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Autism Aspergers Advocacy Australia

Dear Mr Mansfield

I write in relation to your presentation to the recent DRO Forum at Parliament House (4/9/2025). While we have no written record of your presentation, there are two major matters arising from it that I would like to discuss further.

1. The impact of Thriving Kids on the NDIS and the autism sector in Australia.
2. Diagnosis versus functional assessment as it relates to autism spectrum disorder and supports for autistic NDIS participants.

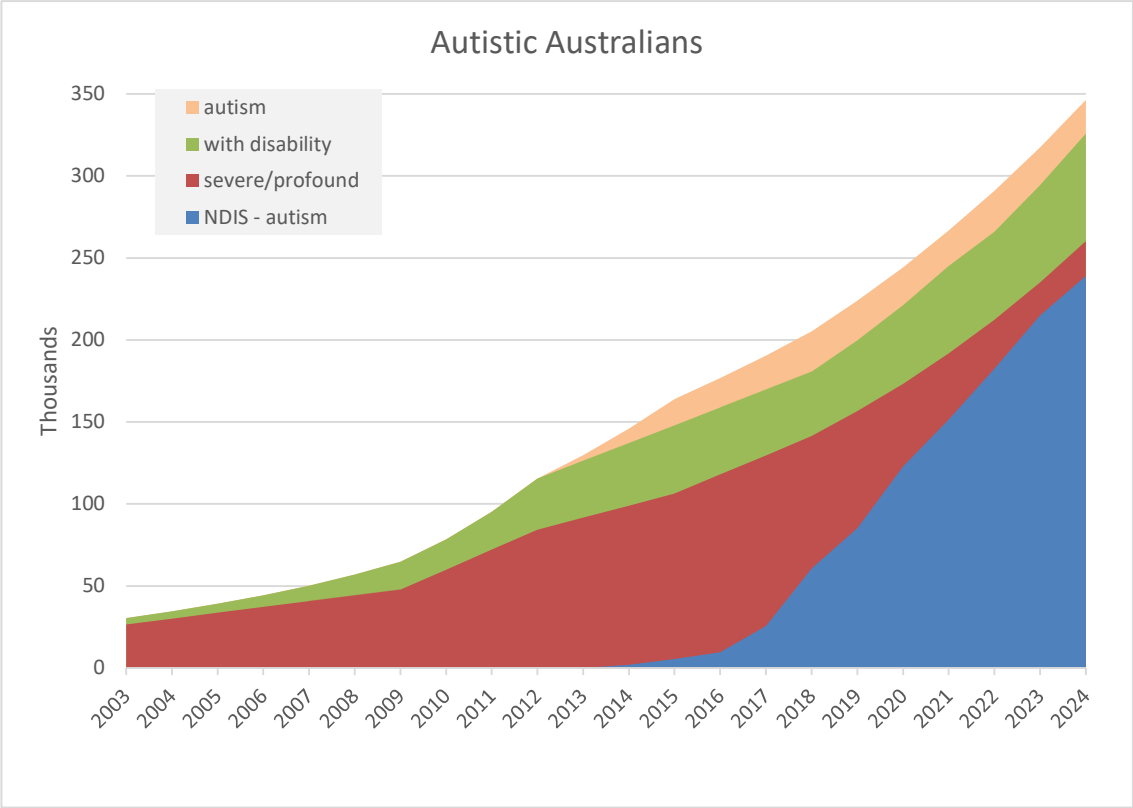
At the forum, I asked how many mild and/or moderately autistic children (who are targets for the Thriving Kids initiative) there are currently in the NDIS, or what proportion of autistic children does government expect to transfer from the NDIS to the Thriving Kids initiative? My understanding is that you said:

- the number autistic children with mild and/or moderate autism currently in the NDIS is unknown … so has not informed the creation of the Thriving Kids initiative; and
- work to understand those numbers is yet to be started.

Data from the ABS SDAC 2022 on autism (see table below) indicates that 73% of autistic Australians have severe or profound core activity limitations (based on a generic disability rating, not autism-specific). The number of autistic Australians with severe or profound limitations was 212,400.

