

Autistic Australians count

Autism diagnosis rates and prevalence estimates

Torture numbers, and they'll confess to anything.
Gregg Easterbrook



Autism Aspergers Advocacy Australia

20 March 2024



Preface

Autism Asperger Advocacy Australia, known as A4, provides this report hoping to inform and improve the government's development of Australia's *National Autism Strategy* through better awareness of available information relevant to the strategy.

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).

Proud member of



AUSTRALIAN
Autism Alliance



[A4 Autism Awareness event](#), Parliament House, Canberra, September 2004

Contents

Preface	i
Introduction	1
Prevalence vs Diagnosis rate.....	2
Observed Autism Diagnosis Rates.....	2
Autism rates in the NDIS.....	5
Recommendation	7
Emerging pathway	8
Overseas	9
Conclusion and recommendation	9



Introduction

Various sources quote different estimates of autism prevalence in Australia. A4 is keen to have the autism sector agree and maintain recent estimates of how many autistic Australians need services and supports in their lives. The autism sector and governments must agree on how many Australians are autistic so we can all develop a credible and effective National Autism Strategy.

Views vary as to how many people are diagnosed autistic in Australia.

- [The AIHW website](#) shows “an overall prevalence rate of 0.7%, or about 1 in 150 people” in 2017. See also <https://www.healthdirect.gov.au/autism>.
- On [its About Autism page](#), Aspect (Autism Spectrum Australia) says 1 in 70 Australians are autistic. Similarly, the basis for this figure deserves explanation. [Autism Qld](#) quotes the same figure.
- “Table 3 in [the NDDA pilot](#) reported 2,107 students identified as on the autism spectrum and Table 4 reports 1,704 autistic students” or about 1.2% of school-age children in SA¹ – SA schools are aware of fewer than 1 in 3 autistic NDIS participants: from [letter to Minister Rishworth](#) (4/3/2024) – see <https://a4.org.au/sites/default/files/EC-TAP.pdf>
- Prof A. Whitehouse, Autism CRC Research Strategy Director, recently [told an ABC audience](#)² that “now we diagnose autism in about 1 in every 50” children. The Autism CRC needs to clarify whether this is its official figure, and if it is, how it was arrived at. See also <https://insightplus.mja.com.au/2022/9/autism-widely-known-rarely-understood/>
- The Olga Tennison Autism Research Centre (OTARC) at La Trobe University [reports studies](#) suggesting prevalence from 0.74% to 3.3%. See also <https://www.latrobe.edu.au/news/articles/2023/opinion/australias-rates-of-autism-should-be-celebrated>.
- ABS, NDIS data and Carer Allowance (child) data from DSS (discussed below) show ASD peak diagnosis rates, indicative of prevalence, above 3% of Australian children.

The following information aims to show that recent data indicates higher autism prevalence than in these reports.

¹ It’s alarming that the NDDA project does not appear to have cross-checked these data with other sources.

² At 3min 15sec in.

