

**The Hon Anthony Albanese MP**

Prime Minister

Parliament House

CANBERRA ACT 2600

Cc: The Hon Jim Chalmers MP, Treasurer  
 Senator the Hon Katy Gallagher, Minister for Finance.

Dear Prime Minister Albanese,

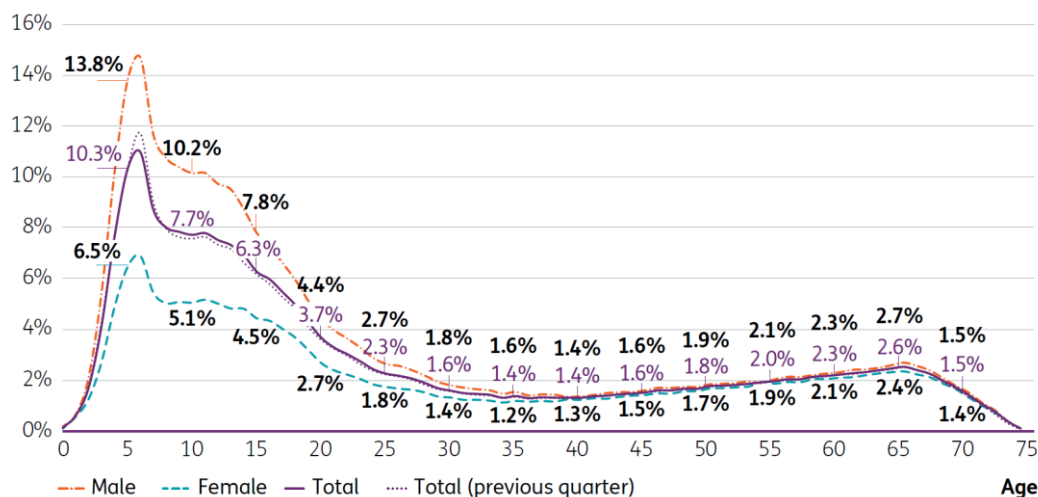
**Subject: whole of government concerns for autistic children**

I write to express concern over the government’s position about young autistic children ... with particular concerns about the NDIS, Foundational Supports, Thriving Kids, abysmal outcomes in education, legal systems, and areas of government responsibility generally<sup>1</sup>.

Government and its agencies are sending very confused messages to the autism sector.

In the early childhood space, government via the NDIS wrote that “your child doesn’t need a diagnosis to get help”<sup>2</sup>. The NDIS epitomises the movie misquote “build it and they will come”: the government created the NDIS and more people with disability have come than were expected. There has been enormous and grossly misguided commentary on the number of young autistic children or children seeking and getting support via the NDIS. While one of your speeches recently exaggerated the numbers, the reality is reflected in the Figure 2 of recent NDIS Quarterly Reports (as follows).

Figure 2: Participation rates



<sup>1</sup> So whole of government ... not just Health and Disability.

<sup>2</sup> See <https://www.ndis.gov.au/understanding/families-and-carers/early-childhood-approach-children-younger-9/getting-help-through-early-childhood-approach>

At the peak around age 6 years, more than 1 on 10 children and 1 in 7 boys get support from the NDIS. The government built the NDIS to support children with concerns about their development and Australians responded by seeking NDIS supports.

By age 10 years, there is a significant drop in participation corresponding partly to the disappearance of children’s developmental delay labels.

The DD definition says:

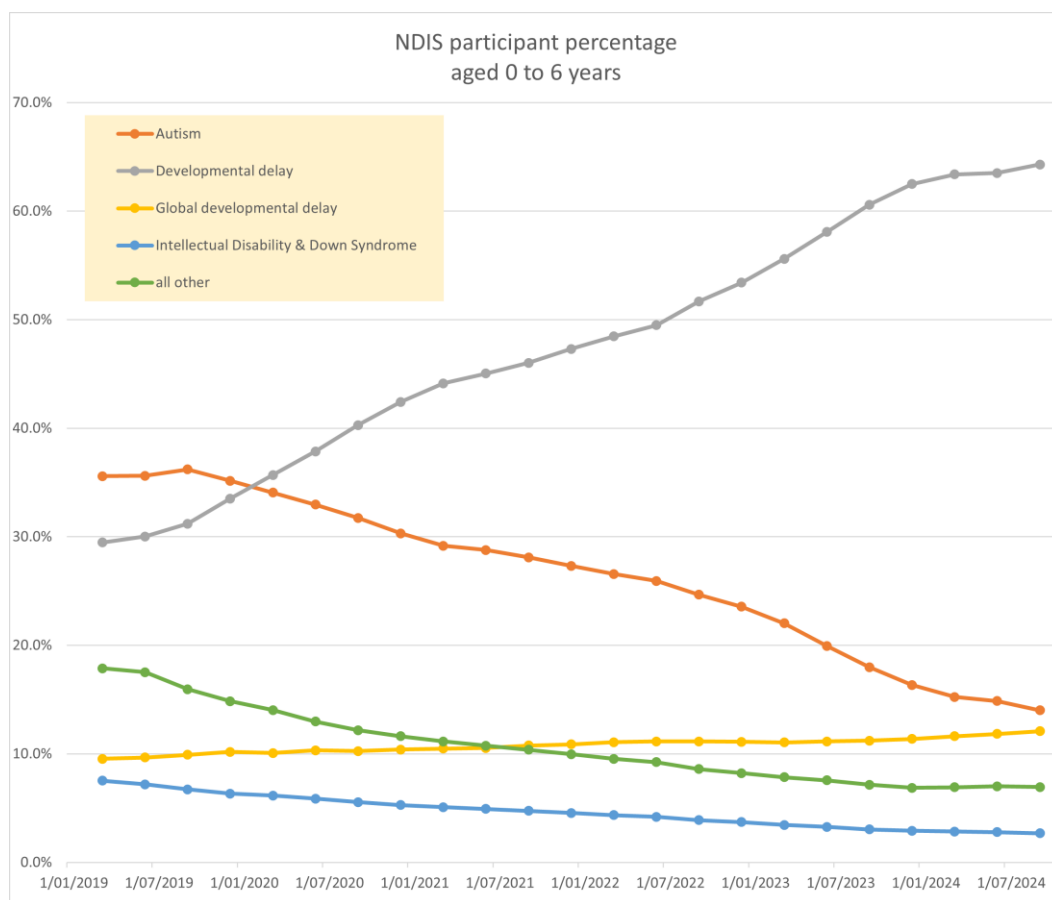
**developmental delay** means a delay in the development of a child under 6 years of age that: ...

The figure above does not show that under age 6 years, most (42%) NDIS participants are considered to have Developmental Delay (DD) – DD is a condition defined in Section 9 Definitions of [the NDIS Act 2013](#). Politicians and law makers created the Developmental Delay label in their NDIS legislation.

Global Developmental Delay (GDD), another temporary label for young children, accounts for a further 11.5%. GDD is not mentioned in discussions about Thriving Kids.

Primary disability types DD and GDD account for 53.4% of NDIS participants in the 0-8-year age group. Autism accounts for 35.9% of NDIS participants in the 0-8-year age group. The peak in the chart above is largely due to this politically created label.

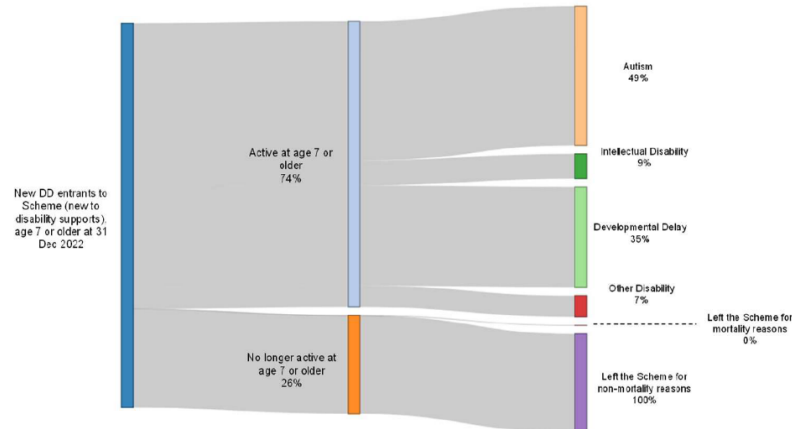
The following chart shows how the major disability types for the 0–6-year age group have changed since full NDIS roll-out until the NDIS stopped publishing data for that age range. Data like these suggest that it is likely that the NDIS affects diagnostic practice significantly. *Autism Aspergers Advocacy Australia (A4)* expects that this is an *unintended consequence* of NDIS legislation.



Some time ago, the NDIS provided information suggesting that most children who enter the NDIS with a DD (or GDD) label are subsequently recorded as having “autism” as their primary disability type.

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## Pathways in the Scheme for participants with developmental delay



- 74% of new entrants to the Scheme with DD continued as NDIS participants after age 6. Of these:
  - 49% have a primary disability of Autism;
  - 35% remained under Developmental Delay (i.e. may not have been reassessed);
  - 9% have a primary disability of Intellectual Disability; and
  - 7% have another primary disability type.