Survey of Disability, Ageing and Carers, 2022	
	Autistic persons
	Proportion (%)
Disability Status	
Profoundly limited in core activities	50.2
Severely limited in core activities	22.1
Total with profound or severe core activity limitation	*#73.0*
Moderately limited in core activities	3.5
Mildly limited in core activities	5.6
Not limited in core activities but restricted in schooling or employment	5.2
Not limited in core activities or restricted in schooling or employment	2.7
No disability	8.9

At the time, the number of NDIS participants in June 2022 was 182,494. So, there were fewer (86%) autistic NDIS participants than the ABS's estimate of Australians with severe or profound disability. NDIS data suggested only about 10% of NDIS participants are recorded as autistic via their secondary diagnosis (this seems incredibly low). These data suggest that even if none of the autistic NDIS participants with autism as their primary disability have mild or moderate disability, there were still likely to be nearly 30,000 severely or profoundly autistic Australians not getting support from the NDIS.



These data are also consistent with NDIS reporting that autistic applicants are accepted at very high rates – there are very few applications for NDIS support from people whose autism is not classified as severe and permanent.

The ABS SDAC data indicates 9% growth p.a. in autism numbers (population grows at about 1.7% p.a.) … and the ABS has reported the proportion of those with severe or profound autism has been relatively stable for a long time (see https://a4.org.au/sites/default/files/Autism%20Spectrum%20Disorder%20in%20Australia_0.pdf).

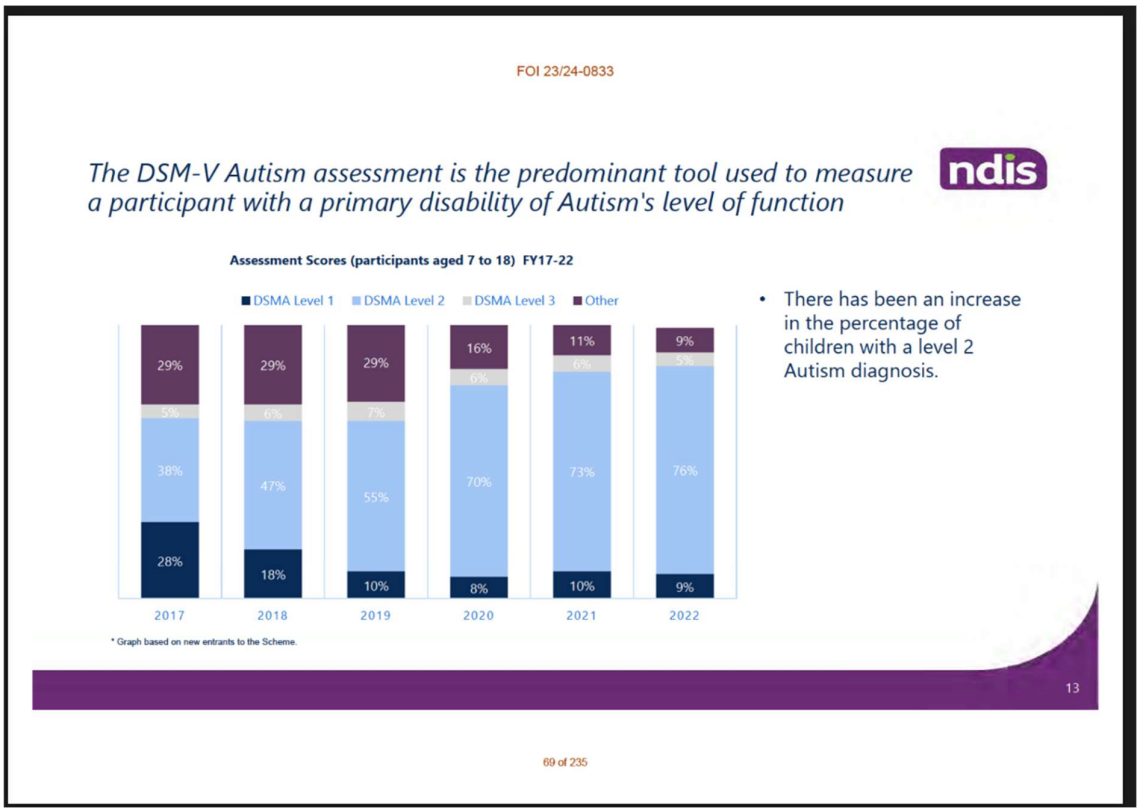
It seems your government respects ABS reports unless they relate to autism.