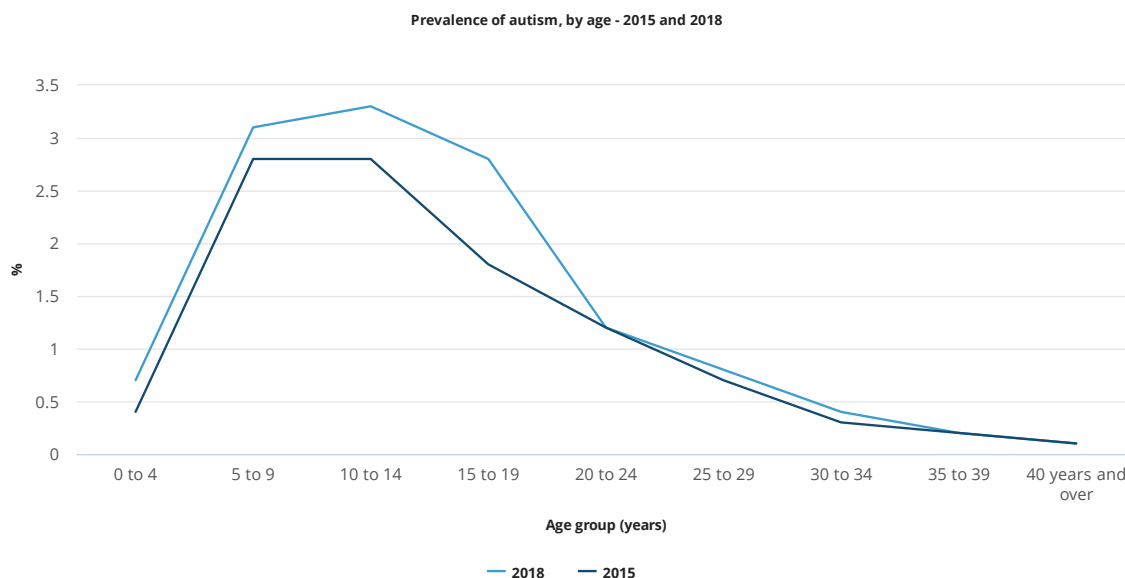
Prevalence vs Diagnosis Rates

For autism, prevalence is usually regarded as the same as peak diagnosis rate based on observations and expectations that most autistic people get diagnosed, that their diagnosis is relatively reliable, and their autistic neurology is lifelong.

A4 is concerned that key government sources, such as the AIHW, Health Direct and state/territory education departments, as well as the Autism CRC, report alarmingly low autism diagnosis rates compared to Australian Bureau of Statistics (ABS) reports and the numbers of autistic participants in the NDIS (see below).

Observed Autism Diagnosis Rates

The ABS published a series of reports that estimate autism diagnosis rates from data collected through its Survey of Disability, Ageing and Carers (SDAC). [The latest report](#) was from data collected in 2018.



Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2018

These data suggest:

- Diagnosis rates, and possibly autism prevalence, are increasing overall with a peak in the mid-teen years.
- Peak diagnosis rate nationally was over 3.25% in 2018 – this might be interpreted as an estimate of ASD prevalence in Australian children.
- Diagnosis rates vary enormously by age (the diagnosis rate for children 10-14 years of age is 10 times that of Australians 40+ years of age).
- 68.9% of autistic Australians have severe or profound³ disability.
- Autistic Australians experience especially poor outcomes in education and employment – significantly worse outcomes than Australians with disability more generally.

³ ABS has a scale of mild, moderate, severe, profound.

The ABS reported 25.1% increase in the three years to 2018: about 7.8% per year. The same rate of growth for the 5 years from 2018 would increase the number of Autistic Australians by around 45%. This level of growth is compatible with the NDIS data from 2023 below.

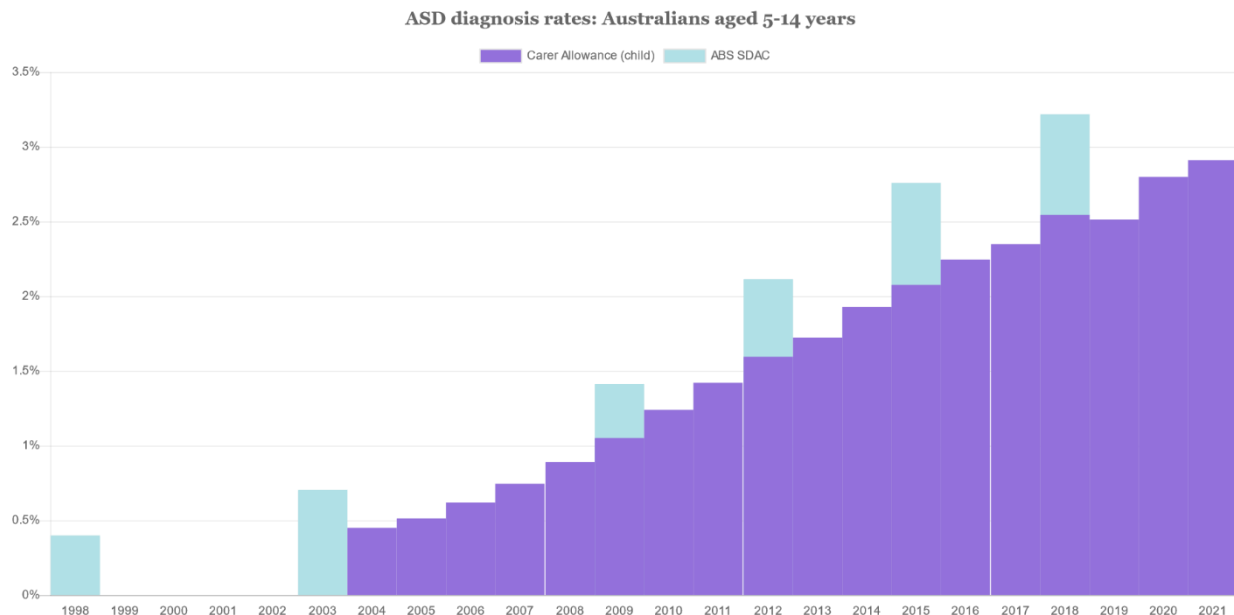
The ABS website says to expect a new ABS SDAC report mid-2024. It is likely that their estimated diagnosis rate will be substantially higher than is shown in the chart above.