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Note: most likely, many of the 35% with DD after age 6 years were also later diagnosed with ASD.

As a child labelled with DD or GDD and getting NDIS support approaches 6 years of age, they face the issue of “what next?”. Clearly, some of them are autistic (and should have been diagnosed earlier so they could access better targeted (disability specific) and more cost-effective early intervention. Diagnostic practice in early childhood needs improvement.

After age 6 years, the NDIS does very much require a diagnosis to prove that a NDIS participant has severe and permanent disability. Suddenly, diagnosis appear more important.

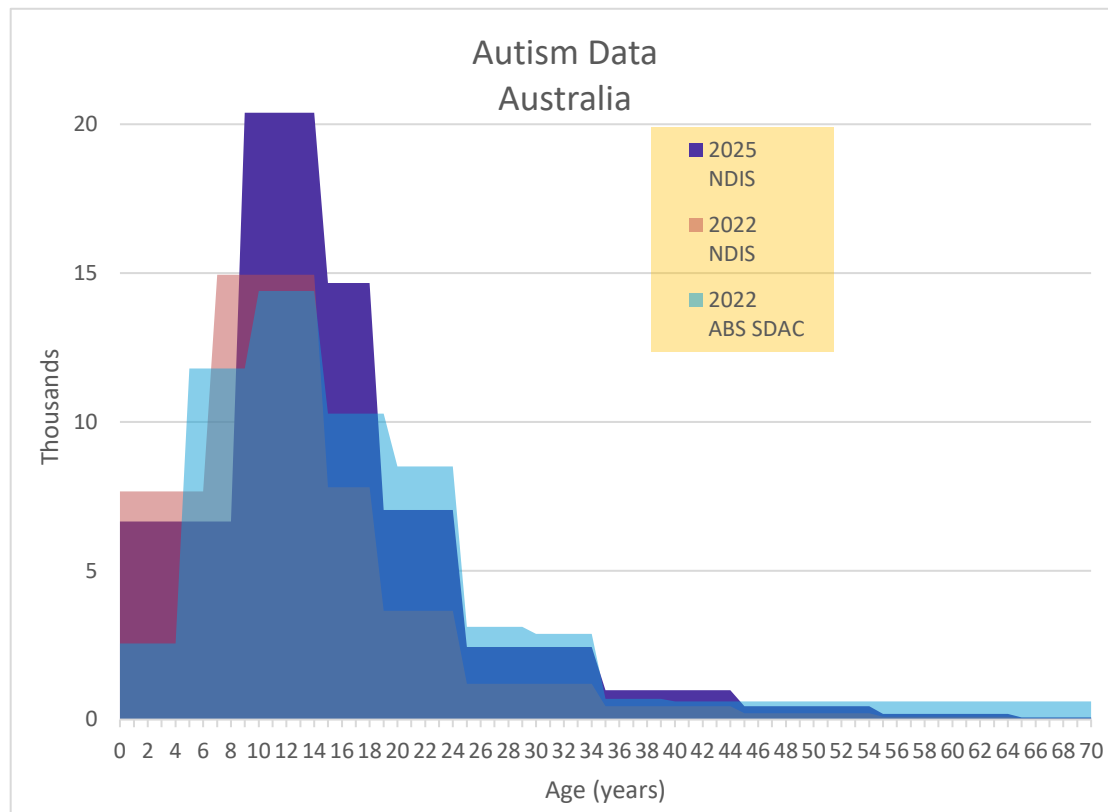
Pressure will mount by or after age 6 years for children with a DD label, less severe impairment, and faced with the prospect of losing NDIS supports, to get a diagnosis so that their disability support can continue.

Once a child has received therapy or early intervention, it is likely clinicians (who risk losing a client) and/or parents of these children (now used to accessing therapy) will expect the child will be diagnosed formally so supports for the child can continue. Or school may require a formal diagnosis to provide or access disability supports for the child in school.

Recent NDIS data show that after age 8 years and until age 25 years, 60-80% of NDIS participants have autism as their primary (severe and permanent) disability type. Much of the autism issue is outside the Thriving Kids age range so the Thriving Kids program is unlikely to properly address your government’s autism challenge.

The following figure shows NDIS numbers compared to ABS estimates of the numbers of autistic Australians at various ages. By 2022, NDIS numbers exceeded

ABS estimates for autistic children. And NDIS growth from 2022 to 2025 exceeded all reasonable projections based on ABS autism data.



