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AUTISM IN AUSTRALIA

DATA AND ITS SOURCES

Autism Aspergers Advocacy Australia (A4)




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Disability in Australia

The Australian Bureau of Statistics (ABS) conducts an occasional [Survey of Disability, Ageing and Carers](#).

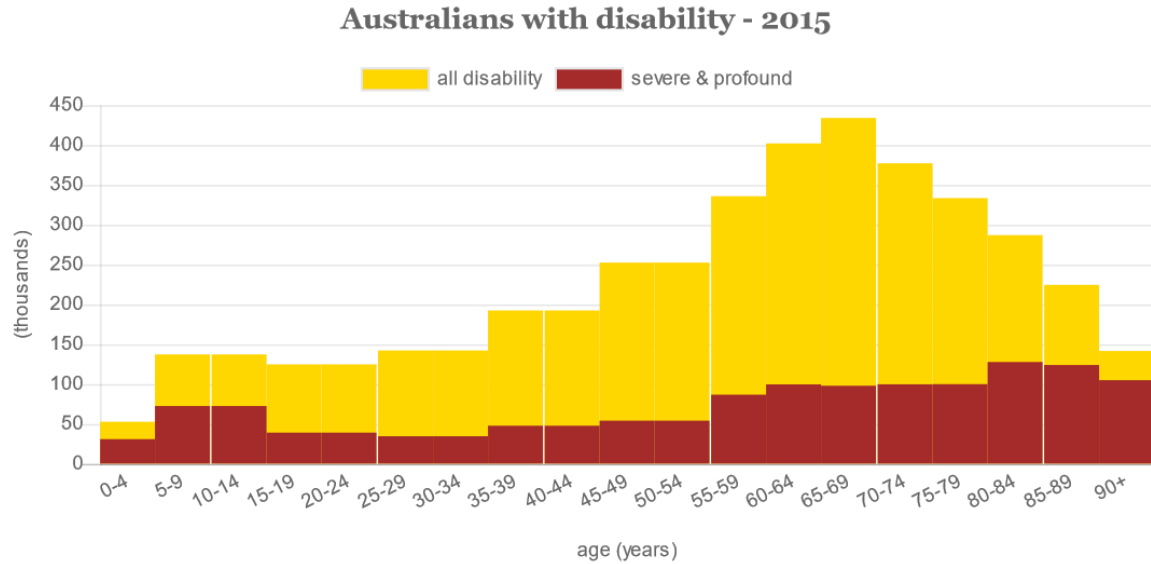


Figure 1. ABS SDAC disability estimates: Australians with disability - 2015

The number of people with disability is not evenly distributed. The age group with the most disabled people is the 65-69 year old age band. The number of people aged 60-69 years with a disability is double the number age 40-45 years.

No one has fully explained the drop in numbers from 10-14 year to 15-19 year age group. Part of this decrease is likely due to the change from parent-reporting to self-reporting in the survey data collection: some young people reject being labelled as "with disability".

Figure 2 below shows Australians with disability as a proportion of the population in the age band. Mostly, the proportion of adults with disability increases with age.

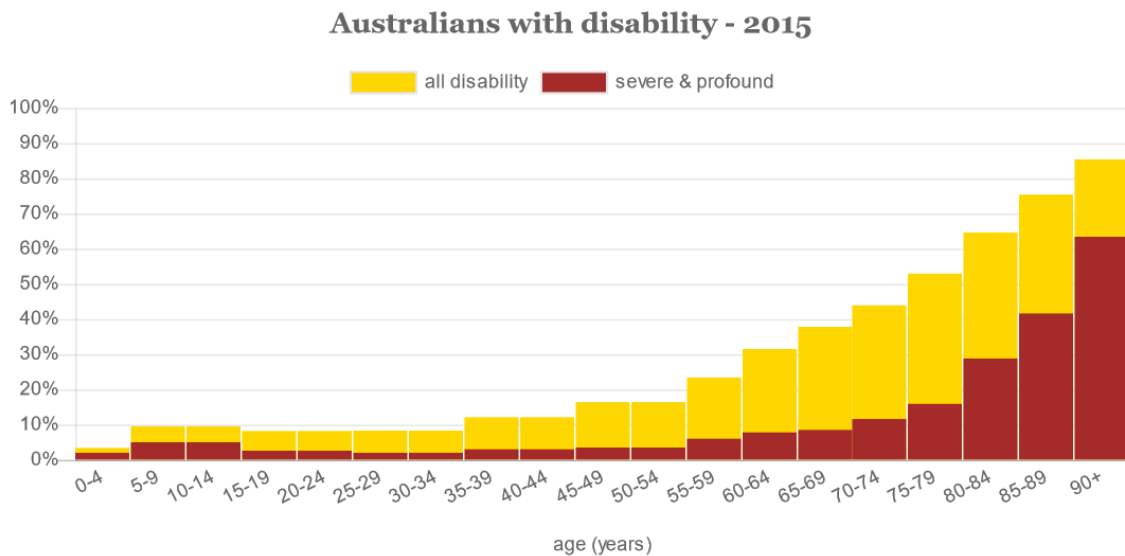


Figure 2. ABS SDAC estimates: Percentage of Australians with disability - 2015

Older people are more likely to acquire or develop disability.

It is misleading to present an average disability rate for disability in general across all ages.

Some disability types have later onset (e.g., dementia, MS, sensory impairment, spinal injury, ...) and some are associated with reduced lifespan. Some disability types, such as ASD and intellectual disability, are usually life-long.

This variability means the disability sector is very diverse. It is unwise and inappropriate to generalise about people with disability.

Autism Spectrum Disorder in Australia

Autism Aspergers Advocacy Australia (A4) reviews and analyses data from various sources hoping to understand the nature and experience of autistic Australian and their associates. A4's focus is national advocacy, so its focus is on national data.

A4's main sources of national data related to autistic Australians are:

- The Australian Bureau of Statistics (ABS), especially its Survey of Disability, Ageing and Carers (SDAC) that it conducts occasionally (every 3 years since 2009)
- annual summaries of autistic children (aged 0-15 years) receiving Carer Allowance (child) from the Department of Social Security (DSS, formerly FaHCS and FaCHSIA)
- quarterly datasets from the NDIS (since full-rollout in 2019, but not all Autistic Australians).

A4 appreciates the access it has to these data. Without these data sources, understanding of ASD in Australia would be far more limited.

Other sources of data about autistic Australians include:

- Medicare
- HCWA data
- NDA and NMDS data from AIHW
- NDDA (in development)

The following reports on Australian data relating to "autism", Pervasive Developmental Disorders (up to 2013) and Autism Spectrum Disorder (since 2013).

The DSM-IV, when it was published in 1994, indicated that the prevalence of Autistic Disorder was 4 per 10,000. It did not provide prevalence estimates for Asperger's Disorder or PDD-NOS. In the 1980s, prevalence for the wider autism spectrum was estimates to be around 10 per 10,000 (see [here](#)). The expectation was that 2 in 5 had Autistic Disorder and the rest (3 in 5) had Asperger's Disorder or PDD-NOS.

Australia's population in June 1995 was 18,100,000 so the expected number of autistic Australian (0.1%) was 18,100; about 7,240 with Autistic Disorder. Diagnosis of PDDs increased substantially through the 90s. Even so, by 1998 the ABS estimated that there were just 13,200 autistic Australians. Australia had low diagnosis rate for Asperger's Disorder and diagnosis rates for PDD-NOS were largely unreported.

Despite increases in autism diagnosis rates starting in the 90s, governments in Australia failed to increase services and supports for the growing number of autistic people. From the perspective of an autistic individual, existing services were increasingly diluted. The lack of essential service for Autistic Australian became chronic.

Australian Governments persist with their unsupportive attitude to ASD today. For example, the planning for the NDIS did not recognise that ASD diagnoses were increasing. Senior NDIA officials

were delighted to hear that the increase in autism diagnoses from 2012 to 2015, for the first time, comprised more autistic people with mild or moderate disability than those with severe or profound disability. They do not appreciate (discernibly):

1. that the needs of the increasing numbers of autistic people with severe or profound disability still need to be addressed;
2. most autistic people with so-called "mild or moderate ASD" also needs acceptance, services and supports;
3. autistic people have poor employment and participation prospects even if their autism is considered mild or moderate;
4. there should always have been more autistic people with mild or moderate disability — there may be substantial and persistent under-diagnosis of less severe ASD; and
5. time has shown much greater levels of autism under-diagnosis for women.

ASD: diagnosis rate vs prevalence

Most reporting of ASD rates/levels in populations are based on number of diagnoses. We can observe (count) the number of diagnoses but determining true prevalence is difficult.

ASD prevalence is the proportion of people who have ASD. Published data is always based on some process for determining who is autistic and who isn't. Differences in interpretation of autism diagnostic criteria account for some of the difference in reporting.

The challenge is to understand and explain the observed increasing ASD diagnosis rates and how they relate to ASD prevalence.

Generally, the expectation is that diagnosis rates are similar to prevalence. Any difference between the two is due to a combination of small numbers of misdiagnosis and missed diagnoses. But the substantial increases in diagnosis rates for ASD tell a different story.

Typically, researchers blame changing criteria for at least part of the increase — but the diagnostic criteria for ASD have changed relatively little. In particular, the criteria did not change to allow easier diagnosis from 1994 when the DSM-IV was published to 2013 when the DSM-5 was published. The changes from the DSM-III to the DSM-IV, then to the DSM-5 all tightened autism diagnosis criteria so changes to the criteria do not contribute to increasing autism diagnoses, those changes were meant to reduce/limit increasing autism diagnosis rates.

Generally, people say "changing criteria" when they actually mean "broader" or "better" *interpretation* of (unchanged) diagnostic criteria.

Differences between "diagnosis rate" and "prevalence" for ASD are due to a combination of:

- undiagnosed ASD - some people simply don't seek a diagnosis, other are given other diagnoses.
- misdiagnosed (or over-diagnosed) ASD - when a person is diagnosed incorrectly with ASD
- data inadequacy.