A4 argues that these data indicate that prevalence should not be estimated based simply dividing the number of autistic Australians of all ages by the population: prevalence is not known to be uniform across the population. Autism diagnosis rates vary:

- over time, and
- with age, gender, and state/territory.

It is not clear how well peak ASD diagnosis rates reflect true prevalence. Describing a single prevalence rate does not reflect observed diagnosis rates across the age ranges.

A4 provided a report on [Autism Spectrum Disorder in Australia](#) to the NAS. This report describes various historical records from government sources, including the ABS SDAC data above. It includes detailed data from DSS's Carer Allowance (child) records.

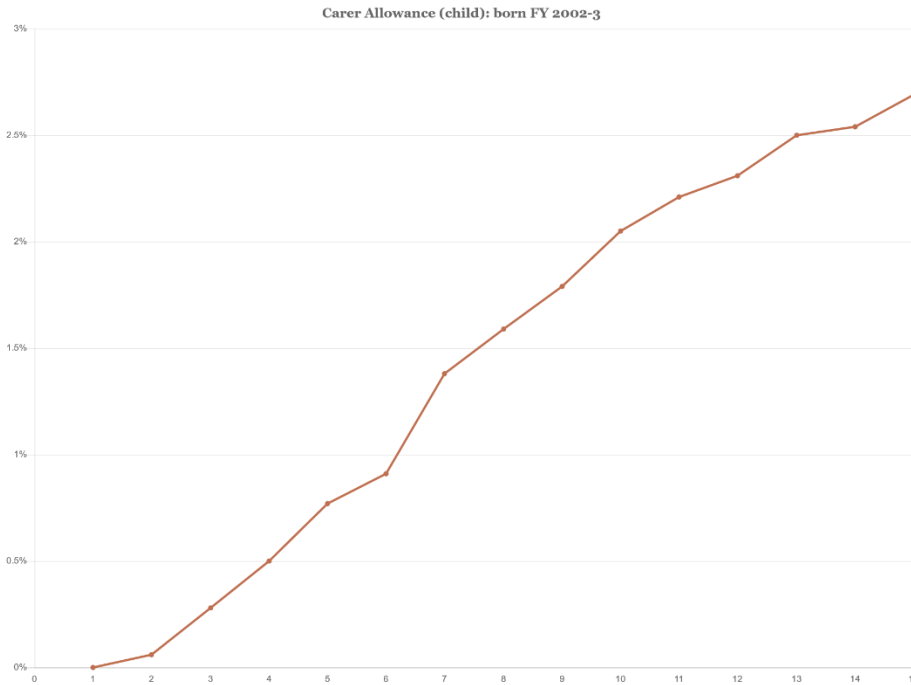


Through the period of *Helping Children with Autism* (HCWA), data from Carer Allowance (child) was considered relatively reliable. Since the start of the NDIS, which shut down HCWA, Carer Allowance (child) data has become less reliable as a source of overall autism numbers in Australian children.