This increased awareness and pressure for supports for autistic Australians may (is likely to) be an unintended consequence of government’s disability policy. Unfortunately, government gets particularly poor advice on such issues from bureaucrats, the media, and preferred (selective and unrepresentative) parts of the autism sector ... and avoids or ignores advice from places like full spectrum representative from the autism sector. NDIS Ministers have declined meeting requests from *Autism Aspergers Advocacy Australia (A4)* for more than a decade, and the NDIS excludes A4 from its DRCO forums, its Autism Advisory Group, discussion/development of its reform agenda, and other forms of direct sector engagement. The disability part of Health (like DSS before it) do not invite A4 directly to their meetings with DROs. The National Autism Strategy ignored completely A4’s input. Australia’s Disability Strategy ignores autism.

Basically, government avoids representative voices for people with autism spectrum disorder, especially the national representative voice for those with severe and profound impairment from their autistic disorder.

NDIS Ministers keep saying that the NDIS will remain for autistic people with severe or profound impairment. What they don’t seem to appreciate is that increasingly, people with severe or profound autistic impairment must contest their support needs in the excessively adversarial Administrative Review Tribunal (ART) against strong opposition from large experienced and well-resourced legal teams. Typically, the NDIS spend more on these cases than it even hopes to save.

NDIS planners do not have the authority to approve high needs or intensive supports for people with severe or profound autistic impairment. Families either must accept reduced supports or get the ART to review their NDIS plan. Unfortunately, ART Members lack relevant qualifications for assessing the evidence before them, are often biased (toward the NDIS), and ignore (or even exclude) Applicants’ evidence.

Government has stacked the system against people who need significant supports for their severe or profound autism.

There was a parliamentary inquiry into autism but few if any of its recommendations have been realised. The government's National Autism Strategy is completely inadequate – the NDIS, Education and Employment parts of government didn't even provide written submissions or advice. Australia's Disability Strategy ignores autism – the NDIS shutdown Labor's Autism Specific Early Learning and Childcare Centres (ASELCCs) that were central to the autism element of the previous National Disability Strategy. The NDIS resists/opposes supporting evidence-based early intervention for autistic children and seeks to deny many families choice and control over their autistic child's early intervention.

The NDIS has failed completely to develop or even regulate clinical/therapy supports for autistic children. For example, the NDIS and its Quality and Safeguards Commission completely ignores professional registration for behaviour supports that are a crucial element of autism supports for many autistic Australians – instead, the NDIS through its website *promotes* many of their “registered” service providers who have no relevant qualification nor experience, and who deliver sub-standard services ... thereby risking the safety of NDIS participants.

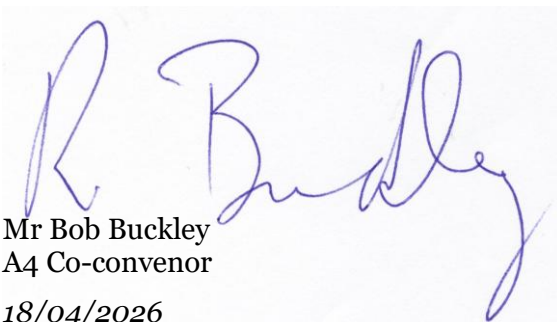
The NDIS plans to kick most autistic kids out of the NDIS or deny them access even though it does not have validated data about the supports they require nor a means to assess their needs accurately. It indicated that it is using its internal severity rating that has no verification or validation associated for autistic NDIS participants. This strategy will especially disadvantage some of the most vulnerable.

Yes – autism is a major problem for government. And it impacts more than disability administration (now located in Health); it impacts education, employment, treasury, finance, justice, and more.

Yes – the NDIS is likely increasing autism diagnoses in Australia (as discussed above) but that is only part of the story since increases in autism diagnoses is a worldwide phenomenon as the OECD recently indicated. Kicking kids out of the NDIS into disparate state schemes that do not recognise autism as a distinct disability type, and cutting their funding from \$5 billion p.a. to \$5 billion over 5 years is not a good solution to the national autism challenge. Nor is a completely inadequate National Autism Strategy, a strategy that Thriving Kids showed had already failed after less than 12 months.

Government needs a more substantial and coordinated national and whole-of-government response to its autism challenge. It needs to work with people who represent and understand autism spectrum disorder, not just those whose “autism” is not a “disorder”. It needs to get serious about autistic *disorder*. Government needs to tackle its autism challenge through better informed policy and programs, and to communicate through clear and accurate messaging. *Autism Aspergers Advocacy Australia* (A4) is happy to help your government do that.

Yours sincerely



Mr Bob Buckley  
A4 Co-convenor

18/04/2026