An autistic person may be undiagnosed (without an ASD diagnosis) for a range of reasons:

- they may be young and are yet to be diagnosed. Various datasets indicate that the ASD diagnosis rate in young children is well below the rate observed in older children.
- a child may be waiting for an ASD assessment — especially when waiting for government diagnostic services that mostly have unacceptably long waiting list.
- people associated with an autistic child may not be aware of ASD nor of its signs.
- some families cannot afford to pay for an ASD assessment — the Medicare item funds only a fraction of the cost of a private assessment.

- for adults, diagnosis is often more complex or difficult to obtain.

Some people are misdiagnosed with ASD when they are not autistic. Suggested reasons are:

- some clinicians may mis-interpret symptoms and diagnose ASD incorrectly
- there are claims that some parents (or schools) demand an ASD diagnosis
- there are some claims that some clinicians diagnose ASD so a child can access services they need and cannot be accessed without the diagnosis
- data collection should be wary of self-diagnosis ... also must ask the right question.

Many autistic people have comorbid conditions: other diagnoses may be recorded but a comorbid ASD diagnosis may not be recorded/registered ... either at time of diagnosis or during subsequent data collection. For example, systems that ask for a primary disability may not record other diagnoses.

The available data suggests that there are substantial levels of undiagnosed ASD among Australian adults. The ABS estimated there were 6,200 autistic Australians aged 20 years or over in 2003. In 2012, they estimated 12,900 autistic adults and 14,500 in 2015 aged 30 years of older. ABS SDAC data from 2018 estimate ASD diagnosis rates for autistic adults (25+ years of age) in Australia start at 0.8% and drop substantially from there.

Other prevalence papers

Williams K , MacDermott S , Ridley G , Glasson EJ , Wray JA: *The prevalence of autism in Australia: can it be established from existing data?* **J Paediatr Child Health** 2008; 44:504–510
<https://onlinelibrary.wiley.com/doi/10.1111/j.1440-1754.2008.01331.x>

Fombonne E: *Epidemiological surveys of autism and other pervasive developmental disorders: an update.* **J Autism Dev Disord** 2003; 33:365–382
<https://link.springer.com/article/10.1023/A:1025054610557>

Fombonne E: *Epidemiology of pervasive developmental disorders.* **Pediatr Res** 2009; 65:591–598
<https://www.nature.com/articles/pr2009131>

Prevalence of Autism Spectrum Disorders in a Total Population Sample, Young Shin Kim, M.D., Ph.D., Bennett L. Leventhal , M.D., Yun-Joo Koh, Ph.D., Eric Fombonne , M.D., et. al.
<https://doi.org/10.1176/appi.ajp.2011.10101532>

Autism in the ABS SDAC

The Australian Bureau of Statistics (ABS) collects data including population data and data for its [Survey of Disability, Ageing and Carers \(SDAC\)](#). The ABS uses its SDAC data to estimate the number of autistic Australian. Note that when smaller numbers reported in these are estimates have significant estimation errors.

In 2004, Bob Buckley (A4 Convenor) asked the ABS for estimates of the number of autistic Australians from the 1998 and 2003 SDAC data. He published¹ the estimates that the ABS provided.

At the time of publication of the DSM-IV in 1994, autism prevalence was generally regarded as being around 1 per 1,000 (or 10 per 10,000). [In June 1995, Australia's population](#) was 18.1 million so the expected number of Autistic Australians was 18,100. The ABS SDAC estimated in 1998 that 13,200 Australians were autistic or 72.9% of the expected number, so from the outset autism was substantially under-diagnosed in Australia.

¹ Buckley, B, *Autism/ASD diagnosis rates in Australia*, Proceedings of 2004 Australian Biennial Autism Conference, Autism Aspergers ACT, Canberra, Australia (see <https://a4.org.au/node/918>).

Since the ABS's 2009 SDAC data collection, the ABS produced its own reports on "Autism in Australia".

- [44280.0 Autism in Australia, 2009](#)
- [4428.0 - Autism in Australia, 2012](#)
- [4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015](#) - "Autism in Australia" is part of the larger SDAC report
- [4430.0 Autism in Australia, 2018](#) - part of the Disability. Ageing and Carers Australia findings.

Each report has an associated spreadsheet that provides more detail than is shown in the reports.

The ABS SDAC 2018 estimates that:

- 205,200 Australians were autistic² — a 25.1% increase on the 2015 estimate.
- 83% of autistic people were aged under 25 years³.
- 22.7% of autistic people were female, a female to male (other?) ratio⁴ over 1:4.
- 68.9% of autistic people have severe or profound disability (core activity limitation).

The ABS released a series of *estimates* (and associated risk of error) from its survey data collections showing statistical aspects of Australia's autistic population.

year	1998	2003	2009	2012	2015	2018
autistic Australians '000s	13.2	30.4	64.6	115.4	164.0	205.2
increase		130.0%	112.5%	78.6%	42.1%	25.1%
annual increase		18.6%	13.4%	21.34%	12.43%	7.75%
severe or profound disability		87%	74%	73%	64.8%	68.9%
0-14 years old	80.3%	66.4%	65.2%	56.7%	53.4%	60.0%
female		16.8%	17.8%	21.9%	19.6%	22.7%

Table 1. ABS SDAC summary information

The ABS SDAC dataset allows a range of analyses.

The increases in ASD diagnosis rates are remarkably high. The data show a greater than 15-fold increase in autism diagnoses from 1998 to 2018. Other major disability types are stable or decreasing.

Some of the increase in numbers is due to Australia's population increase.

² Citing averages for disability ASD is misleading as diagnosis rates for ASD vary substantially by age; the average diagnosis rate across all ages is not meaningful.

³ While research indicates life expectancy for autistic people is reduced, reduced life expectancy is not sufficient to explain low numbers of autistic adults. Apparently, Australia has significant under-diagnosis of Autistic adults.

⁴ There is increasing recognition that gender is a more complex issue in the Autistic sector.

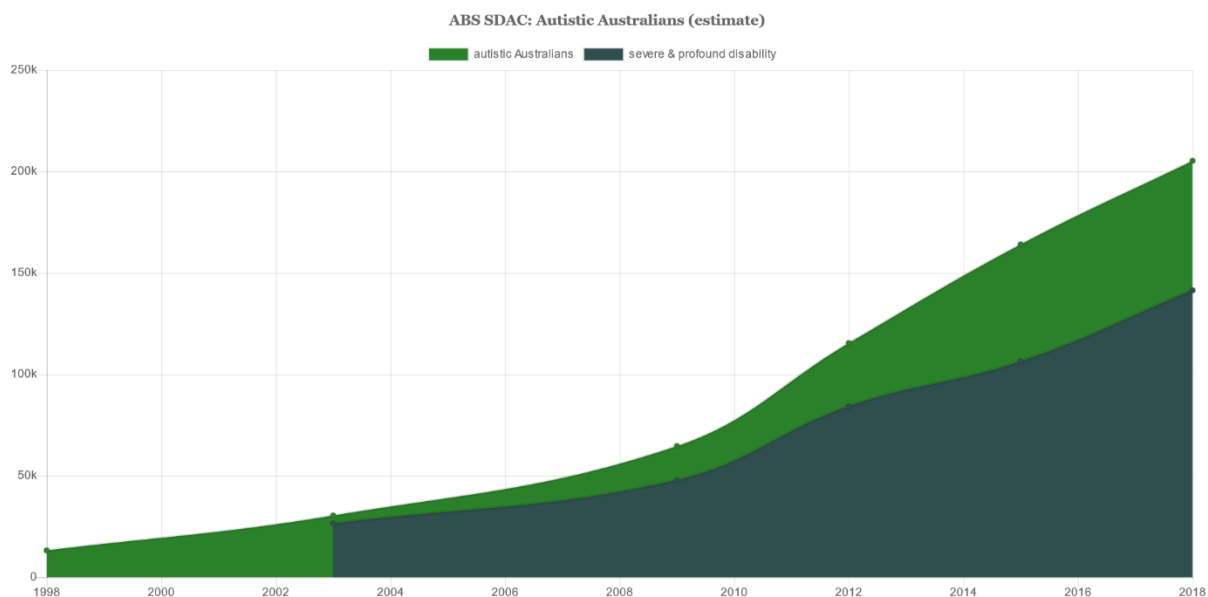


Figure 3. Number of Autistic Australians

Data from 2003 show 87% of autistic Australians had severe and profound disability compared to 68.9% in 2018. This suggests chronic under-diagnosed of mild and moderate ASD in Australia may be moving slowly in the right direction.

The ABS SDAC provides estimates separated in to 5-year age bands. The ABS varies the bands provided between the survey years to allow for higher error rates when numbers are small. Values in italics were derived from the data provided.

	1998	2003	2009	2012	2015	2018
0-4 years	1.0	1.2	3.5	6.0	6.2	10.8
5-9 years	10.5	8.2	19.4	33.0	41.9	49.0
10-14 years		10.8	19.2	26.4	39.4	50.3
15-19 years	1.7	3.9	11.4	21.8	26.4	40.2
20-24 years		6.2	3.7	11.5	20.0	19.8
25-29 years			2.8	3.5	11.9	15.6
30-34 years			4.6	3.2	5.1	7.1
35-39 years				2.7	2.5	3.5
40 years and over	7.0	6.9	8.4			
Total	13.2	30.4	64.6	115.4	164.0	205.2

Table 2. Autistic Australians by age (thousands)

Figure 4. Autistic Australians age breakdown below shows estimates of Autistic Australian in 2018 .