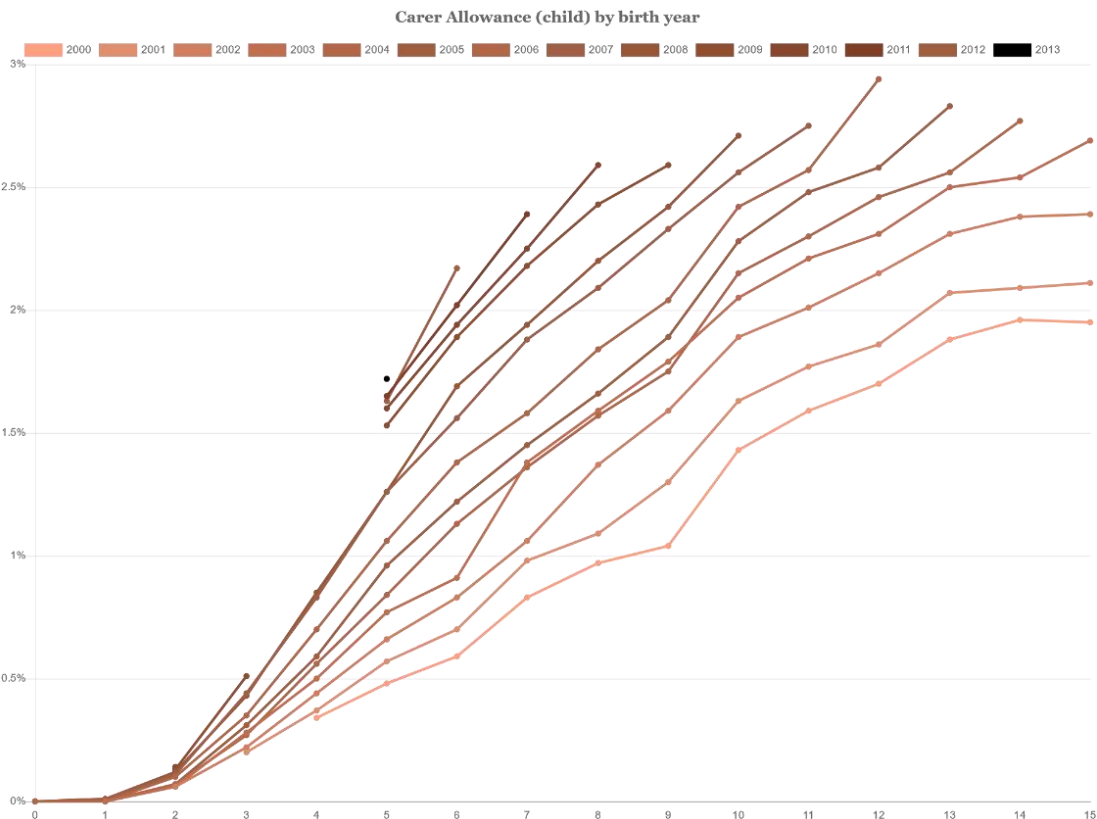
The diagnosis rates from Carer Allowance (child) population data were comparable to, albeit a little lower than, the ABS estimates derived from SDAC data. Both increased substantially over time.

A4 also found minimal differences between the Carer Allowance (child) data for South Australia with the Autism SA records.

Carer Allowance (child) data was very detailed. It allowed much detail to be examined; for example, the age of diagnosis could be estimated.



This figure shows that over half the children born in 2002-3 FY were diagnosed after age 7 years. The following figure shows detailed growth in numbers since 2004 when the first dataset was collected.



This chart (Figure 14 from [Autism Spectrum Disorder in Australia](#)) shows more than 50% of autistic children in Australia are diagnosed after age 7 years and the diagnosis rate for 15-year-olds was around 3% of children in 2018 (based on Carer Allowance (child) data from DSS). Note that the number of children getting Carer Allowance (child) has now fallen below the number of children who are autistic NDIS participants⁴. The quality of Carer Allowance (child) data decreased substantially – see <https://a4.org.au/node/2580>.

Autism rates in the NDIS

Currently in Australia, the NDIS is the main support for Autistic Australians. The NDIS is meant to support people with disability and either early intervention or substantial and permanent support needs. It is unclear, but possibly early investment (intervention) for autistic children up to 9 years and autistic Australians with substantial support needs after that age make up the autistic NDIS participants who are almost 36% of all NDIS participants. Most autistic NDIS participants are young.

The following table is the number of autistic NDIS participants in each state from the NDIS’s website as of June 2023.

