Submission to Thriving Kids inquiry

Autism Aspergers Advocacy Australia

3 October 2025

Preface

Autism Asperger Advocacy Australia, known as A4, appreciates the opportunity to contribute to discussion about creating a Thriving Kids program in Australia.

This submission was prepared very quickly. We apologise for its rawness and incompleteness.

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.

Contents

Introduction

Autism Aspergers Advocacy Australia (A4) prepared this submission for the Thriving Kids Inquiry - https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Disability/ThrivingKidsinitiative by **Standing Committee on Health, Aged Care and Disability**.

What is the problem?

For a starter, A4 argues that there are multiple problems; there is not a single problem to be solved. And few if any people properly understand what the problems are that we are trying to solve.

Problem #1. The NDIS is a big political target

Political dog-whistling over spending large amounts of money to help vulnerable people is a growing enterprise in mainstream media. The scale of the NDIS is the problem.

One solution would be to separate the NDIS into smaller parts, possibly with one scheme for children and a separate scheme for adults (post-school) each with separate bottom lines in the Budget. This would turn each part into a smaller target for the media and political dog-whistlers.

Potentially, Thriving Kids could further separate into pre-school and school-age schemes … making those schemes even smaller (and less palatable as) targets for dog-whistling; it is harder to go after vulnerable children.

Problem #2. Identify the issue

Minister Butler announced Thriving Kids as targeting "children with mild to moderate developmental delay and autism". We understand "mild to moderate" applies to both developmental delay and autism. And that children with severe or profound autism are meant to remain as participants in the NDIS.

As yet, no one has clarified what is considered "mild to moderate autism".

And parts, often especially vocal parts, of the autism sector object to the terminology.

Developmental delay is a condition defined in Section 9 of the NDIS legislation; before the NDIS started it was not normally recognised as a clinical condition … though the phrase was sometimes used for children with subclinical needs.

But the NDIS legislation created a support mechanism for these children.

So developmental delay mostly means mild to moderate delay. Children with more delay should be diagnosed with

- global developmental delay (GDD), a separate and more recognised temporary diagnosis that is briefly described in the DSMs, or
- a more specific condition such as autism spectrum disorder (ASD).

The Minister's speech-writer should have used the phrase "developmental delay and mild to moderate autism"; it would have been much less alarming.

Since the announcement, senior officials advised the last DRO Forum that work on defining and quantifying the number of young NDIS participants with mild to moderate autism has not started.

Also, an FoI response from the NDIS says that the NDIS gave no advice on the numbers to the Minister before Thriving Kids was announced.

A comparison of ABS estimates of the number of autistic Australians with severe or profound disability with the number of autistic NDIS participants indicates that there were fewer autistic NDIS participants than there are autistic Australians whose disability due to autism is severe or profound. It is unlikely that autistic NDIS participants have mild or moderate autism.

So it is unlikely that there are significant numbers of NDIS participants whose primary diagnosis is recorded as autism but who have mild or moderate autism.

Maybe there are autistic NDIS participants with mild to moderate autism, but their NDIS records show them as having developmental delay or global developmental delay. Or they have another disability that is severe or profound.

So mild to moderate autism is unlikely to be the real problem.

Problem #3. Broken promises

The government promised that no one would be worse off under the NDIS.

The problem is that the NDIS was meant for some people with profound disability and some (not all) people with severe disability.

The problem was that the NDIS rolled around the country absorbing all the disability funding … leaving no funding (so no supports) people with mild, moderate, and severe disability who were not eligibility for the NDIS.

Clearly some people were worse off … such as autistic children with less severe autism.

The original NDIS design talked about Tiers 1 & 2 that was meant to support these people … but was never designed, let alone implemented.

Problem #4: lack of evidence-based early intervention

From what A4 has observed, the NDIS avoids evidence-based approaches to supports for autistic children.

Since developmental delay is peculiar to the NDIS there does not appear to be a solid evidence base for therapy supports for children who are given this label.

From what we see, there is not a strong evidence base for global developmental delay either.

This issue deserves far more attention that government has given it.

Problem #5: autistic kids not thriving in education

There is substantial evidence that autistic children are not thriving in Australian education systems. The Australian Bureau of Statistic reports on autism and NDIS autism participant dashboards repeatedly report especially poor education outcomes.

The problem is exacerbated especially in the autism sector.

