (30/9/2011) – see <https://apo.org.au/node/27667>

³ Jacqueline Roberts, Katrina Williams, Mark Carter, David Evans Trevor Parmenter, Natalie Silove, Trevor Clark and Anthony Warren, “A Randomised Controlled Trial of Two Early Intervention Programs For Young Children with Autism: Centre-Based with Parent Program and Home-Based”, *Research in Autism Spectrum Disorders*, Volume 5, 2011, pp. 1553-1566

left scrambling to get the support they need from (to use Minister Shorten’s metaphor) the only available “lifeboat”.

For autistic children, even the Carer Allowance (child) support was made increasingly inaccessible. A4 understands that access to this is Minister Shorten’s responsibility (via Services Australia). Actions speak louder than words; if Minister Shorten was serious about other “lifeboats” and Foundational Supports, he would already have taken steps to improve the uptake of Carer Allowance (Child), an under-used “lifeboat” that is his responsibility.

The NDIS Review suggested creating Foundational Support as a possible approach to this issue, but it is hard to see how that will tackle the issues for children.

At this stage, it is not clear what Foundational Supports are. It appears that they will largely lie with state/territory governments.

Some of us in the disability sector remember that the primary need for a NDIS in the first place was that state/territory governments did a poor job of disability support. In other words, they just did not deliver the fundamental disability supports people needed. So, returning to what was being done before (albeit with a new name) and expecting a different outcome does not seem like a wise strategy.

There need to be good reason to believe improved outcomes are likely before anything is set in legislation. The proposed legislation changes seem very premature; we need to know beforehand what Foundations Supports are and to have credible policy and programs for their implementation.

3.6. Assessment tools

The proposed s32L requires an assessment tool (or tools – the two mentions in the proposed legislation vary on plurality) that may assist in describing a NDIS participant’s “need for support”.

S32L(8) allows, but does not require, the Minister to decide the assessment tool(s) that will be used ... and the form of the assessment report that results for each NDIS participant.

A4’s view is that this is worse than the previous government’s attempt at creating independent assessors (IAs). At least, the IAs were meant to be allied health clinicians/professionals who would have been subject to professional conduct standards. A4 is not aware of any such protection in the proposed legislation; there is no formal complaint or review process available for challenging outcomes from the assessment tool and its uses (or misuse). A4 did not find any indication/guidance of how the AAT or its replacement should address issues relating to the assessment tool outcomes for NDIS participants.

A4 cannot see where there is any provision for testing or challenging the Minister's decisions on the “assessment tool”. It seems that the proposed

legislation ensures that the Minister must unilaterally decide on an assessment tool whether an appropriate assessment tool for autistic NDIS participants even exists.

Currently, the NDIA uses the PEDI-CAT to assess young children. The NDIA has been repeatedly told that the PEDI-CAT is inaccurate hence inappropriate for autistic children, but the NDIA refuses to stop using it. Note that most young NDIS participants are autistic. Some are labelled with Developmental Delay or Global Developmental Delay but have yet to have their autism diagnosed; the PEDI-CAT does not give accurate results for these children.

This is not a simple problem. The authors of [the PEDI-CAT](#) recognise that this assessment tool is not suitable for autistic children which is why they created [the PEDI-CAT \(ASD\)](#) hoping to address the problem. The NDIA commissioned the Autism CRC to report on the PEDI-CAT (ASD). [The negative result](#) is available on the CRC's website.

This attempt to develop an assessment tool that works for autistic children was not successful. Other attempts have also failed. While different clinicians use different assessment tools in the context of their clinical supports for autistic patients, there is no agreed assessment tool in Australia.

A4 is not aware of any assessment tool used effectively and consistently to assess autistic adults.

Can we expect to see the return of Cate Blanchett as Nadia II, the Disability Assessment Tool, - shades of RoboNDIS? See <https://www.abc.net.au/news/2017-09-21/government-stalls-ndis-virtual-assistant-voiced-by-cate-blanchet/8968074>

Currently, the sector is not ready for legislating an assessment tool for use on autistic NDIS participants.

Any progress on assessment tools for autism must be informed by comprehensive sector consultation.

3.7. Assessment tools for autism

There is no agreement that an appropriate assessment tool exists for autistic children ... and previous attempts to create one, such as the PEDI-CAT and the PEDI-CAT (ASD), failed. There is no guarantee that one can/will be created. It may be that creating an assessment tool for autistic children is just "too hard". So, legislation on this issue is extremely premature.

The current proposed legislation aims to impose assessment tools without any meaningful guarantee that they have been properly validated. How does this make sense for the biggest "primary disability" in the NDIS?

Every properly documented autism diagnosis comes with functional measures. But the NDIA chooses to ignore the available information. If it

can't use the information already available to it, why should anyone expect that the Agency will make better use of more information.

It is not clear that a practical assessment tool is feasible for the autism spectrum. It may be more practical to follow the original intent of the NDIS and base an individual's disability supports on the individual's support needs.

That would mean that treating clinicians would monitor and continuously advise on individual supports.

Recently, the Minister and various officials have claimed there is a serious problem with NDIS participants over-spending the NDIS plans, then seeking funding top-ups. A4 recently requested evidence to back those claims but we have not received any information as yet.

3.8. NDIS “appropriately funded supports”

The section labelled “10 Definition of NDIS support” is extremely scary for some autistic NDIS participants with higher support needs. It appears to allow the NDIA/NDIS to create at whim lists of “declared supports” s10(b) and “excluded supports” s10(c). The excluded supports are especially scary.

Through its existing ABA policy (see <https://a4.org.au/node/2567>), the NDIA had already shown that it intends to make evidence-based supports for severely and profoundly autistic children as difficult to access as possible: families have to spend more than a year in the AAT review process fighting the NDIA at its most litigious.

Similar issues exist around behaviour supports for autistic people who need them.

A4 has seen examples of the NDIS deciding to not fund toilet training for autistic children, preferring instead that they remain incontinent through their life ... and instead accessing continence products from an approval panel of continence product providers.

Legislation cannot allow this type of operation; if any such list is to be legislated then it must have checks and balances that requires comprehensive sector agreement (not just consultation) and proper external oversight options.

3.9. Independence of Q&SC

The disability services Quality and Safeguards Commission needs to be completely independent of the NDIS/NDIA. It seems that the proposed legislation allows the NDIS to decide on aspects of the operation and jurisdiction of the Q&SC; that is not acceptable.

The Q&SC needs to address equity, quality, and safety in relation to Navigators, Foundational Supports, Health, etc. to be effective, its powers needs to extend beyond the NDIS.

4. Conclusion and Recommendation

This legislation is extremely dangerous. It gives uninformed and prejudiced officials unrestricted control over the provision of disability supports for the most vulnerable Australians. It removes choice and control and essential independent review of decisions that control the lives of vulnerable people and their Informal Supports.

This proposed legislation must be rejected.

Bob Buckley

Co-convenor, Autism Aspergers Advocacy Australia.