

Dear Minister Rishworth

Subject: **DRO request for meeting about improving autism policies**

I write to request a meeting ... and belatedly in relation to the Australian Government's [Early Childhood Targeted Action Plan](#) (EC TAP) that indicates it is part of *Australia's Disability Strategy 2021-31* (ADS). Government policies like the EC TAP and ADS must do far more to improve outcomes for autistic children ... who later become autistic adults.

A4 and other autism representatives attended various *stakeholder engagements* including DSS's Early Years Consultation in 2023. A4 finds it hard to recognise any consequence of the autism sector's contributions to those events.

The Australian Bureau of Statistics has [reported](#) repeatedly that:

- “Many children on the autism spectrum struggle socially, needing additional support throughout their education”;
- “Almost half the young people with autism aged 5 to 20 years (45.9%) indicated they needed more support or assistance at school than they were receiving”; and
- “People with autism are less likely than others to complete an educational qualification beyond school and have needs for support that differ from people with other disabilities”.

Many deficiencies in government policies contribute to these poor outcomes. The NDIS, and policies such as the EC TAP, fail to invest adequately in many autistic children to prepare them to benefit from school education. The current (Dec 2023) average NDIS capacity building annual budget for an autistic NDIS participant aged 0 to 6 years is \$26K, which maybe pays for one hour weekly of speech and occupational therapies and an annual report from each, compared to \$30K for a participant with intellectual disability<sup>1</sup>.

Notably, the NDIS is reducing support for individual autistic NDIS participants supports for most other disability types have rising funding or funding that is at least keeping pace with inflation. The [lifetime cost of an autistic NDIS participant](#) (to age 70 years) exceeds \$6.6m – down from \$7.6m in 2020 which is a substantial cut in just 3 years. A4 estimates that 60-70% of Autistic Australians are NDIS participants ... which is comparable with the ABS 2018 estimate of 68.9% of autistic Australians having severe or profound<sup>2</sup> disability.

All Autistic youth and adults had autism in their early childhood though ASD diagnosis rates have recently started to decline with many younger children being

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<sup>1</sup> The DSM-IV and DSM-5 regard autism spectrum disorder as a primary “disorder” presumably needing focussed support/attention. It is unclear why the NDIS average funding for intellectual disability exceeds funding for autistic participants.

<sup>2</sup> ABS reporting uses a four-category severity scale of mild, moderate, severe, and profound.

diagnosed first with developmental delay or global developmental delay instead of ASD – see <https://a4.org.au/node/2587>

Notably,

1. The NDIS is increasingly concerned about the number of children entering the NDIS. The [Q2 2023-24 NDIS Quarterly Report](#) shows (Figure 2, p14) that 9.1% of children aged 5 & 6 years of age are now in the Scheme.
2. Autistic children are a substantial proportion of young NDIS participants. The following table shows the proportion of participants in the age ranges as of Dec 2023.

	0 to 6	7 to 14	15 to 18
Autism	16.4%	69.5%	68.9%
Developmental delay	62.5%	7.4%	
Global developmental delay	11.4%	2.7%	
Hearing Impairment	3.7%	3.3%	3.8%
Intellectual Disability	2.9%	10.2%	18.1%

3. While children diagnosed with Developmental Delay (DD) and Global Developmental Delay (GDD) dominate the 0-6-year-old NDIS participant numbers (73.9%), the Scheme Actuary reported that most of those children are subsequently diagnosed with autism spectrum disorder (ASD). Increasingly autistic children are directed/diverted to early investment/intervention for DD or GDD and miss out on accessing the ASD-specific early capacity building and school preparation that they need for best outcomes (and to reduce/minimise their long-term NDIS support needs).

The EC TAP and the ADS neglect autistic children: both fail to recognise and address key challenges for autistic children. This repeats the autism sector's experience with the previous *National Disability Strategy 2010-20* (NDS) with its inadequate strategy for the emerging needs of increasing numbers of autistic Australians.

Despite the significance of autistic children in the early childhood cohort, the EC TAP makes just two mentions of autism (one each on pages 7 and 14).

Pages 6 & 7 say:

#### **1.4 Develop online resources for educators**

Develop online resources to promote initial dialogue between schools and families on adjustments for children in their first year of school with characteristics consistent with autism.

Experience of initial “dialogue between schools and families” of autistic children about their first year of school are typically brief:

- Why don't you take your child to another school?
- We know all about autistic students – we had one before ... a few years ago.
- You can't expect much as our school has no capacity to meet your child's individual needs.
- Schools are very busy - the time to develop your child's Individual Education Plan for this school year is late in third or sometime in fourth term.

Of course, there are a few good schools and teachers, but they are hard to find.

Also, note that average age of autism diagnosis is after starting school. Earlier diagnosis is likely to improve life outcomes.

The EC TAP lists the following “Indicators(s)” for Actions 1.4

- Discovery phase and stakeholder consultation.

- Resources developed with stakeholders.
- Resources published online.
- Resources evaluated.
- Professional learning for educators on using the resources.

In relation to autistic students, A4 doubts these “indicators” were realised in the prescribed timeframe. Execution/delivery of the EC TAP has already fallen short – at least in relation to Objective 1.4. Will the government act to recover from this failure?

The EC TAP’s second mention of “autism” (on page 14) is specific to Tasmania even though substantial need exists for “Improved timeliness to diagnostic services for [autistic] children” across the whole nation. A4 would be interested to see what improvement is achieved by 2025. We are also interested to know how this outcome of Tasmania action 1.2 is being measured.