Many autistic children are sent to school unprepared. Early years teaching is schools is predominately based on teachers saying, "do this" and demonstrating the skill they are trying to teach. But many autistic students start school without basic imitation skills, so the instruction provided does not address their needs. Few teachers know how to develop imitation skills in autistic students … so success in teaching these students is limited. Many young autistic students lack receptive language to follow verbal instructions. And they often do not have the socials skills needed to imitate and learn from peers.

Many autistic children miss out on effective education from the outset. And without the foundations, they continue to fail in education as they get older.

Bullying and school refusal are increasing issues for autistic students.

Recently, government bureaucrats wrote their National Autism ¾-Strategy (NA¾S). While they included a representative from Education, they did not request any input. The FoI response[i] from the Education Department shows that the only communication with the Education representative was to invite the Education representative to the launch of their final document. There was no government contribution of education to the NA¾S.

There was no discernible attempt to recognise and address the especially poor outcomes in the education sector for autistic Australians … despite the issues being raised repeatedly by representative from the autism sector.

Autistic children in Australia will not thrive when this is how government conducts itself.

NDIS bureaucracy is a problem

The NDIS is becoming increasingly bureaucratic.

The original idea was that people with disability would articulate their disability-related goals, and the NDIS would provide the reasonable and necessary supports to help achieve those goals.

But the NDIS has annihilated that vision.

Basically, the NDIS moved its planning process further and further from the participants' goals.

For young autistic children, the NDIS's strategy for autism-related goals is to "provide opportunities" for the child to be less- or non-autistic. But autistic children have that opportunity without needing the NDIS.

And the evidence base shows that is rarely, if ever, an effective strategy.

A better system has eligible participants first documenting their goals (as is now the case), but then the participant and the NDIS would negotiate how the NDIS would support them to achieve those goals.

And it would monitor the effectiveness of the supports in relation to the goals.

In the NDIA's current approach, the person with a disability, the participant, needs to deal with a growing army of bureaucrats:

- LAC
- Support coordinator
- NDIS plan manager
- NDIS planner
- NDIS internal reviewer

These all involve more work and increase costs substantially.

And if your NDIS plan emerging from all this is unsatisfactory, then more people are involved: case manager, advocate, external lawyers, ART officials, …

The goals and purpose of the NDIS are lost in a miasma of bureaucracy.

The planning process is increasingly remote from the original individual goals that are meant to be central to the whole thing.

Wilfully uninformed NDIS

The NDIS bureaucracy is wilfully uninformed about autism. For example, it's planners and early childhood partners often tell families that "the NDIS does not fund ABA". However, the AAT and ART have always recognised ABA as being reasonable necessary supports for severely or profoundly autistic children – the issue of contention has been what intensity ABA is "acceptable". The NDIS wilfully ignore many of the AAT/ART decisions when making new cases. And there is no sign that it has learned from its experience.

The NDIS created its ABA Case Management Guide with no input from relevant clinicians. Nor does it reflect its experience through AAT/ART decisions.

Autism is a spectrum disorder which means there is a spectrum of appropriate supports needed for autistic people. Expert advice always says there is no one approach that suits all autistic children. And there exists a

variety of approaches that families of autistic children can choose from. Many families do not want ABA-based therapies … but those who make an informed choice should be able to try it properly to see whether or not it meets their child's needs.

Inquiry - Terms of Reference

- Examine evidence-based information and resources that could assist parents identify if their child has mild to moderate development delay and support parents to provide support to these children.

Parents should see a GP or a paediatrician regularly. They should discuss any concerns they have with these clinicians.

Parent should have their young children seen by a child and family health nurse regularly. The service is meant to be free and accessible to all children.

Properly trained child and family health nurses should help families recognise signs of developmental delay, even mild and/or moderate delay, and other conditions that need attention and provide appropriate referrals.

Government could implement a more proactive approach to follow-up and help families act on recommendations and advice.

A4 is not aware of evidence that a child and family health nursing services are implemented effectively across the country. Nor whether there is any attention being given to ensure sufficient capacity, capability, and consistency across service delivery.

Given the scale and significance of emerging issues in the early childhood sector, this is an inadequate approach from government.

Government could do much more to avoid or correct mis-information about autism in the media.

- Examine the effectiveness of current (and previous) programs and initiatives that identify children with development delay, autism or both, with mild to moderate support needs and support them and their families. This should focus on community and mainstream engagement, and include child and maternal health, primary care, allied health playgroups, early childhood education and care and schools.

In terms of previous programs, a short section from the NDIS website is provided as 0 below

Prime Minister John Howard created the *Helping Children with Autism* (HCWA) program immediately before announcing the 2007 federal election. At the announcement, John Howard promised that HCWA was just the beginning and more would follow for autistic Australians.