The number of NDIS participants with autism as their primary disability are still growing substantially: 18% p.a. to June 2023, 11% p.a. to June 2024, and 23% p.a. to June 2025. NDIS numbers may now be caught up with or passed ABS SDAC estimates (unfortunately, we were told that government has deferred the next ABS SDAC data collection, so we won't be able to compare for some time).

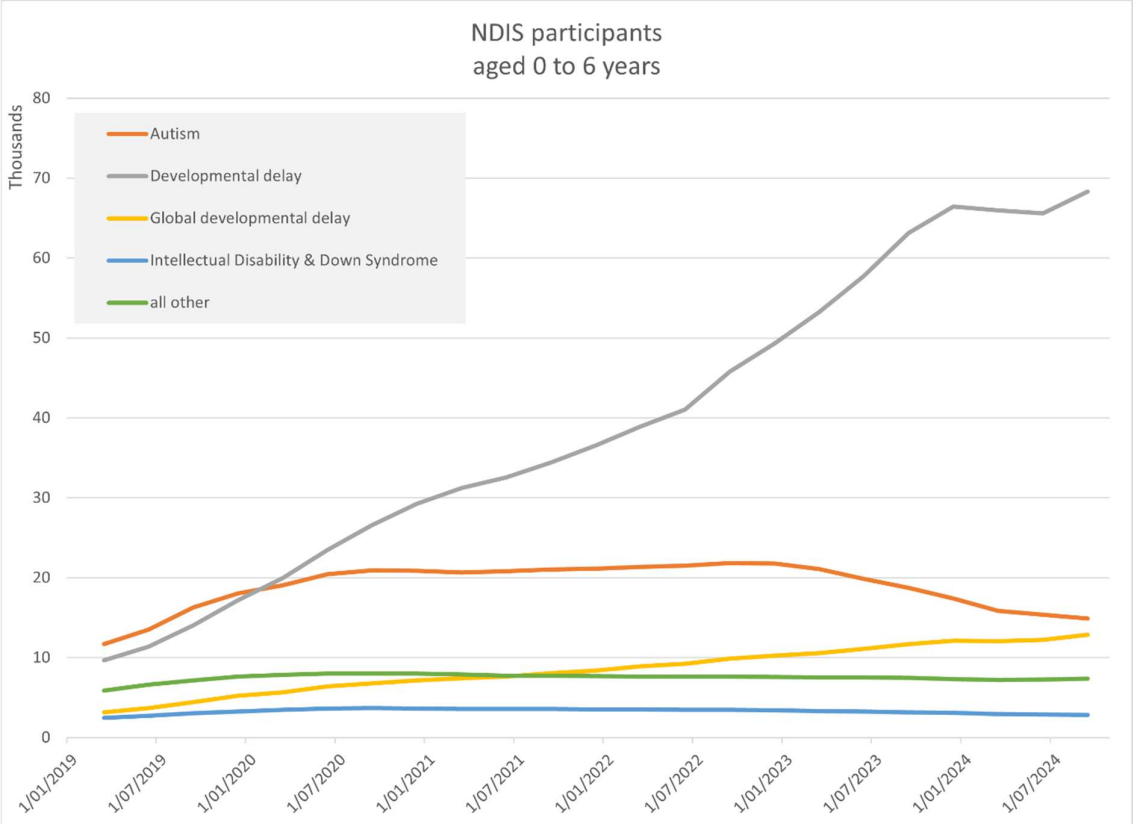
The NDIS rarely reports on its autism numbers differentiated by severity ratings. I am not aware that the NDIS has ever reported these data publicly. We

understand that few NDIS participants with autism as their primary disability have a Level 1 severity rating. These data indicate that there are very few NDIS participants with autism as their primary disability so it is unlikely that Thriving Kids will make much difference in relation to autism.

The only reporting I am aware of came from information presented to the NDIS Autism Advisory Group (accessed via FOI 23/24-0833 – see below). But this was for the age range 7 to 18 and only up to 2022. See also https://a4.org.au/node/2713.