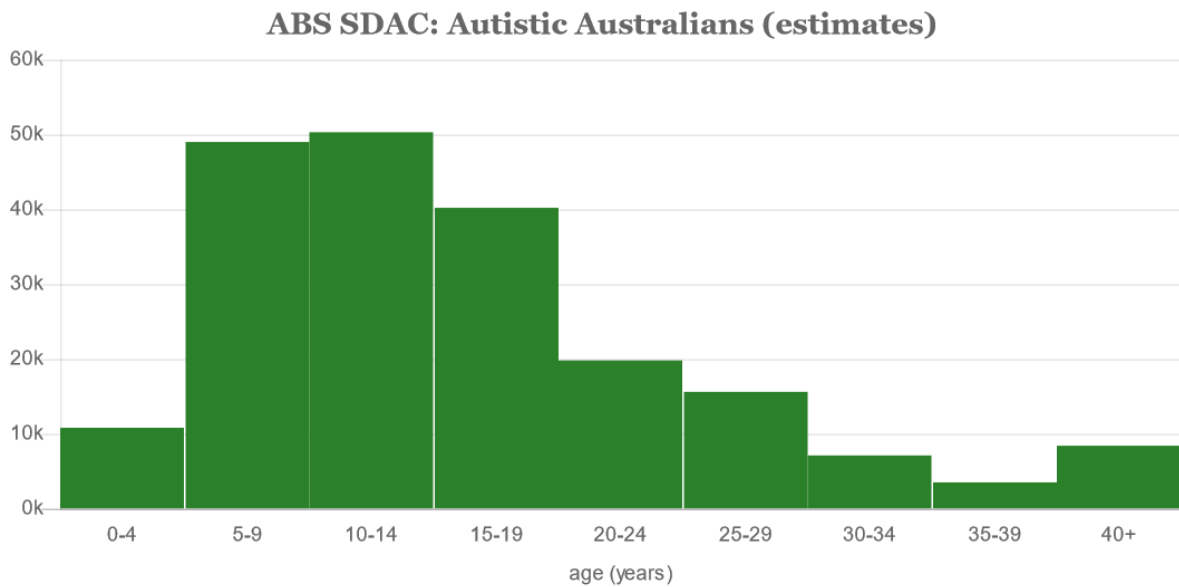


Figure 4. Autistic Australians age breakdown

The clear feature of these data is that most Autistic Australians are aged under 25 years. In 2018, over half (53.7%) of autistic Australians were aged under 15 years.

The population of Autistic Australians is distinctly different from the population of people with disability more generally (see Figure 1 and Figure 2 above):

- the scale is different;
- the proportion of people with disability is relatively stable, while the proportion of Autistic Australians is experiencing substantial growth (see Table 3 below); and
- the age profiles of the groups are very different.

Diagnosis rate is often easier to understand than raw numbers: it adjusts for increasing population. The following Table shows diagnosis rates broken down by age across the years.

	1998	2003	2009	2012	2015	2018
0-4 years	0.078%	0.095%	0.245%	0.401%	0.399%	0.687%
5-9 years		0.617%	1.441%	2.325%	2.727%	3.054%
10-14 years		0.399%	0.788%	1.385%	1.899%	2.793%
15-19 years			0.287%	0.780%	1.493%	1.796%
20-24 years				0.234%	0.706%	1.193%
25-29 years				0.178%	0.206%	0.666%
30-34 years					0.036%	0.201%
35-39 years						0.173%
						0.291%
						0.381%
						0.203%

	1998	2003	2009	2012	2015	2018
40+ years				0.067%	0.062%	0.072%

Table 3. Autistic Australians by age (percentage of population)

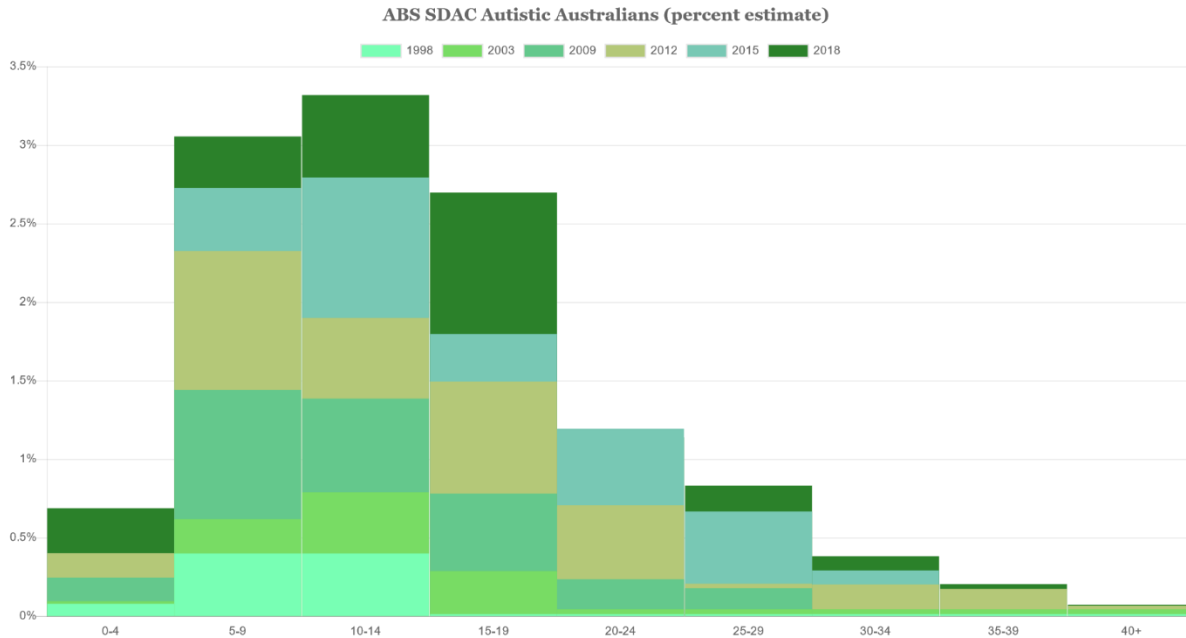


Figure 5. Diagnosis rates for Autistic Australians

In 2018, a child aged 5-14 years was 44 times more likely to be diagnosed autistic than an adult over 40 years of age. The ABS says, "males were 3.5 times more likely than females to have the condition ...".

Some people see autism prevalence differently (see <http://a4.org.au/node/1449>). Some claim that autism/ASD prevalence is stable at around 1.1% of the population. [Professor Andrew Whitehouse](#), Director, CliniKids, Telethon Kids Institute, said that Australia's autism diagnosis rate was now in line with other countries at around 1.1 per cent.

If the true prevalence of ASD is 1.1%, then 14 of every 15 autistic adults in Australia aged 40+ years are yet to be diagnosed which means very few adults receive the services and supports that they need for their ASD. And about 3 in 5 children aged 5-14 have an ASD diagnosis but they are *not* autistic — which means they may be getting inappropriate services and supports and missing out on different services that they need. If ASD prevalence is 1.1% of the population, then there are massive ASD diagnosis errors in Australia for most ages; ASD diagnoses are wrong far more often than right.

Frankly, this is hard to believe; it is much more likely that the 1.1% uniform prevalence estimate is wrong.

Figure 4 below shows the annual growth in the number of autistic Australian children and as a fraction of the population (compensating for population growth).

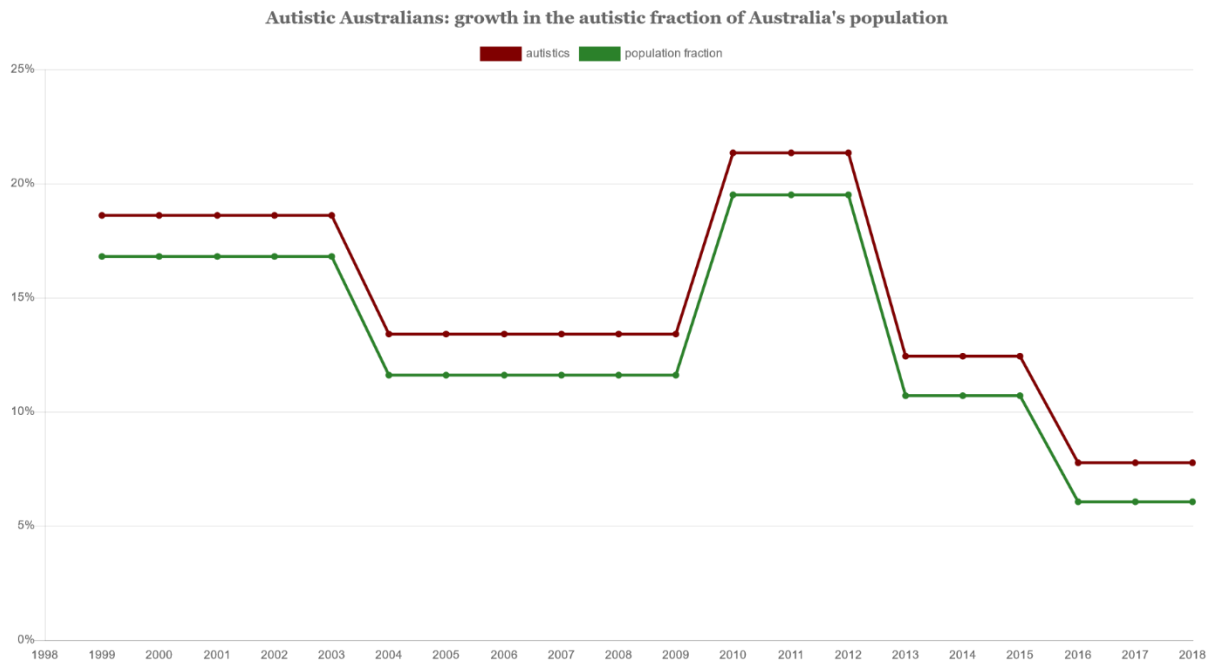


Figure 6. Growth rate (rate of increase) for Autistic Australians

Part of the increase in numbers over time relates to Australia's growing population. Following shows the growth in diagnosis rate (ABS calls this "prevalence") for "autism" as a proportion of Australia's population.

The data collected in 2012 seems anomalous. There is some speculation that this increase may be associated with the introduction of the HCWA package.

The following shows the variation in growing diagnosis rate across age ranges.