The ALP responded to the Howard Government's HCWA announcement with an election promise of an Autism Specific Early Learning and Care Centre (ASELCC) in each state.

The ALP won the 2007 election and Minister Bill Shorten was charged with delivering both programs – HCWA and the ASELCCs. After consulting the autism sector, Shorten's HCWA roll-out provided $12K of therapy for each young autistic child with a maximum of $6K in any year. Families had access to impartial Autism Advisors who helped them access services and supports. As a result, as well as HCWA, a high percentage of autistic children accessed Carer Allowance (child), a long-running Foundational Support of children with disability.

Both HCWA and Carer Allowance (child) supported all autistic children in their respective age ranges in Australia, whether their autism was considered "mild to moderate" or caused greater impact on their wellbeing.

Children do not have both – but increasingly, they are diagnoses first with DD (or GDD) then subsequently with ASD. They should be diagnosed with ASD from the outset and provide early intervention for their ASD.

- Identify equity and intersectional issues, in particular, children who identify as First Nations and culturally and linguistically diverse.

A major equity issue revolves around children who are labelled with developmental delay of global developmental delay apparently get access to NDIS supports, but children who are diagnosed with Autism Spectrum Disorder Level 1 are often denied access … even though they could be labelled with DD or GDD.

Many autistic children are diagnosed with genetic conditions like Fragile X or Down syndrome, but they are not given the functional assessment that would also identify the ASD. Many of the children are assumed to have intellectual disability/impairment and their only impairment – their communication, social and behavioural impairment are unrecognised.

The NDIS does not seem to recognise Fetal Alcohol Spectrum Disorders (FASD) … and any autism associated with this condition is likely to have been missed[1].

Autism diagnosis rates in the Northern Territory[2] are much lower than in other states. This appears to be associated with reduced capacity and capability in health supports for First Nations people.

- Identify gaps in workforce support and training required to deliver Thriving Kids.

Autism diagnosis rates have risen substantially in the last 20-30 years.

There were insufficient clinical services from the start. Workforce capacity and capability have not increased to keep up with support demand.

The fact that autism diagnosis typically take 2 or more years is testament to service inadequacies.

[1] https://www.nofasd.org.au/event/228633/
[2] As observed in NDIS data.

The recent decline in autism diagnosed in Australian children aged 0-6 years (see https://a4.org.au/node/2587) is another indication.

Service quality in relation to behaviour support is a major and ongoing issue – after a damning review, annual reports show the Quality and Safeguards Commission are yet to achieve a satisfactory service standards.

Recognition of and access to evidence-based supports for severely and profoundly autistic children are unreasonably difficult – see https://a4.org.au/node/2567

- Draw on domestic and international policy experience and best practice.

Domestic policy relating to autism in Australia is to do everything possible to ignore it.

Autism is largely omitted from Australia's Disability Strategy.

The development of a so-called National Autism Strategy developed by DSS and Health officials avoided input from government departments and agencies such as the NDIS, Education, Employment, "Justice", etc. And it excluded much of the input from the autism sector; key issues and concerns were ignored. Perhaps most remarkably, it ignored representative voices of people with severe and profound autism despite repeated reminders of this deficiency in DSS's NA¾S and Health's unfunded Autism Roadmap. In it's Glossary (at page 44) the final NA¾S describes "Autistic people with very high support needs" but prioritises "people with very high support needs" (not specifically autistic) in parts of the document … and without any real strategy to recognise and address their needs or improve their outcomes. This is a serious failure of the NA¾S; it reflects government's especially poor understanding of autism in Australia.

The Health Department's component of the NAS remains unfunded; without funding, it is not best practice and unlikely to achieve positive outcomes. It also failed to adequately recognise many of the health and mental health issues raised by the autism sector.

Internationally, very contentious autism policy is emerging in USA.

None of these experiences can be considered "best practice".

- Identify mechanisms that would allow a seamless transition through mainstream systems for all children with mild to moderate support needs.

Conclusion and Recommendations

Government needs to develop better informed understandings of autism … and mild to moderate autism if it wants to develop effective policy. It may even need to reach consensus with the autism sector about who fits in such a category.

Government, end especially the NDIS, have lost the trust of much of the disability sector. This severe lack of trust needs to be recognised, respected, and addressed.

A4 is not opposed to separating disability support for children from supports for adults. What matters is that children get the supports they need to realise their best lives

Annex A: About Developmental Delay

Developmental delay (DD) is not a clinically recognised condition. It is not defined in the DSMs or the WHO's ICDs.