It was not for younger children nor for more recent times when autism rates in 0- to 6-year-olds dropped dramatically (see below and https://a4.org.au/node/2587).



In the meantime, families are being scared witless that their children will not be able to access NDIS support into the future. The government's message is confused, inconsistent, and threatening for autistic Australians. Clearly, government intends to move substantial numbers of autistic children off the NDIS … but since there are very few NDIS Participants whose autism in "mild to moderate", then many of those to be moved off the NDIS with be more severely autistic. The fears are reasonable.

The other aspect of your presentation to the DRO Forum was what you said about NDIS reform seeking to be based not on diagnosis, but more on functional assessment instead.

Your commentary on this suggested that an autism/ASD diagnosis was simply not helpful.

You and the NDIS seem to not understand that each and every ASD diagnosis that is based on DSM criteria is a functional assessment in every aspect of the diagnosis.

It is generally recognised that the 3-level severity assessment scale used in the DSM-5 (and DSM-5-TR) are not standardised. While the DSMs state clearly that the severity rating should not be used for resource allocation, it is important to recognise that these diagnoses represent a form of functional assessment.

From the start of the NDIS, A4 has been telling the NDIA and government officials, that it can and should improve the quality of ASD diagnosis and it should also collect and use all the data that comes with a proper DSM-5 or DSM-5-TR ASD diagnostic report. Note that the DSM-5 stated that two severity ratings were required; while the DSM-5-TR only requires one severity rating, it

also advises that "Severity of social communication difficulties and restricted, repetitive behaviors should be separately rated".

The severity specifiers required for a DSM-5 ASD diagnosis could be developed and improved to provide more comprehensive information.

If the NDIA or the government expect more standardised functional assessment, then they could consider steps to improve the quality of the functional assessment … perhaps through more standardised, quality assured, and monitored methods.

This is perhaps most apparent when ASD is diagnosed as a comorbid condition with specific genetic disorders. For example, many people with Down Syndrome or Fragile X also have autism. The NDIS could check its data to see whether reporting of these comorbidities in the Australian population match research findings. If they do not, is it because the ASD is not diagnosed in cases where the genetic condition is identified first or is it because the NDIS does not record the data for the secondary ASD. I suspect there are problems in both regards.

I note that the NDIS uses ICD-10 classification … which still includes Rhett's Disorder as autism, a practice that mostly ceased back when the genetics of Rhett's Disorder was identified. There are also surprisingly low levels of Asperger's syndrome reported in NDIS data relative to autism generally.

You did not mention the National Autism Strategy (NAS) at the DRO Forum. We take this as a sign that government largely regards the strategy as over and done with. This is no surprise to the 50% of Australians who are profoundly autistic … and who were largely disregarded in the development of the NAS, and whose representative are not heard in disability discussions.

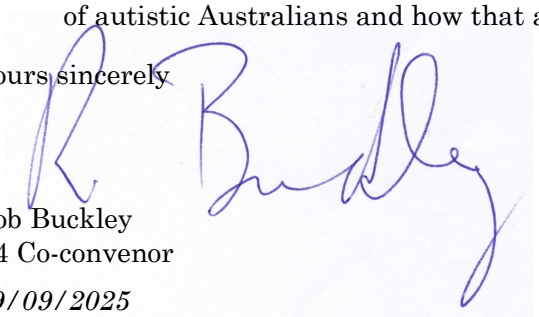
We are concerned by many of the changes government is making to the NDIS. For example, impairment notices are imminent. These are a major issue for autistic Australians since the NDIS legislation omits the triad of impairments that define autism, social, communication, and behavioural impairments, are all omitted from the legislation. From what we see, autism is shoe-horned into a *chosen* list of impairment types. Disability legislation that ignores autistic impairment, yet puts impairment at the centre of access to supports, is unfair and unjust.

There are many other fundamental issues relating to autistic NDIS participants that require attention. It would be good to choose a few that we can agree should be given priority and to make some actual progress.

So, in conclusion, I would like to meet you to discuss the two key issues here:

1. Which autistic Australians the government intends to remove from the NDIS and where they will go, and
2. How government intends to progress its desire for functional assessments of autistic Australians and how that affects access to disability supports.

Yours sincerely



Bob Buckley
A4 Co-convenor

19/09/2025