

A better NDIS for Autistic participants

Finding all the colours of the spectrum

Just keep moving forward.
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Preface

[Autism Asperger Advocacy Australia](#), known as A4, appreciates the opportunity to suggest improvements to the National Disability Insurance Scheme via the 2023 NDIS Review.

A4 has great optimism. We are keen to see the NDIS move forward positively.

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).



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Proud member of



AUSTRALIAN
Autism Alliance

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A better NDIS for Autistic participants

The following provides broad concepts to substantially improve the NDIS for Autistic participants rather than detailed solutions. A4's response below focuses more on underlying principles than specific solutions. We do this because Autism Spectrum Disorder (ASD) and Autism Spectrum Conditions (ASC) are, as their names say, spectrums.

Autistic people have a wide range of needs that demand a spectrum of solutions. There are many prospective solutions but A4 lacks the capacity to provide a plethora of detailed explanations.

Previously our evidence-based advice and suggestions have not been considered. However, if the NDIS Review is open to any of our suggestions, we would be delighted to provide detail to help progress ideas.

Funding goals – get the NDIS working better

The establishment of individualised plans that deliver each Autistic person's goals is sound, however, the implementation of the scheme has contributed to excessively expensive, complex, and ineffective processes.

What to do:

- Develop NDIS plans (Statements of Participant Supports) directly from the participant's individual goals and the client's desired *supports* to help achieve the goals.
- Help people better describe and articulate their goals and refine the description of goals progressively as participants' requirements change.
- Permit the participants to respectfully determine their own priorities, not the NDIS, recognising that people with similar goals may want to choose different supports to successfully achieve their targets.
- Allow for the monitoring of a participant's goal progress to permit some flexibility
- Develop better reporting systems that capture data that demonstrate what supports are effective for different disabilities and conditions.
- A focus on meeting participants' support needs rather than cost would achieve overall savings.
- Make scheme modifications which allow for the financial relationship to remain between the NDIA and the provider; in cases where the participant does not want to be involved.
- Measure and report on service quality based on measured outcomes. Preferably, make service quality data accessible to participants to improve their choice and control.

- Recognise that supports should change over time, and plan flexibly anticipating change¹.

The Scheme needs to be more flexible; to meet the varied needs of Autistic participants. For many Autistic people the NDIS's existing system is satisfactory, and the NDIS should be acknowledged for these successes. However, for others it is incomprehensible and highly dysfunctional system.

Some participants require the support of an ally, guide, or navigator (less ideally, a family member or friend) to act as a support person during every interaction with the NDIA. There may be other support models that also work for some Autistic NDIS participants.

Service Providers

We would encourage the NDIS to identify, respect, and reinforce good service providers while providing support for informed choice and control in the disability services and supports "marketplace".

The NDIS should monitor and manage service gaps and workforce capacity. This includes monitoring workforce development from the training of people entering the workforce to the maintenance of up-to-date professional practice.

In relation to workforces throughout the disability sector, more effort is needed to:

- + measure service demand based on goals and support needs,
- + match demand with capacity. Identify gaps e.g., numbers, skills, quality, etc.
- + Implement programs for individual participants that fix gaps and monitor progress closely.

Other suggested improvements

- The NDIA is still to implement recommendations like stop using the PEDI-CAT (not even the PEDI-CAT (ASD)) with Autistic children.
- The NDIS needs to boost its knowledge of autism, evidence-based practice, and improve many essential capabilities to function effectively.
- Develop respect for external stakeholders.

What the NDIS should not to do:

- Limit flexibility.
- Fit goals into a small number of boxes (like core supports and capacity building), then normalise the boxes. That is not individualised support as the Scheme is meant to deliver.
- Focus on money. Instead, focus on outcomes and how to achieve them (not what they cost). Individual outcomes are associated with the individual's own goals, not some collective notion.
- Focus on statistical averages. The NDIS must deliver outcomes for everyone, not the biggest groups or those who are easiest to support. The NDIS needs

¹ When planning for an individual, it is OK to check for duplicated supports and efficiencies; no need to duplicate supports that help achieve more than one goal for the participant.

exception reporting of every failed outcome and a credible plan for subsequent success.