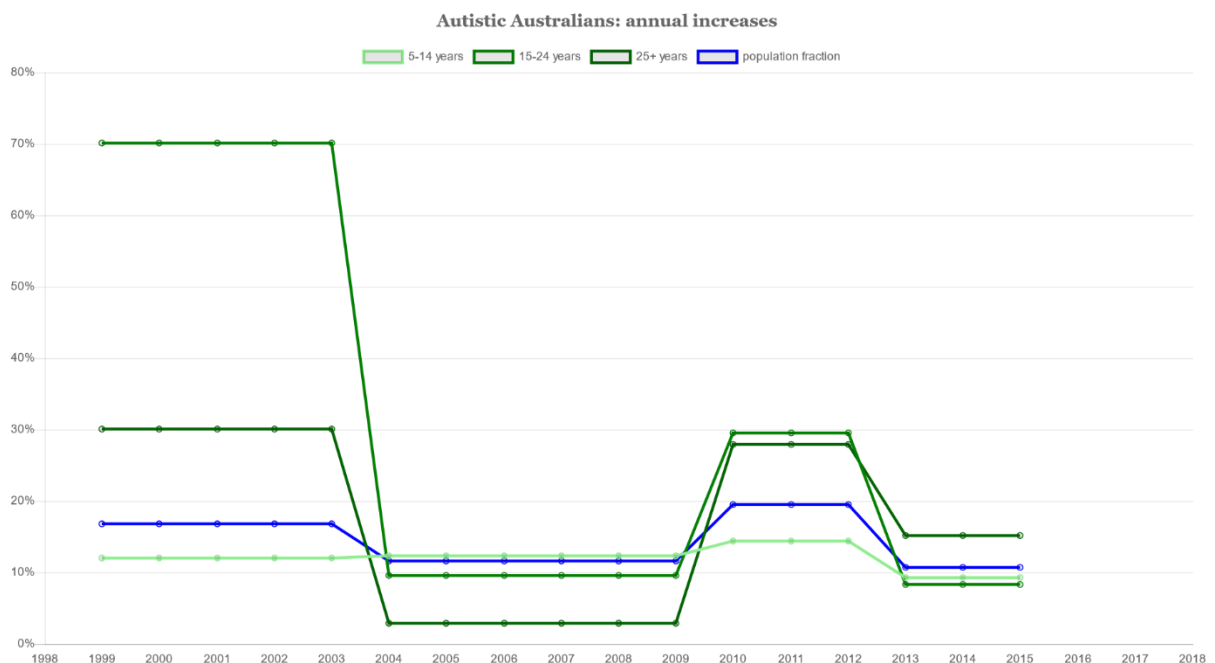


Figure 7. Increasing autism diagnosis rates by age group

Growth in the age range 5-14 years is relatively stable; more stable (the line is flatter) than for the whole population. Autism diagnosis is growing fastest mostly for Australians aged 15 years and over.

These data do not support the hypothesis that increasing growth in diagnoses was due to the HCWA package.

Education and employment

Some of the most valuable measures reported from the ABS SDAC is the unacceptable education and employment outcomes observed for Autistic Australians. Just read what [the report](#) says.

Autism and education

...

In 2018, 92.3% of young people (101,900) aged 5 to 20 years on the autism spectrum attending school had some form of educational restriction (92.3%), including a small number who were unable to attend school because of their disability. Two in five (40.8%) of the children attended a special class in a mainstream school or a special school.

Of the 106,600 young people (aged 5 to 20 years) with autism who were attending school or another educational institution, 77.7% reported experiencing difficulty at their place of learning. Of those experiencing difficulties, the main problems encountered were fitting in socially (59.8%), learning difficulties (55.3%) and communication difficulties (51.5%).

...

and

Autism and work

...

The labour force participation rate was 38.0% among the 94,600 people of working age (15-64 years), living with autism spectrum disorders. This is compared with 53.4% of all working age people with disability and 84.1% of people without disability.

The unemployment rate for people with autism spectrum disorders was 34.1%, more than three times the rate for people with disability (10.3%) and almost eight times the rate of people without disability (4.6%).

Note that there had been very little progress on these challenges through the series of reports.

AIHW autism report

In 2017, the AIHW used ABS SDAC data to produce produced its report about autism: see <https://www.aihw.gov.au/reports/disability/autism-in-australia/contents>

Much of this report's content is similar to the ABS report. For example, it uses the term "prevalence" instead of diagnosis rate.

The report describes "an overall prevalence rate of 0.7%, or about 1 in 150 people". We have already described this "statistic" as misleading since this "average" figure describes just two tiny age bands; most age ranges have a substantially different diagnosis rate.

One of the more "interesting" claims in the AIHW report is that just 88% of autistic Australians "were identified as also having disability" even though the DSM-5 diagnostic criteria for ASD require the diagnosing clinician to report that the person at least "needs support" in the two key diagnostic areas. This may be at odds with the ABS reporting from the same data collected in 2015, that 64.8% of autistic Australians had severe or profound disability (this rate rose to 68.9% in 2018).

The AIHW report suggests that:

- 27% of autistic school students have intellectual disability.
- 29% of autistic adults (those over 15 years of age) are unable to work.

The AIHW goes on to describe data it collects for the National Disability Agreement.

Autism in DSS Carer Allowance (child) data

The DSS database for Carer Allowance (child) is another source of data about autistic children in Australia. These data summarise autistic children in Australia from 0-15 years inclusive (ages 0-4 years are usually aggregated due to lower numbers).

Autism Aspergers Advocacy Australia (A4) has analysed and reported on data from the Centrelink Carer Allowance (child) database since 2006 (the first report was in [A4 Update Dec 2006](#)).

Subsequently, the data was published as Williams K, MacDermott S, et. al. (2008), *The prevalence of autism in Australia. Can it be established from existing data?* (published [here](#) or [here](#)). The article observed that:

This study has shown that Centrelink [now described as DSS Carer Allowance (child)] is the most comprehensive single source of national information about the number of individuals seeking funding with a diagnosis of autistic disorder or Asperger disorder.

A4 has obtained summary annual data summaries from DSS (formerly FaHCS) from 2004. Since 2013, the datasets have included Autism Spectrum Disorder (DSM-5). The continued availability of these datasets is a luxury; rarely is population data available as an ongoing series and in detail that allows analyses like the following.

These data describe the population of autistic Australian children who registered for Carer Allowance (child). This means that a health or allied health professional signed a comprehensive document as evidence of the child's formal autism diagnosis.

These are not sample data; they are population data. As population data, there are no error estimates: "errors" are people who have not been diagnosed or have a diagnosis but have not registered to receive Carer Allowance (child) — either because they are unaware of the allowance or because they have not completed the registration process. Consequently, these data are conservative, an under-estimate of ASD diagnosis numbers.

The data presented below are for "primary disability". There are a few (additional) children who register with autism as a secondary disorder.

Table 4. Summary data from Carer Allowance (child) Table 4 below shows the number of autistic children registered for Carer Allowance (child) in June of each year. The "increase" column shows the annual increase (the number of new registrations) each year, assuming there are no deaths or drop-outs.

year	total 0-15	increase	rate (0-15 years)	rate increase	rate (5-14 years)	peak* rate
2004	14,495		0.34%		0.450%	0.50%
2005	16,549	14.1%	0.39%	13.7%	0.513%	0.62%
2006	19,975	20.7%	0.47%	20.1%	0.620%	0.71%
2007	23,786	19.1%	0.55%	17.8%	0.745%	0.83%
2008	28,648	20.4%	0.65%	19.0%	0.891%	1.01%
2009	34,084	19.0%	0.77%	17.4%	1.051%	1.18%
2010	40,358	18.4%	0.90%	17.3%	1.240%	1.43%
2011	46,726	15.8%	1.04%	15.0%	1.421%	1.63%
2012	52,943	13.3%	1.15%	11.6%	1.595%	1.89%
2013	58,018	9.6%	1.25%	7.9%	1.723%	2.05%
2014	65,976	13.7%	1.40%	12.2%	1.929%	2.21%
2015	72,508	9.9%	1.52%	8.5%	2.076%	2.31%
2016	79,134	9.1%	1.63%	7.5%	2.245%	2.50%
2017	84,460	6.7%	1.72%	5.4%	2.349%	2.58%
2018	91,992	8.9%	1.85%	8.0%	2.545%	2.84%
2019	91,704	-0.3%	1.83%	-1.5%	2.513%	2.88%
2020	102,944	12.3%	2.03%	11.2%	2.799%	3.41%
2021	107,703	4.6%	2.10%	3.6%	2.911%	3.58%

Table 4. Summary data from Carer Allowance (child)

*Peak rate is the highest rate of diagnosed autism for any 1 year age group (mostly one of 12-14 years)

Figure 8 below shows increasing numbers of autistic children in Australia.

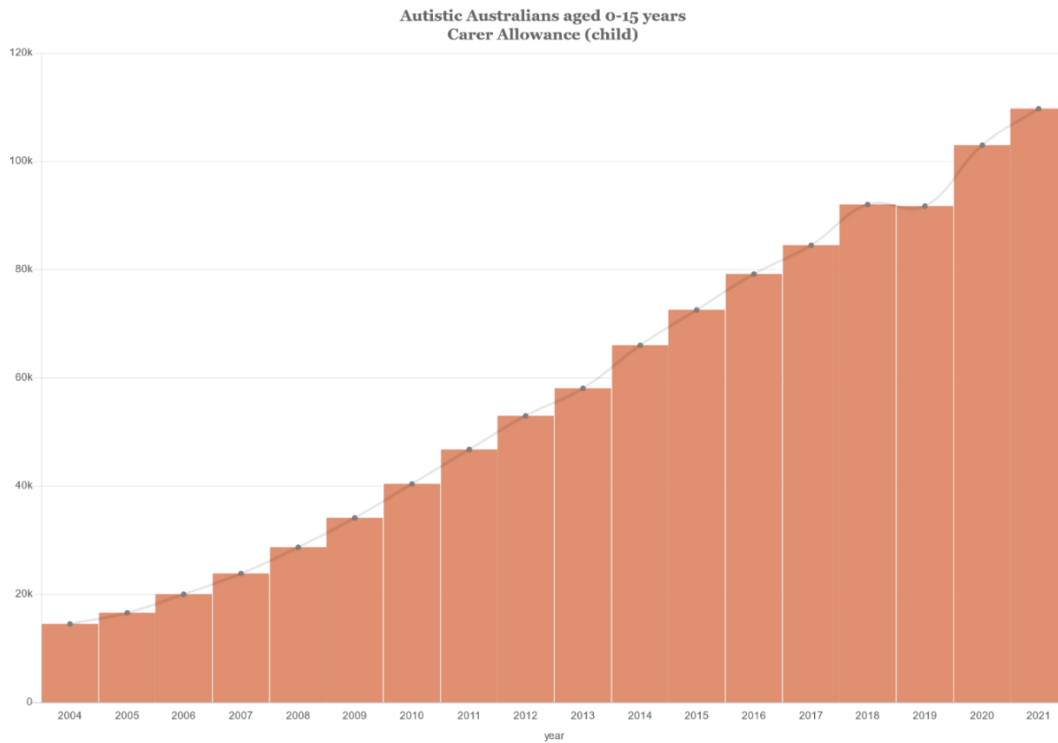


Figure 8. Autistic children aged 0-15 years registered for Carer Allowance (child)

Figure 8 above shows visible dips in growth in 2013, 2017 and 2019. These are more apparent in a chart showing annual growth (the 2nd derivative for the mathematically inclined).