	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	ALL
0 to 6	233	7396	0	3926	1625	435	4477	1603	19828
7 to 14	1785	32099	764	25517	10914	2053	30123	9299	112565
15 to 18	572	9639	190	8363	3928	744	8461	3472	35374

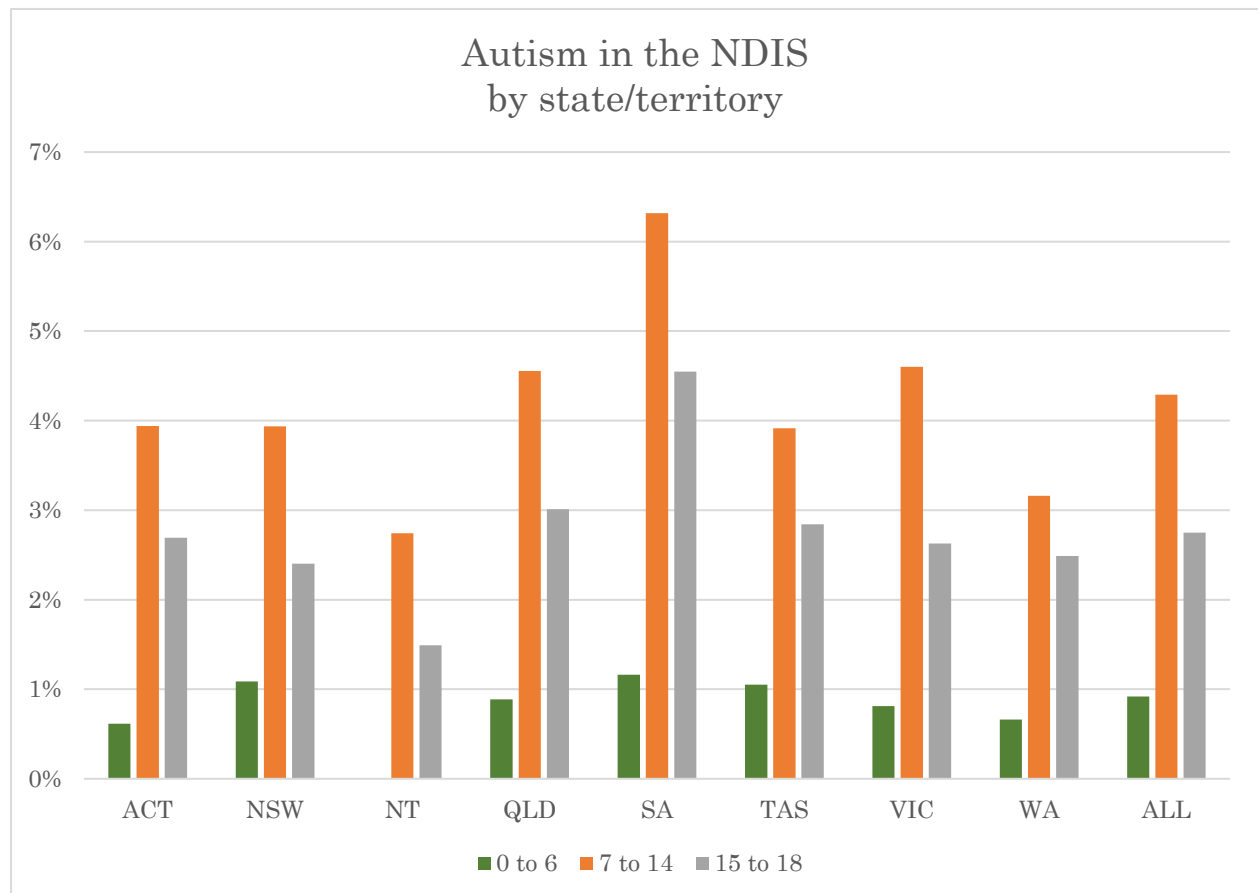
The following table shows data from the Australian Bureau of Statistics on the [population by age in each state/territory ...](#) also in June 2023.

Age (yrs)	ACT	NSW	NT	Qld	SA	Tas	Vic	WA	Australia
0–4	26,433	479,844	16,996	309,101	97,686	28,875	387,721	169,137	1,516,003
5–9	28,570	498,982	17,468	335,633	105,085	31,426	409,004	183,938	1,610,397
10–14	28,147	516,237	17,367	358,724	109,710	33,581	409,327	183,991	1,657,381
15–19	26,549	501,281	15,930	347,248	107,981	32,728	402,440	174,416	1,608,827
0-6	37,861	679,437	23,983	443,354	139,720	41,445	551,323	242,712	2,160,162
7-14	45,289	815,626	27,848	560,104	172,761	52,437	654,729	294,354	2,623,619
15-18	21,239	401,025	12,744	277,798	86,385	26,182	321,952	139,533	1,287,062

⁴ The means test on Carer Allowance (child) excludes very few children so the number of children on CAC should easily exceed those who are NDIS participants. Since the demise of HCWA Autism Advisors, the government has instigated numerous barriers to children accessing CAC and the participation rate appears to have dropped significantly.