Issues within the NDIS specific to autism

Currently a lack of understanding has led to the NDIS embracing discriminatory policies and practices, that disadvantage some Autistic participants.

1. Every Autistic child also meets the criteria from Developmental Delay as defined in **Section 9** of the *NDIS Act 2013*. A child diagnosed with “developmental delay” has a relatively direct pathway into the NDIS. If the *same* child seeks access to the NDIS with a so-called “ASD Level 1” diagnosis, then the child’s access to the NDIS is more difficult. This is discrimination against children who are diagnosed Autistic.
2. Severely Autistic children who are advised that they need evidence-based intensive early intervention for their autism are subject to the NDIS policy² that says, “the NDIA is likely to run the matter to hearing”. The NDIA makes it most difficult for the most severely Autistic children to have their support needs met. Increasingly, the time the AAT hearing process takes (usually over a year) denies them most of the support they require.

The NDIA and its associates have massive gaps in their knowledge and understanding of Autistic participants, even though autism is the biggest “primary disability” type among NDIS participants.

The NDIA needs to engage more comprehensively with Autistic participants, especially the most severely affected ones. Few severely Autistic participants communicate and participate in conversations with NDIA officials.

Some of the issues raised by self-advocates, while important, fall outside the domain of the NDIS. Autism is a spectrum, so approaches that are preferred and effective for different parts of the spectrum differ ... and may conflict. The challenge is for the NDIA to recognise and respect the different and conflicting needs, choices, and expectations of the various stakeholders.

The terms “best practice” and “good practice” relate to multiple practices varied across the autism spectrum. For example, some Autistic children need intensive early intervention, and some do not. Regular review of the existing approaches and current research will result in better evidenced-based responses and greater success.

Before the DSM-5, the DSM-IV and DSM-IV-TR described *Pervasive Developmental Disorders* as a group of disabilities, the main ones being Autistic Disorder, Asperger’s Disorder and PDD-NOS. Research of the time focussed mostly on Autistic Disorder.

The DSM-5 (and now the DSM-5-TR) combined these three disabilities into one diagnostic label: Autism Spectrum Disorder. Typically, researchers now study the whole spectrum under the one label. Numerous research reports and reviews,

² OFFICIAL For Internal Use Only - **AAT Case Management Guide Applied Behavioural Analysis (ABA)**

including the report on early intervention (commissioned from the Autism CRC) have concluded that the previous research results obtained for subjects fitting the DSM-IV Autistic Disorder classification differ from research results where subjects are selected based on DSM-5 ASD diagnoses³.

The CRC's report concludes that the previous results for Autistic Disorder differ from more recent results for autism or ASD. The report confuses different parts of the autism spectrum; it misinterprets old results for DSM-IV Autistic Disorder when it combines them with results for DSM-5 ASD. The resulting confusion helps drive poor policy in the NDIA forcing the most affected Autistic children into long legal battles with the NDIS in the AAT.

Lawyers and witnesses for the NDIS provide misleading evidence at AAT hearings because they do not understand that previous research remains relevant and applicable for children who today still meet diagnostic criteria for DSM-IV Autistic Disorder.

Most of the Autistic children that the NDIS insists on sending to AAT hearings with the consequent delay⁴ accessing clinically recommended intensive early intervention meet diagnostic criteria for DSM-IV Autistic Disorder, so previous research remains relevant for them. But AAT Members are extremely reluctant to accept evidence that differs from what the NDIS says.

People seem to assume/expect that every Autistic child will, when given a chance, request intensive early intervention. This hypothesis is not evidence-based. The NDIA is not reporting how many Autistic children get and pursue recommendations for intensive early intervention.

We must address the NDIS's system that makes the most vulnerable with the most urgent needs navigate the AAT to receive support. It should be noted that in all cases where has been A4 involved⁵, the participants' claims have been successful⁶.