A major part of the problem for most autistic young people is that state education systems do not recognise their disability. See

- <https://a4.org.au/node/2597> for the ACT, and
- the [National Disability Data Asset \(NDDA\) pilot](#) where data from the South Australian education system recognised about 1 in 3 autistic students relative to the NDIS – around 2 in 3 students who are autistic NDIS participants did not get disability support in SA schools<sup>3</sup>.

The EC TAP might be more credible were it to recognise and respect the existing resources and experience (such as <https://www.positivepartnerships.com.au/>) rather than trying to reinvent policy without an adequate evidence base.

When the NDIS started, it showed state/territory government had no idea how many autistic citizens they had in their region; they were unaware of and not supporting most autistic students. Their data was the foundation for the Productivity Commission’s estimate that 9% of NDIS participants would be autistic, when the current rate is just short of 36% - a factor of four error. There is no credible reason for expecting that state/territory governments can develop and deliver so-called *Foundational Supports* (as the NDIS Review proposes) for autistic students in far greater numbers than they have ever even acknowledged exist. Note that these supports are already state/territory responsibility; there are no short-term cost savings to the NDIS even if those “foundational supports” do eventuate.

The NDIS terminated the HCWA Autism Advisor program and dissipated the intellectual capital that had accumulated. Now the Government wants to create “navigators” who will be trying to reinvent help autistic Australians.

The ILC and its implementation have done little to address essential supports for the 30-40% of autistic Australians who are not NDIS participants and still have significant support needs. Access to non-NDIS services and supports remains difficult especially in households where autism has an estimated<sup>4</sup> \$35K p.a. impact on income – see <https://a4.org.au/node/881> . The gap for private fees is high with Medicare rebates nowhere near the actual cost (up to 8 sessions of 1 hour and only covers direct contact not report writing etc \$93.35 - substantial gap given e.g., Aus. Psych Society recommends we charge \$300/hr see [How much does seeing a psychologist cost? | APS \(psychology.org.au\)](#))

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<sup>3</sup> Table 3 in the NDDA pilot reports 2,107 students identified as on the autism spectrum and Table 4 reports 1,704 autistic students. NDIS data for show 5,688 autistic NDIS participants aged 7 to 14 years inclusive in Mar 2019 (and 5,995 in June).

<sup>4</sup> 10 years ago.

After over 10 years, the NDIS has yet to deliver an evidence-informed policy/approach for early investment/intervention for autistic children. It failed to complete that part of its ECEI Reset<sup>5</sup>. And the NDIS Review apparently just wants this national issue transferred to so-called Foundational Supports ... outside the NDIS and federal responsibility.

A major source of policy deficits for Autistic Australians is that DSS officials do not engage adequately with autistic stakeholders in developing strategies like the EC TAP and the ADS. DSS officials lack a sufficient understanding of the impact of autism in Australia and are unwilling to engage sufficiently with the autism sector. Simply, Australia needs much better policies and programs for its autistic citizens.

When will DSS recognise and address the chronic lack of individual advocacy for autistic Australians? What will it do to address this issue?

The *National Autism Strategy* (NAS), that's development has already started, might be able to assist significantly with many of the issues above if (and only if) the strategy is well designed and implemented. Hopefully, the NAS will also address chronic disadvantage and inequity in Australia's health, education, employment, and legal systems ... though health is the only one of these with discernible indications that the issues and concerns are even being recognised.

The whole autism sector is keen to know when the draft strategy will be available for comment.

A4 and many others in the autism sector regard as unacceptable that the DSS officials who took charge of the NAS excluded A4, the recognised autism disability representative organisation (DRO), from its NAS Oversight Committee and the three working groups run by DSS. A4 would like to know why does the government regard the exclusion of the recognised autism DRO from key policy considerations to be acceptable; and will it change this practice?

Please can A4 meet with you ASAP to discuss the above issues and answer any questions you have about any of this as best we can?

## Summary of Questions

Following is a concise summary of the questions contained above.

1. What will government do now to achieve the outcomes intended through Objective 1.4 of the EC TAP?
2. how are the outcomes of Tasmania action 1.2 is being measured?
3. why a national effort to improve timeliness of ASD diagnoses was not included in the EC TAP?
4. why does the government regard the exclusion of the recognised autism DRO from key policy considerations:
  - a. to be acceptable? or
  - b. as practice that needs to change? If so, then how will this happen?
5. When will the draft *National Autism Strategy* be available for comment?

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<sup>5</sup> In preparation for an up-coming meeting, the NDIA recently advised A4 and the Australian Autism Alliance that the NDIA's Childhood Taskforce "does not have any specific issues [related to autistic NDIS participants] at present". So, Item 18 of [the ECEI Reset](#) is no longer "an issue" for the NDIA's Childhood Taskforce. Nor are any of the other concerns that A4, the Australian Autism Alliance, and other issues for autistic children that we have raised with the NDIA before. Not even the negative media commentary on autistic children in the NDIS is an issue.

6. When will DSS recognise and address the chronic lack of individual advocacy for autistic Australians? What will it do to address this issue?
7. Please can A4 have a meeting with Minister Rishworth to discuss improving the Government's autism policies and consequent outcomes for autistic Australians?

A4 provides this clear list of questions so it is easy for you to check that your response answered specifically all the questions that A4 asked. A4 has a [policy on unanswered questions](#): basically, failure to answer a question fully, or misinterpreting a question, acknowledges that the actual answer is so embarrassing that you cannot bring yourself to put it in writing. Thus, failing to answer a question from A4 is taken to mean you intend the worst possible answer.

A4 looks forward to your timely response.

Yours sincerely

4/03/2024 