Based on the above data, the following table shows the percentage of children diagnosed autistic and NDIS participants as of June 2023.

	ACT	NSW	NT	QLD	SA	TAS	VIC	WA	ALL
0 to 6	0.62%	1.09%	0.00%	0.89%	1.16%	1.05%	0.81%	0.66%	0.92%
7 to 14	3.94%	3.94%	2.74%	4.56%	6.32%	3.92%	4.60%	3.16%	4.29%
15 to 18	2.69%	2.40%	1.49%	3.01%	4.55%	2.84%	2.63%	2.49%	2.75%



Clearly, there is not one diagnosis rate that can be used as a prevalence estimate for all ages. The diagnosis rates for states/territories vary substantially: for 7- to 14-year-olds NT and WA are 2.74% and 3.16% while SA is 6.32% - twice the diagnosis rate. There is wide variation between autism participation rates for the different states/territories which needs to be recognised, understood, and possibly addressed (to reduce inequities in supports and outcomes).

Perhaps, the best estimate is the 4.29% of children aged 7 to 14 years for the whole country. This is substantially more than 1 in 50 (Whitehouse above) or 1 in 70 (Aspect and Autism Qld above) ... but it is likely to be a conservative estimate of autistic school age children.

Recommendation 1

The Australian Government, via the Department of Social Security and the Department of Health and Ageing, must recognise formally that at least 4.29% of children nationally are diagnosed with Autism Spectrum Disorder.

There are more children diagnosed with autism spectrum disorder than this number. These include Autistic children who:

- have not been diagnosed (for a range of reasons)
- are not NDIS participants
- have ASD but it is not recorded as their primary diagnosis by the NDIS.

This under-reporting is likely to far exceed children who are mis-diagnosed with ASD and become NDIS participants with ASD as their primary disability.

[A more recent report](#) also reported “Parent-reported ASD prevalence in 2016 in 12-year-old children from the Birth cohort of the Longitudinal Study of Australian Children was 4.4%”.

Western Australia, Professor Whitehouse’s home state, has the second lowest autism diagnosis rate for 7- to 14-year-old children (just 3.16%). Even so, the rate for 7- to 14-year-olds autistic NDIS participants in WA who are a proportion of autistic children is significantly higher than 1 in 50 he reports (see above).

A4 estimates that 60-70% of autistic children are NDIS participants so autism prevalence in children is likely significantly higher than the NDIS figures suggest. A better estimate may be available when the ABS publishes the next SDAC report (expected by June 2024).

The [National Disability Data Asset](#) (NDDA) will have a challenge to estimate diagnosis rates and prevalence for autism in Australia. Data that is as unreliable as the number of autistic school students (see <https://a4.org.au/sites/default/files/EC-TAP.pdf>) and the [Medicare items for ASD diagnosis](#) are not helpful.

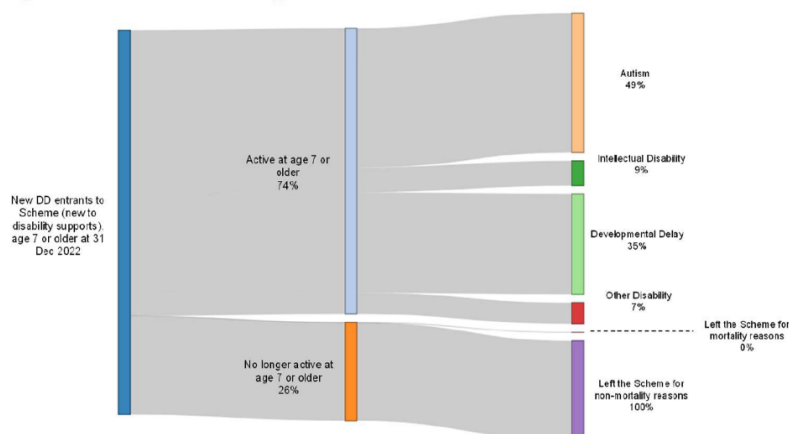
Just as over 2 in 3 autistic school students were missing from data the South Australian Education Department provided for NDDA pilot (see EC-TAP letter above), the Canberra Times reported that ACT Education also missed substantial numbers of students with disability – see <https://a4.org.au/node/2597>.