Evidence-based supports

There is currently an unreasonable view that all families of Autistic children exaggerate their child's needs and expect support that are not "reasonable and necessary" for the child. Experts recognise that families know their Autistic children best, and that while some families want intensive early intervention for their Autistic child, while many families do not. These perceptions need to change.

A major challenge is that solutions aimed at the average Autistic person, under the broader DSM-5 Autistic label, are unlikely to suit many Autistic people. There are very few average Autistics, just as the average diagnosis rate for autism/ASD (around 1% of the population) does not represent the diagnosis rate at any age⁷.

³ DSM-IV Autistic Disorder did not include Asperger's Disorder and PDD-NOS; these are all together as ASD in the DSM-5 ... so the subject group in recent research is different from earlier research.

⁴ delay in accessing early intervention for autism is detrimental for the Autistic child.

⁵ As with Autism Partnership Australia, see <https://www.theguardian.com/australia-news/2023/aug/29/national-disability-insurance-agency-accused-of-failing-young-children-with-autism>

⁶ Though this may not always be apparent without fully understanding the outcomes.

⁷ Autism/ASD diagnosis rate for children in Australia is over 3% and for adults is under 0.5% - the average does not describe autism/ASD diagnosis rates across the age range of the population.

There needs to be a greater understanding of why autism diagnoses are increasing and policy that addresses the diverse needs of Autistic NDIS participants across their spectrum of needs. There are very few average or typical Autistic NDIS participants; the rest do not need a *typical* autism plan that suits very few of them.

The optional 1-page (2 sides) sheet on autism and unlocatable brief video on autism are not enough training for NDIS planners who write NDIS Plans for Autistic people, or for LACs, plan managers or support coordinators involved with Autistic participants.

NDIS Plans for many Autistic children fund generic speech therapy and/or occupational therapy even though generic therapies are not good or evidenced-based practice: research demonstrates that generic therapies are mostly ineffectual for severely affected Autistic children. Speech or occupation therapy for severely affected Autistic children should be restricted to evidence-based practices for Autistic children⁸.

Frankly, the outcome results for generic speech therapy and/or occupational therapy in control group outcomes reported in research show that treatment-as-usual (TAU) functions for Autistic children like any other placebo would.

There are major changes in treatment goals that early intervention for Autistic children now aims to deliver. There is an increased emphasis on Inclusion in education and more generally which “normal” with neuro-affirming as a goal. Since the early autism research, the skills that an Autistic child needs to enrol in a mainstream school have changed substantially. Inclusive education has eliminated the need for Autistic children to present as “normal” so they can attend mainstream school.

Where is the research that achieves modern goals right across the spectrum? That’s what must be considered good/best practice.

The NDIS must create and develop the workforce required to deliver neuro-affirming therapies and intervention with substantially improved outcomes in education, employment, living and well-being.

Behaviour Support Challenges:

After 10-years of operations, the sector still hasn’t provided real solutions for behaviour support. The NDIS lists over 4,000 service providers, but there are fewer than 150 clinicians with any credible registration and most of those work ~~mostly~~ in early intervention for Autistic children.

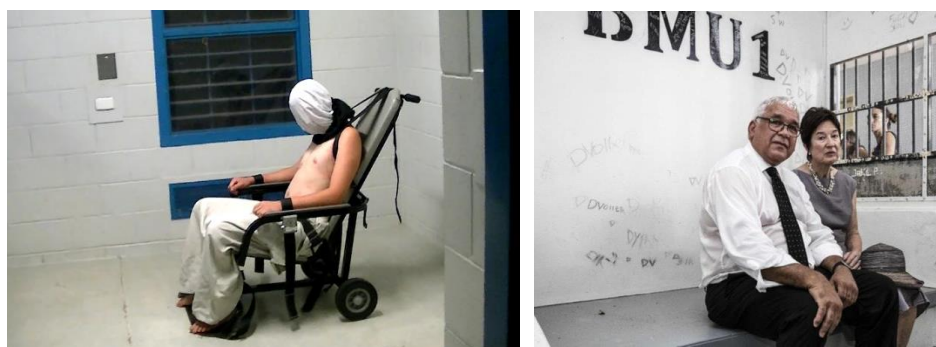
Recently, the NDIS told the AAT that behaviour support plans from the biggest (apparently most preferred) autism service provider were “not current good practice.”