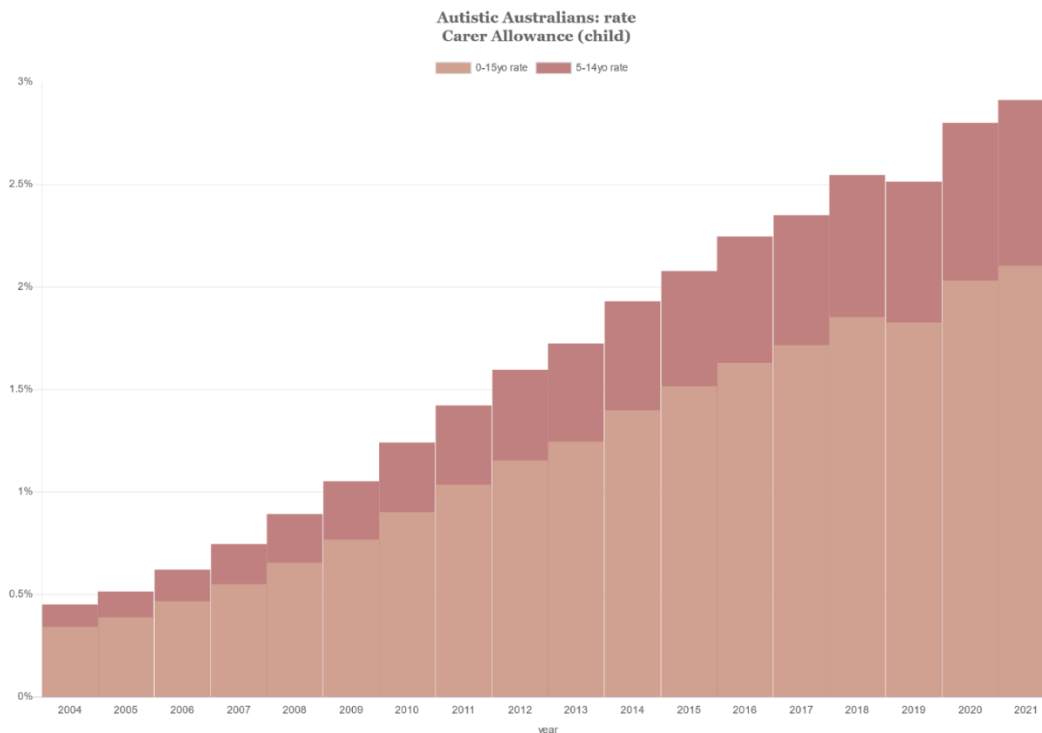


Figure 9. Autistic children aged 0-15 years registered for Carer Allowance (child)

Plotting the rate (or proportion as a percentage) of autistic children in the population removes the effect of population growth.

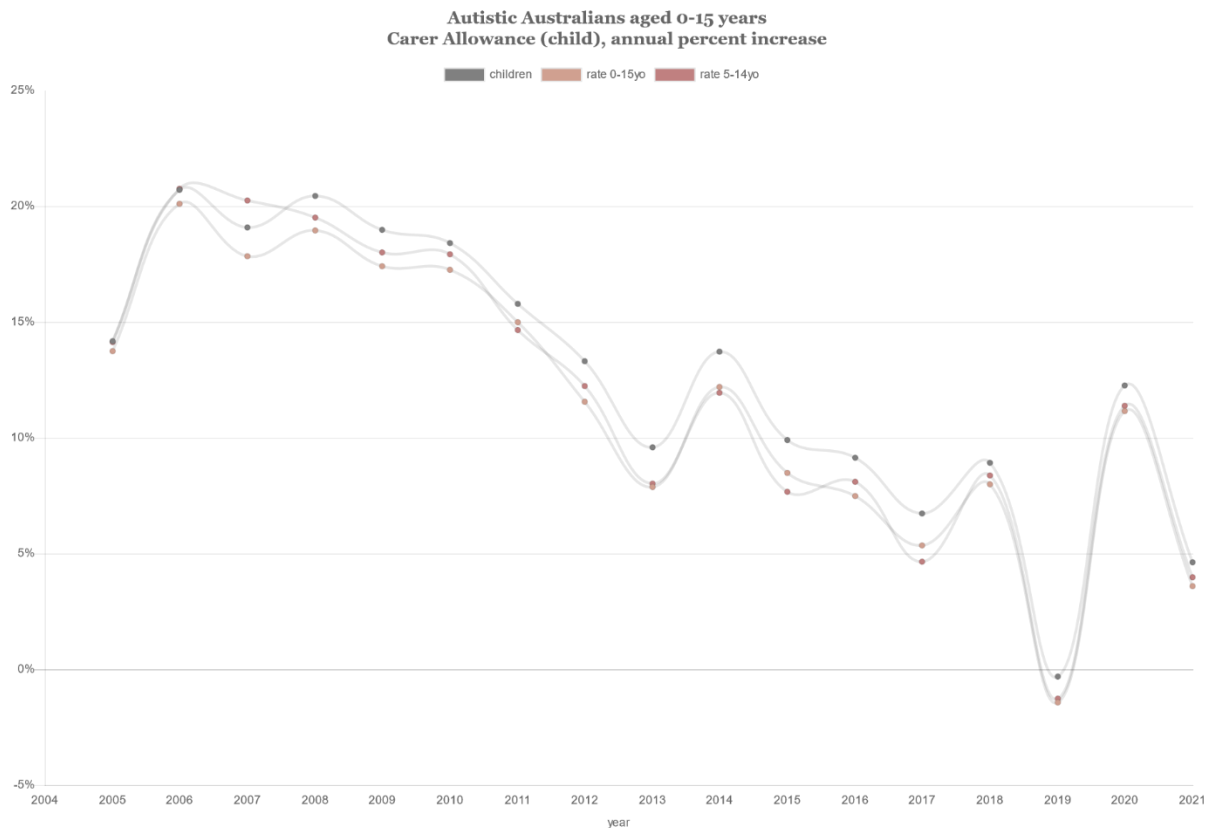


Figure 10. Autistic children aged 0-15 years registered for Carer Allowance (child)

Figure 10 above shows the growth rate for Carer Allowance (child), that is the difference between successive years. It shows growth both in the actual numbers and in the rate/proportion of autistic children.

Figure 10 shows that the rate of growth appears to be decreasing generally. The glitches (dips) in the graph may be relate to:

- 2005-2006 increased when Asperger's Disorder was added to Carer Allowance (child)
- 2007: a small dip as families focused on the 1000 hours campaign and the imminent *Helping Children with Autism* (HCWA) package.
- 2013: saw the publication of the DSM-5 ... which may have delayed some diagnostic assessments.
- 2017: is the start of the NDIS full roll-out.

Figure 11 below shows the percentage of children receiving Carer Allowance (child) for their diagnosis of Autistic Disorder, Asperger's Disorder or Autism Spectrum Disorder in 2021.

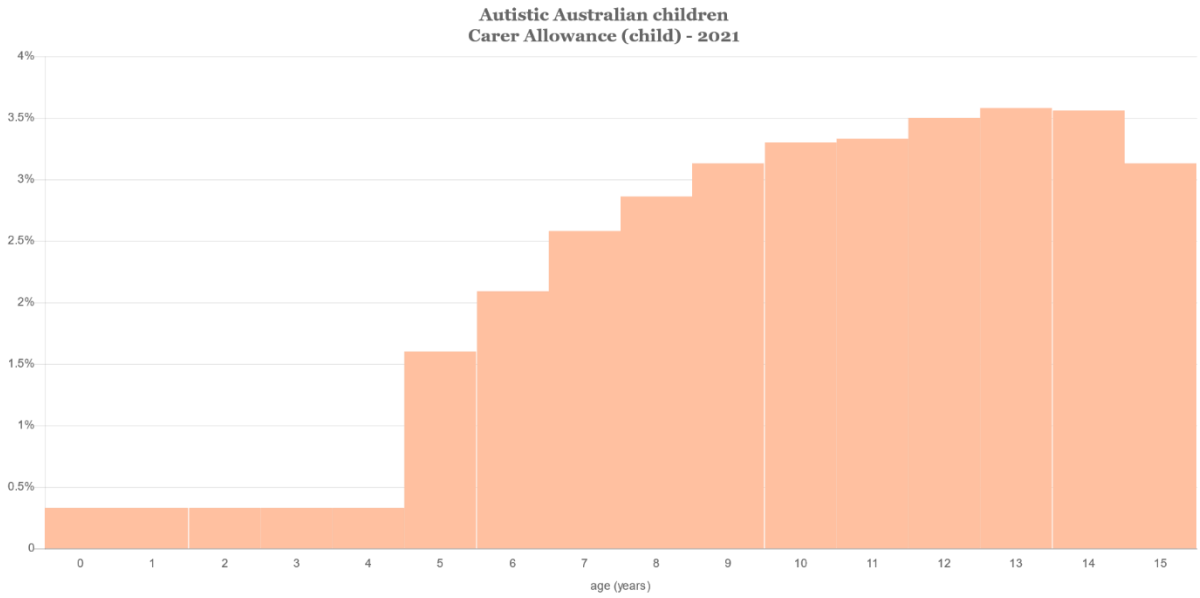


Figure 11. Age breakdown

Since 2013, DSS provided aggregated data for the 0-4 year age range so a single rate is shown for that age range.