Emerging pathway

Note that increasingly, autistic children are not diagnosed in Australia under 7 years of age. The diagnosis rate for 0- to 6-year-olds is not indicative of ASD prevalence since many children are labelled as having Developmental delay or Global developmental delay but should have an ASD diagnosis – see <https://a4.org.au/node/2572>.

OFFICIAL

Pathways in the Scheme for participants with developmental delay

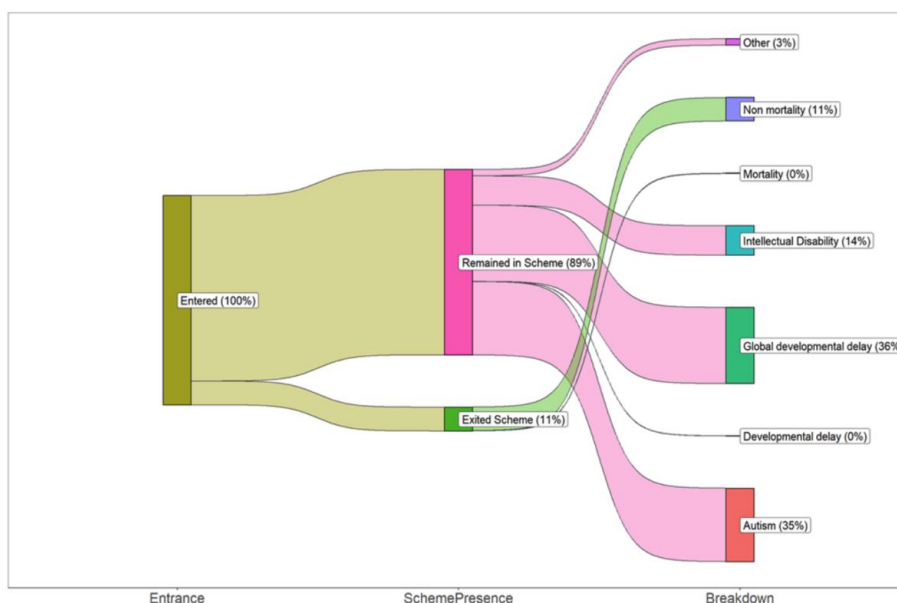


- 74% of new entrants to the Scheme with DD continued as NDIS participants after age 6. Of these:
 - 49% have a primary disability of Autism;
 - 35% remained under Developmental Delay (i.e. may not have been reassessed);
 - 9% have a primary disability of Intellectual Disability; and
 - 7% have another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

OFFICIAL

The following picture, from the Scheme Actuary, is probably for NDIS participants who enter the Scheme with Global developmental delay.

Pathways in the Scheme for participants with developmental delay



Increasingly, an autistic child's pathway to their ASD diagnosis is via a Developmental delay or Global developmental delay label that prevents or diverts them from accessing ASD-specific early investment/intervention and better prospects for improving their life outcomes.

Government needs to urgently review its overall approach to DD and GDD; it needs to consider whether the existing approaches to early intervention and capacity building, as reflected in DSS's Early Childhood Targeted Action Plan and the NDIS, are meet the requirements of the CROC and CRPD ... or are effective.

Recommendation 2

Governments need to review urgently their approach to Development delay and Global developmental delay. Explanations are needed as to why numbers are growing substantially and whether existing supports achieve optimal outcomes for children with DD or GDD and for the community generally.

Overseas

[The CDC's estimate for autism diagnosis rate in the USA](#) is 1 in 36 (2.76%) for children 8 years of age. This figure is comparable to Australian data (above) for children of the same age.

Conclusion and recommendations

The National Autism Strategy needs to be built on foundations of good evidence that would include at least sound diagnosis rates or prevalence measures. A4 is not confident that is happening.

This report recommends:

1. formal recognition of national data indicating that in 2023 at least 4.29% of school-age Australian children were diagnosed autistic and needing support via the NDIS. Autistic children who do not meet NDIS eligibility criteria usually need accommodations and assistance with their learning in education settings and into their adult lives.
2. An urgent and comprehensive review of Australian children with Development delay and Global developmental delay; it must ask "how can Australia achieve optimal outcomes for children labelled temporarily with DD or GDD and for the community generally?"

Bob Buckley