In relation to the NDIS, Developmental Delay is defined in Section 9 Definitions of the *NDIS Act 2013* (the Act) The Act says:

> **9 Definitions**
>
> …
>
> ***developmental delay*** means a delay in the development of a child under 6 years of age that:
>
> (a) is attributable to a mental or physical impairment or a combination of mental and physical impairments; and
> (b) results in substantial reduction in functional capacity in one or more of the following areas of major life activity:
> (i) self-care;
> (ii) receptive and expressive language;
> (iii) cognitive development;
> (iv) motor development; and
> (c) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated.

The NDIS website has the following (see here – 21/8/2025):

> **What is developmental delay?**
>
> Developmental delay is a term used to describe a delay in a child's development. It means that a child finds it much harder to do everyday things that other children their age can do, for example dress themselves, talk or walk.
>
> A child with developmental delay needs lots of extra help to do everyday things compared to children of the same age. Learn more about the definition of developmental delay in our guideline – applying to the NDIS.

General research and academic literature provides some relevant material, such as https://www.ncbi.nlm.nih.gov/books/NBK562231/.

A4 understands that originally Developmental Delay was defined in the Act and included in the NDIS at the insistence of the Victorian Government.

Other conditions related to Developmental Delay

The DSMs defines Global Developmental Delay (GDD) in a section on Intellectual Development Disorders. The entire section on GDD in the DSM-5-TR (2022) says:

> **Global Developmental Delay**

F88

This diagnosis is reserved for individuals *under* the age of 5 years when the clinical level severity cannot be reliably assessed during early childhood. This category is diagnosed when an individual fails to meet expected developmental milestone in several areas of intellectual functioning, and applied to individuals who are unable to undergo systematic assessment of intellectual functioning, including children who are too young to participate in standardized testing. This category requires reassessment after a period of time.

There is very little evidence-based information and resources for this reason. Since it is not formally recognised as a disability type other than by the NDIS, it is not the subject of research and reporting.

We rely on NDIS for data about DD and GDD. The NDIS needs to provide better access to data (the NDDA is not yet being realised).

We expect that most DD is mild or moderate since more severe delay is usually attributable to specific conditions.

Parent identifying any DD

Parents responses to children vary. Some pathologise every difference, some are reluctant to recognise problems.

Parent should be encouraged to have their children's development reviewed.

Early childhood services should be cautious in pathologizing children – as with parents.

Parents providing support

This is a fundamentally unresearched issue.

Some parents are very good … but research does not support this model generally.

c.f. with autism experience.

Annex B. Previous support – NDIS website

Following is an extract from National Disability Insurance Scheme, Consultation paper: Interventions for children on the autism spectrum, March 2021 | Version 1.0 | ndis.gov.au

7.3 Previous support provided

We have considered historical funding arrangements for comparable early childhood and early intervention services that existed prior to the NDIS.

The **Helping Children with Autism (HCWA)** program provided families of children with an eligible diagnosis with access to early intervention funding up to $12,000 (up to $6,000 per financial year) until children turn seven years of age. The funding supported delivery of multidisciplinary evidence-based early intervention to facilitate improved cognitive, emotional and social development, including through one-on-one activities and tailored group and individual programs. Families accessed support through a panel of providers approved by the Australian Government and the Early Intervention Service Provider Panel Operational Guidelines provided the operational framework for service provision. The HCWA program also included information and support through a variety of sources to assist families in their decision making. All eligible children receiving individualised HCWA funding are transitioning to the NDIS and the program will close on 31 March 2021.

State/Territory funded ECI services also supported children on the autism spectrum through the state early childhood education and disability systems. Quality approved providers supported children through best practice approaches from one hour to 8 hours per week. Most children were supported through both specialist supports and to access a broad range of early childhood development services provided through a broad range of Commonwealth and State funded programs.

The **Autism Specific Early Learning and Care Centers (ASELCC)** provide early learning programs and specific support for children aged zero to six years on the autism spectrum or with autism-like behaviour in a long day care setting. They also provide families with education and support to use early intervention strategies in the home to maximise the positive impact on children's long-term outcomes. The long day care model allows parents the opportunity to participate more fully in education, employment and the community. This model is individualised and can bridge group based and individualised early intervention programs, supported mainstream participation and supported childcare that has a focus on facilitating successful transition to school. All eligible children attending an ASELCC are transitioning to the NDIS and children now enrolling in ASELCCs need to fund their place through their NDIS plan or privately. Each ASLECC has a different delivery model which results in differing cost structures and differ minimal days attendance.