Figure 12 below shows an age breakdown of growing ASD diagnosis rates in Australia.

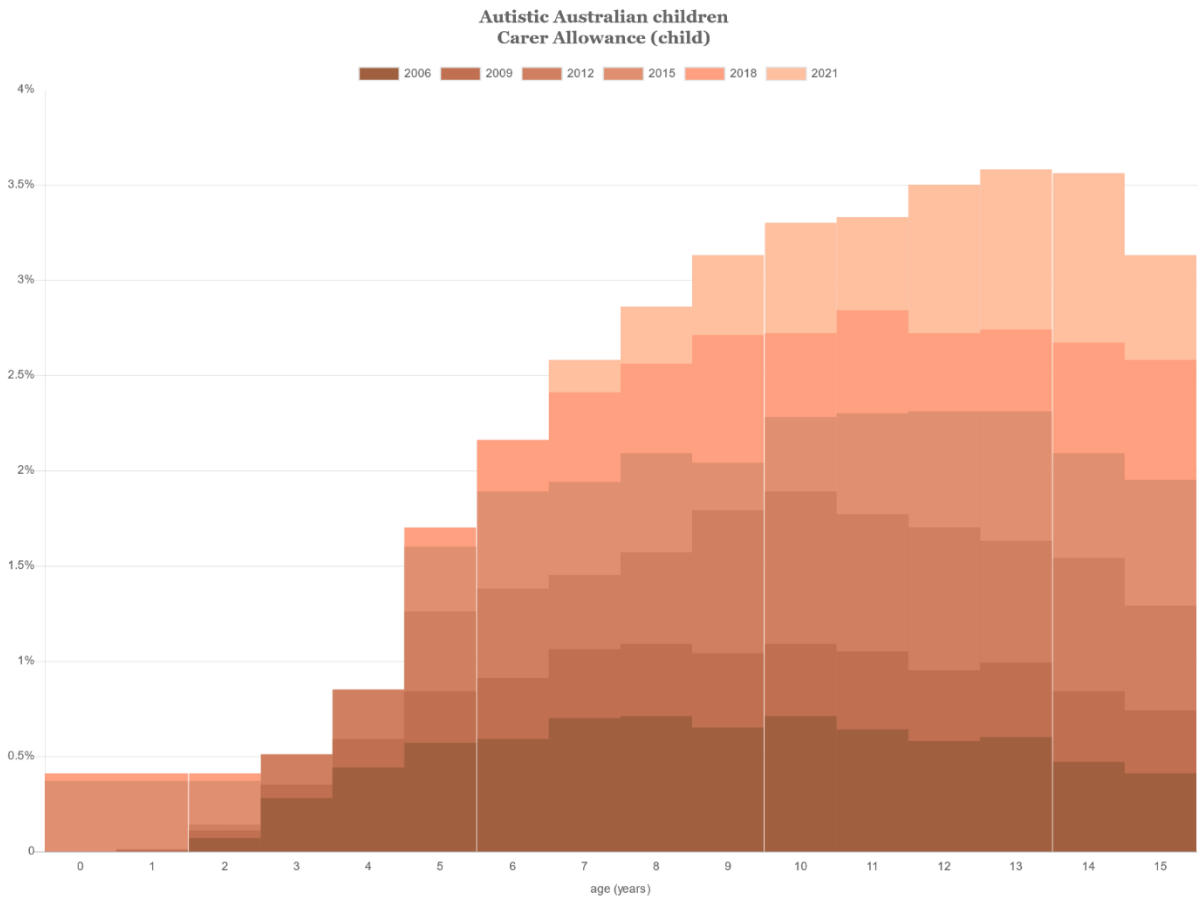


Figure 12. Increasing numbers of autistic children — Carer Allowance (child).

As above, recent (since 2013) DSS provided datasets with aggregated data for the age range 0-4 years. These aggregated values are shown for the 2021 series in Chart 2 above.

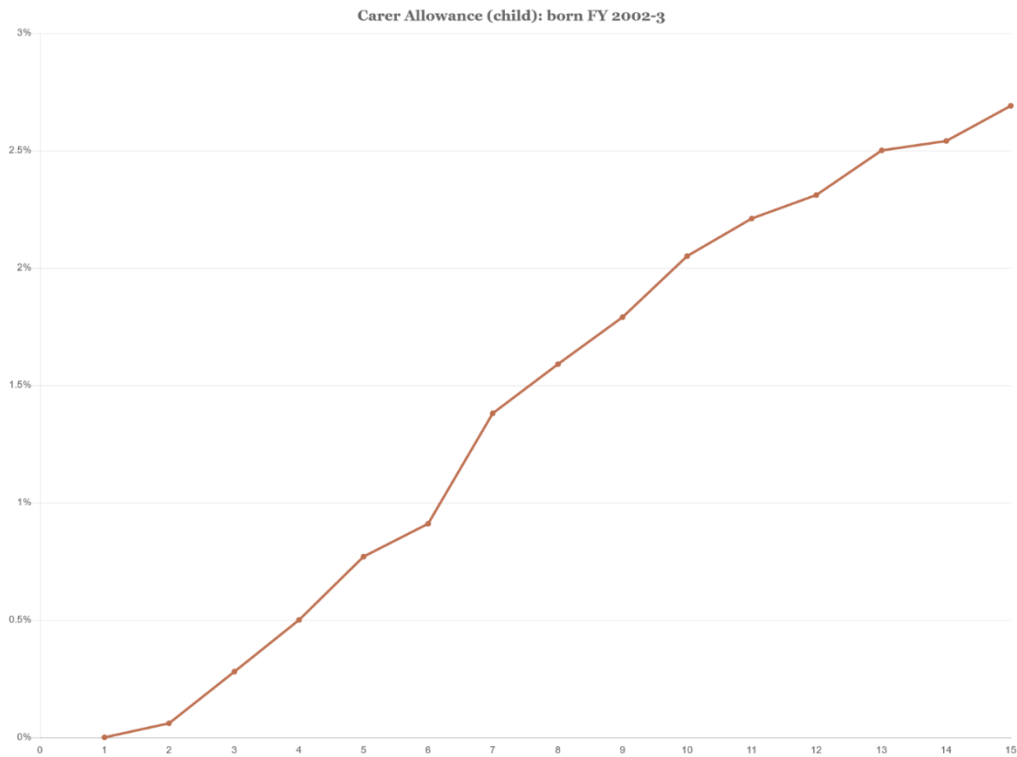


Figure 13. Diagnosis rate (percentage) by age for year of birth 2003.

Figure 14 below shows how the age of diagnosis varies over time.

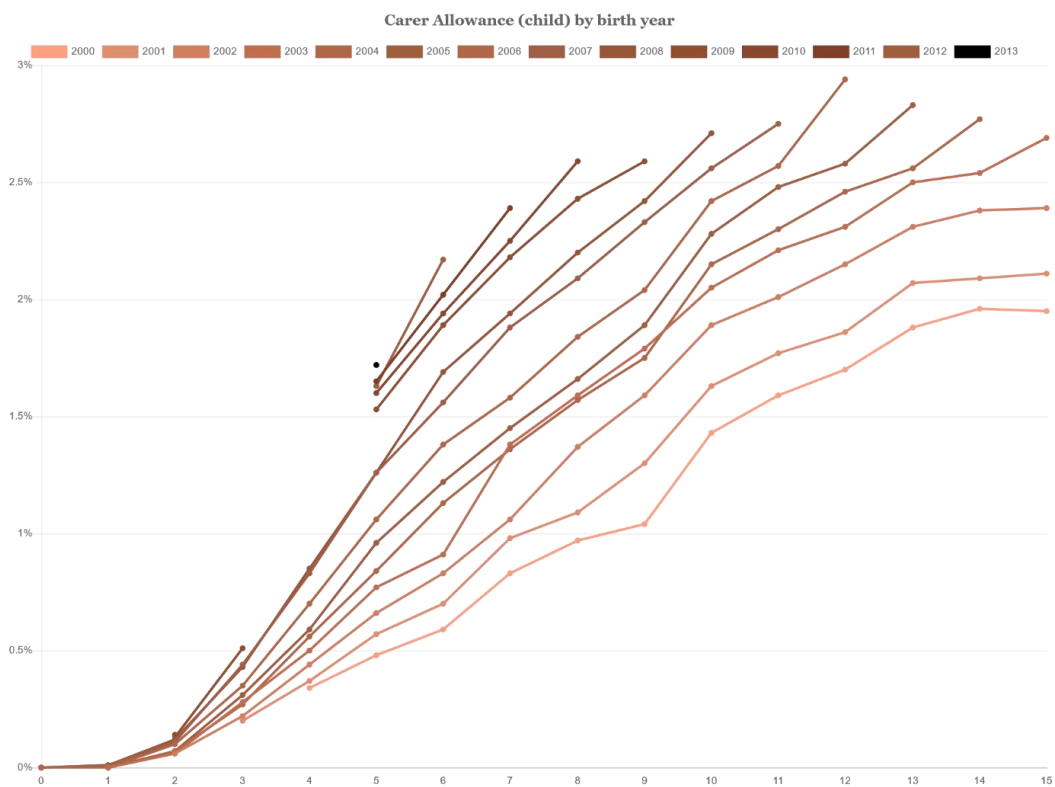


Figure 14. Diagnosis rate (percentage) by age for year of birth.