⁸ E.g. Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yucesoy-Ozkan, S., & Savage, M. N. (2020). *Evidence-based practices for children, youth, and young adults with Autism*. The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team.

The current self-assessment approach for behaviour support service providers is unsatisfactory. It delivers and promotes many risky, ineffective, and dangerous practices. Autistic people and their families should be extremely wary.

The NDIS does not recognise professional conduct in behaviour support, which makes accessing quality service unreasonably difficult for NDIS participants.

Unilateral opposition to the professionally managed and supervised application of behaviour science endorses and promotes the alternative, which is unregulated restrictive practices. The following pictures⁹ remind us of how that approach can be sub-optimal.



Other

The NDIS needs to improve its performance in relation to housing and accommodation.

The disability sector needs supported decision making (SDM) for Autistic participants.

The disability sector must start to consider issues of autism and genetics. There have been no Down Syndrome births in the ACT so far this year. In relation to autism, genetic issues are more complex and barely getting started.

There is no autism-specific disability advocacy service. Generic advocacy services have very little idea of how to advocate for Autistic people.

Support for Autistic people outside the NDIS is minimal at best. Hopefully, the National Autism Strategy (NAS) will tackle all the issues in this category.

ASD diagnosis challenges

The ASD diagnosis rate varies substantially between states and territories, and between regions within states. Many factors may contribute to this variability, including:

- The local clinical culture in ASD diagnosis
- State funding for ASD diagnoses
- The option to diagnoses Developmental Delay instead

⁹ BMU is for Behaviour Management Unit.

The autism sector is not aware of any justification for the Medicare item cut off at (recently increased) 25 years of age.

This issue may be shared between the NDIS and Health.

Issues specific to Autistic children

For many Autistic children, first getting a diagnosis of Developmental Delay or GDD results in delay getting their ASD diagnosis.

Delay getting an ASD diagnosis is detrimental.

There needs to be a new and improved focus on varied evidence-based early intervention practices for the full spectrum of Autistic children

At this time, more than 50% of NDIS participants aged 0 to 6 years have Developmental Delay (which is defined in Section 9 of the NDIS Act 2013) as their primary disability. We see very little published research on early intervention for Developmental Delay in the literature.

Every child with an autism diagnosis meets the criteria for “Developmental Delay”. It seems that a child diagnosed with so-called “ASD Level 1” may experience barriers accessing the NDIS. However, if the diagnosing clinician also provides a diagnosis of Developmental Delay and the child’s application to the NDIS uses their DD diagnosis, it seems likely that they will meet the eligibility criteria. This presents as disability discrimination.

Attending School

If a child is unable to attend school and seeks NDIS support instead, the NDIS should provide the required support and recover the full cost supports plus a commission from the education authority where the child is enrolled.

The nation need substantially better outcomes for Autistic students. School-age Autistic children need far better disability support than what currently exists.

NDIS ICT systems

The information I can see about the new system is not convincing.

Does the NDIA’s new system have an appropriate data model: for example, how does it represent people, participants, history of participant goals & outcomes, service providers, service and supports, disability types, participant relationships with disability types, relationships between people, participants, providers and the NDIA officials involved in participant planning & admin, etc.?

The information given to A4 does not show how necessary flexibility in the system is addressed.

I am not confident that the new NDIS ICT system design and its implementation plan recognise that the NDIS Review is likely to require some significant changes.

Conclusion

The NDIS has headed off in many wrong directions. There is a massive amount to do.

The NDIS needs to reform its culture.

The NDIS probably needs its own autism strategy; that means skills, policy and program development, specific and detailed measurement and reporting on a wide range of outcomes for Autistic NDIS participants.