A notable feature of this chart is the small fraction of autistic children who are diagnosed in time to access government funding for early intervention. Substantially less than half the autistic children born in any year are diagnosed by age 7 years when early intervention funding cuts off⁵.

Subsequent analyses include:

differences between the states and territories

diagnosis rates from females and males

ASD and Carer Allowance history

From the outset, children with Autistic Disorder were eligible for Carer Allowance (child). In 2004, A4 negotiated eligibility for children with a diagnosis of Asperger's disorder.

In Dec 2006, A4 published a short analysis of the data it received from the Centrelink database on Carer Allowance (child) (see [2006, Update Issue No. 7](#)). Soon after, AABASD also produced a report and a research paper⁶ using these data.

During the planning of the Helping Children with Autism package, A4 worked closely with FaCHSIA (now DSS) staff to understand the population of autistic children.

ASD data from the ABS SDAC and Carer Allowance (child)

Data from these two sources at the same can be compared.

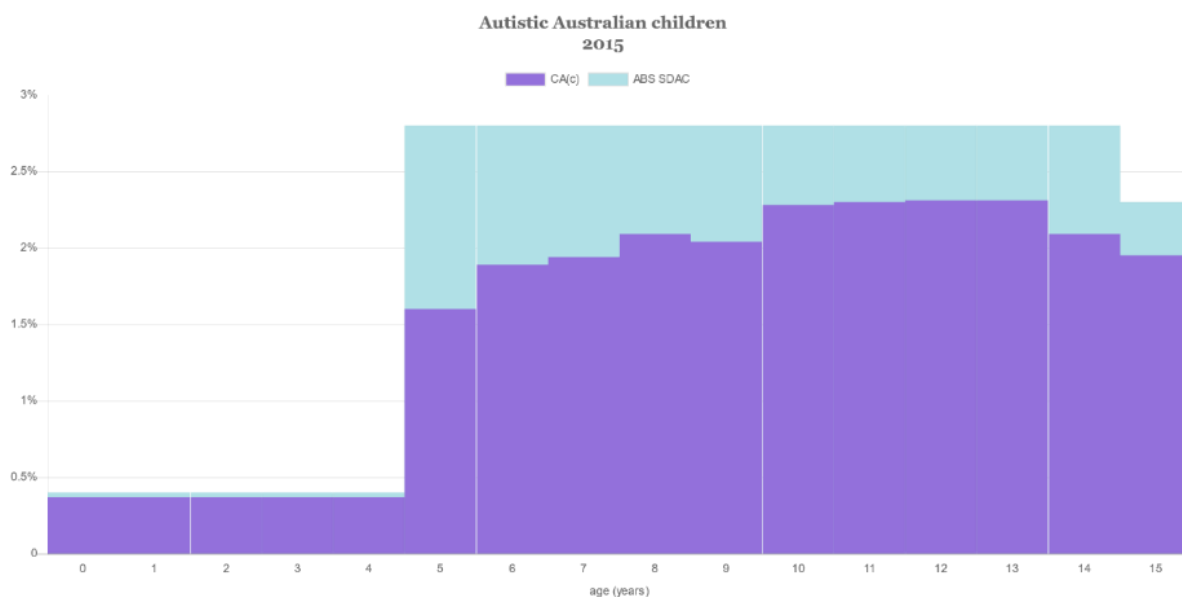


Figure 15. Reported diagnosis rates by age from ABS SDAC and Carer Allowance (child) in 2015

⁵ This may change; the NDIS is lifting the age to 9 years inline with WHO guidelines.

⁶ Williams K , MacDermott S , Ridley G , Glasson EJ , Wray JA: The prevalence of autism in Australia: can it be established from existing data? *J Paediatr Child Health* 2008; 44:504–510
<https://onlinelibrary.wiley.com/doi/10.1111/j.1440-1754.2008.01331.x>

The following table compares the data from these sources for the age range 5-14 years.

	ABS SDAC '000s	ABS SDAC rate	Carer Allowance (child) '000s	Carer Allowance rate
1998	10.5	0.399%		
2003	19.0	0.704%		
2004			12.163	0.450%
2005			13.891	0.513%
2006			16.786	0.620%
2007			20.203	0.745%
2008			24.210	0.891%
2009	38.6	1.413%	28.721	1.051%
2010			34.021	1.240%
2011			39.443	1.421%
2012	59.4	2.114%	44.807	1.595%
2013			49.162	1.723%
2014			55.896	1.929%
2015	81.3	2.759%	61.191	2.076%
2016			67.313	2.245%
2017			71.878	2.349%
2018	99.3	3.218%	78.565	2.545%
2019			79.098	2.513%
2020			88.977	2.799%
2021			93.437	2.911%

Table 5. ABS SDAC rates vs Carer Allowance (child) data

Figure 16 below shows these figures in graphical form.

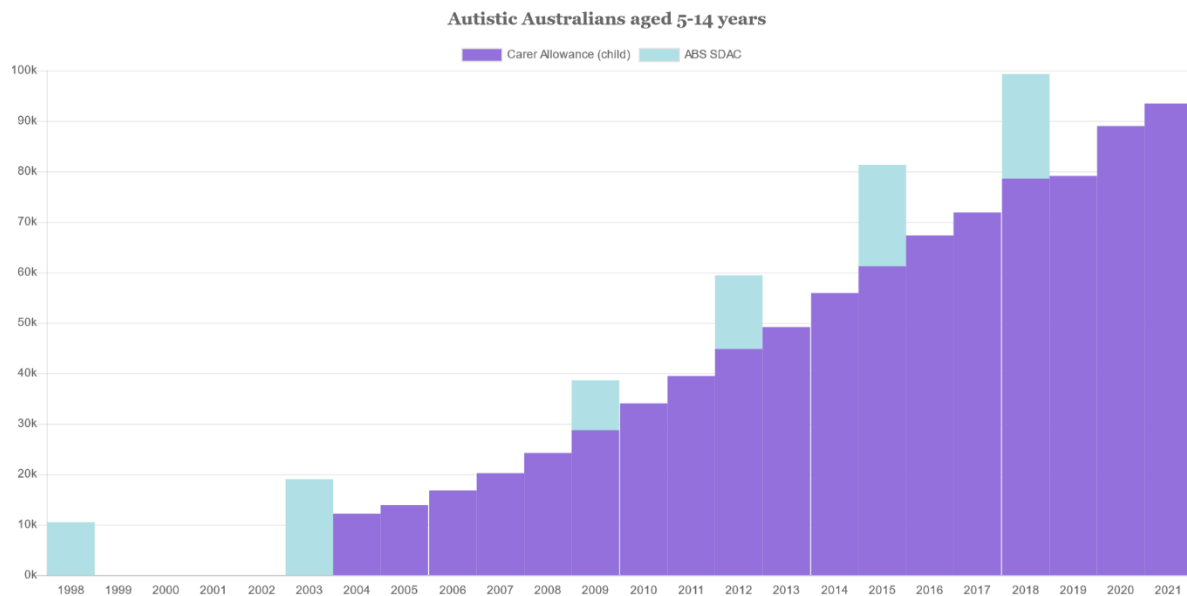


Figure 16. ABS SDAC and Carer Allowance (child) — autistic Australians aged 5-14 years

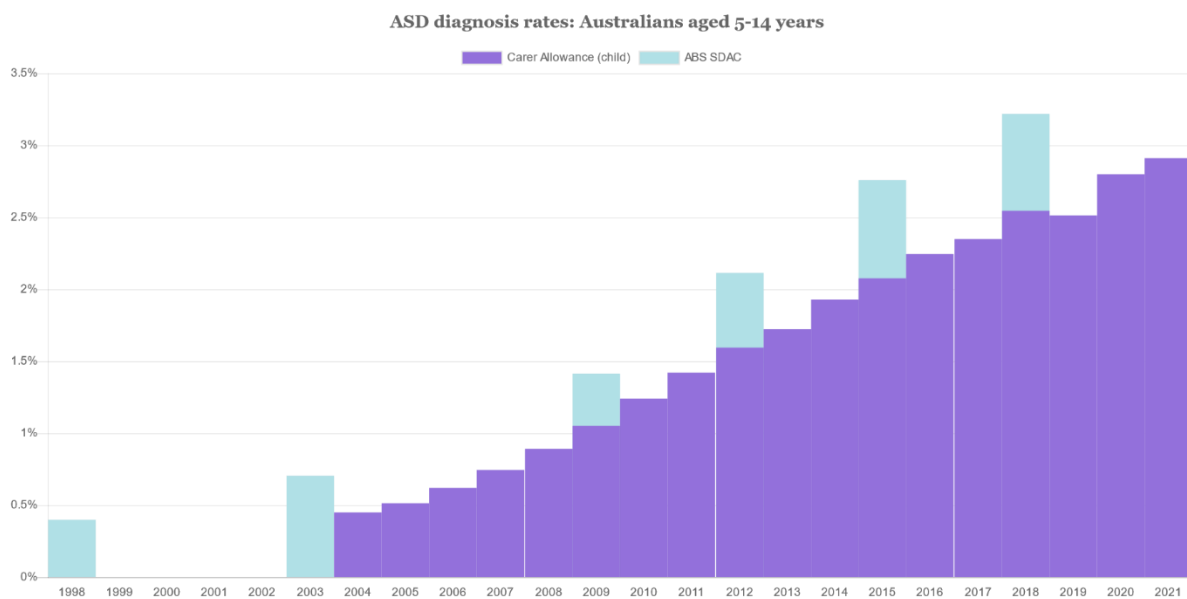


Figure 17. ABS SDAC and Carer Allowance (child) — ASD diagnosis rates for Australians aged 5-14 years in 2015

Juxtaposing these data shows their resemblance. The shape and the scale of growing ASD diagnoses in both these datasets are similar. It seems that not every family of a child they identify as autistic decided to register for Carer Allowance (child) or completes the registration process successfully.

A chart of the growth in the diagnosis rates makes the pattern of growth in the data sets clearer.

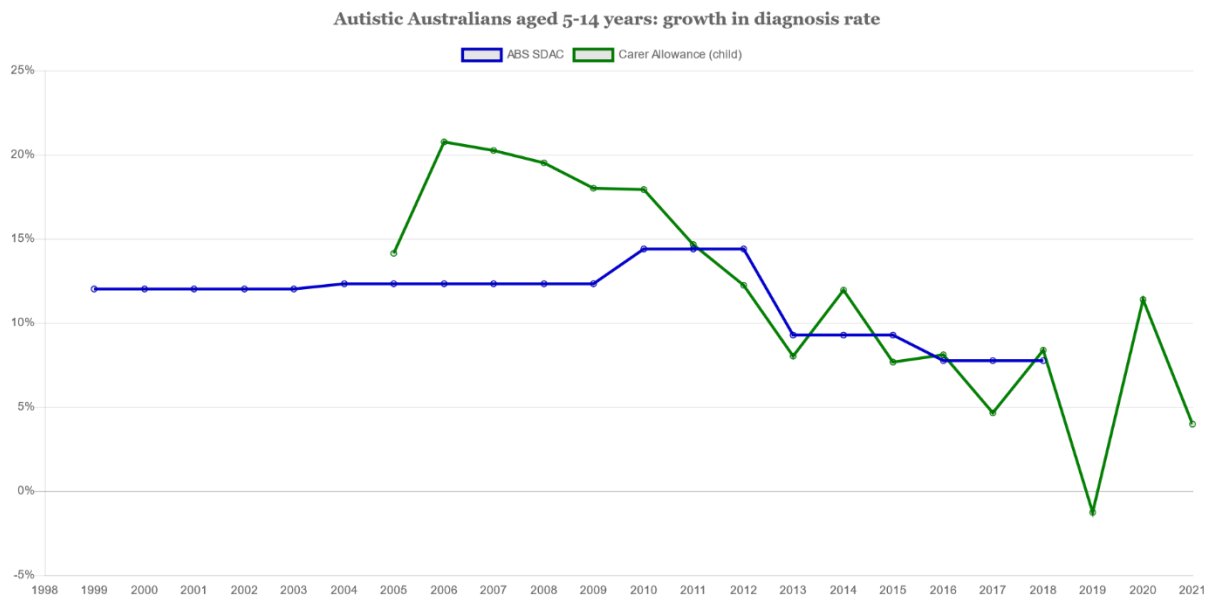


Figure 18. ABS SDAC and Carer Allowance (child) — annual growth

ASD in Australia's states and territories

Table 6 below shows ABS SDAC 2015 percentage results for autistic people in the population of each state for all ages. These data show very rough relative proportions only.

Autism by state ABS SDAC 2015	
ACT	0.6%
NSW	0.6%
NT	0.6%
Qld	0.8%
SA	1.0%
Tas	1.0%
Vic	0.8%
WA	0.5%

Table 6. ABS SDAC 2015 rough proportions of Autistic Australians by state/territory

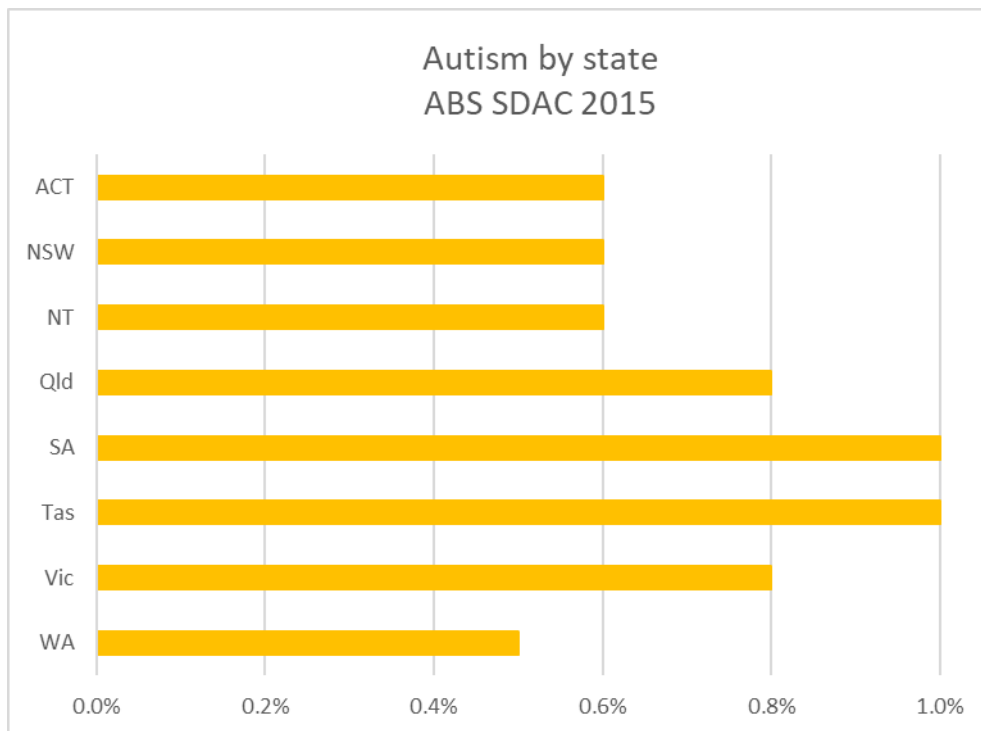


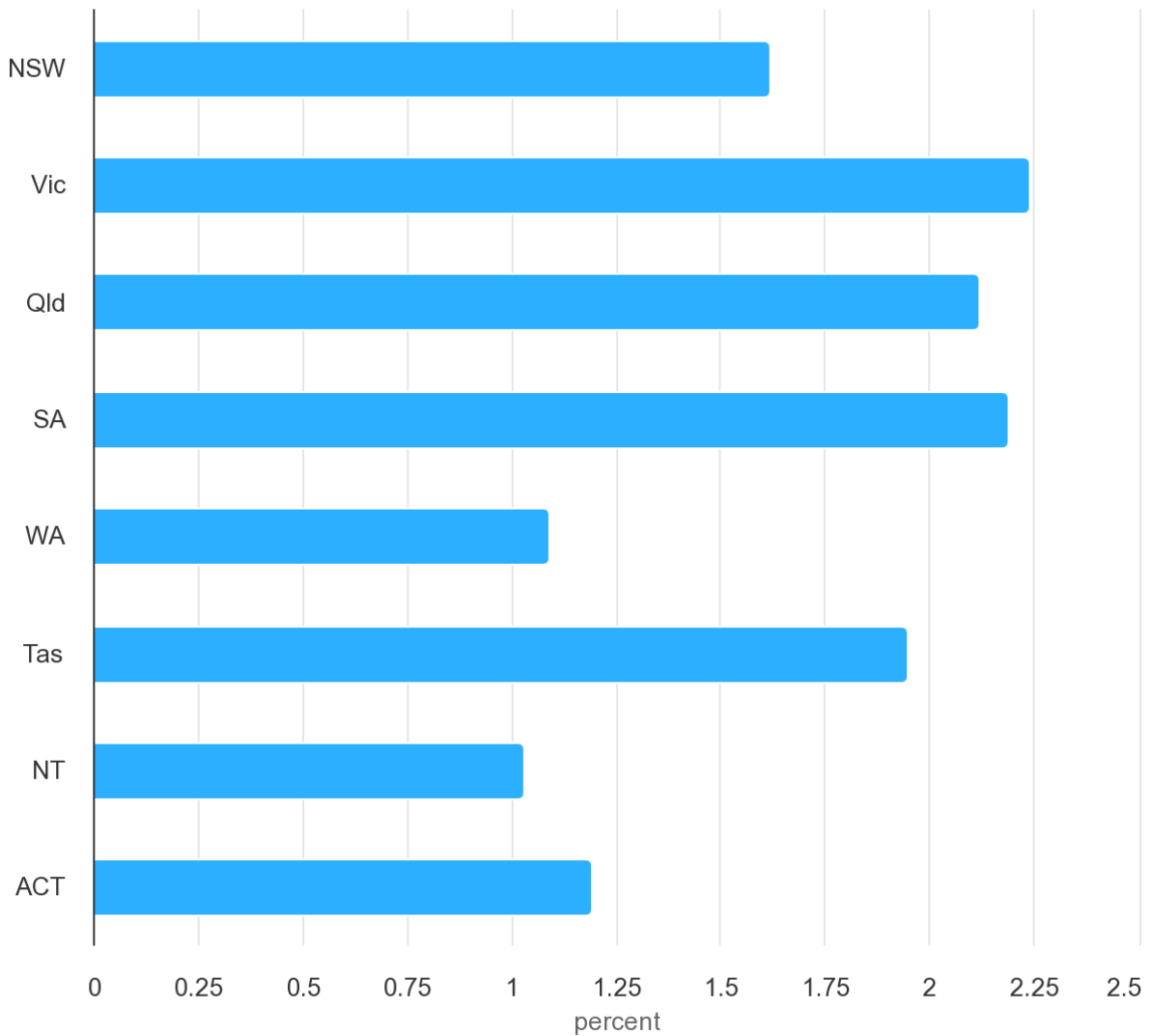
Figure 19. Percent of autistic Australians in each state/territory.

Different datasets show the substantial differences in ASD diagnosis rates between the different Australian states and territories.

Carer Allowance (child) data is population data for children aged 0-15 years for children registered to receive Carer Allowance (child) with Autism Spectrum Disorder (DSM-5), Autistic Disorder (DSM-IV) or Aspergers Disorder (DSM-IV).

Percent per state/territory

Carer Allowance (child) - 2018



Highcharts.com

Figure 20. Percent autistic Australian children receiving Carer Allowance (child).

In 2018, NDIA officials estimated that autistic NDIS participants would be 20% of the full NDIS roll-out. But so far (as at October 2018), NDIS data published in the NDIS Quarterly Reports Year 5 Q1 indicate 29% nationally of participants are autistic.

The following shows different rates of autistic NDIS participants in the different states & territories.

Percent per state/territory - Y8 Q1 (Sep 2020)

NDIS Participant plans - primary disability: autism

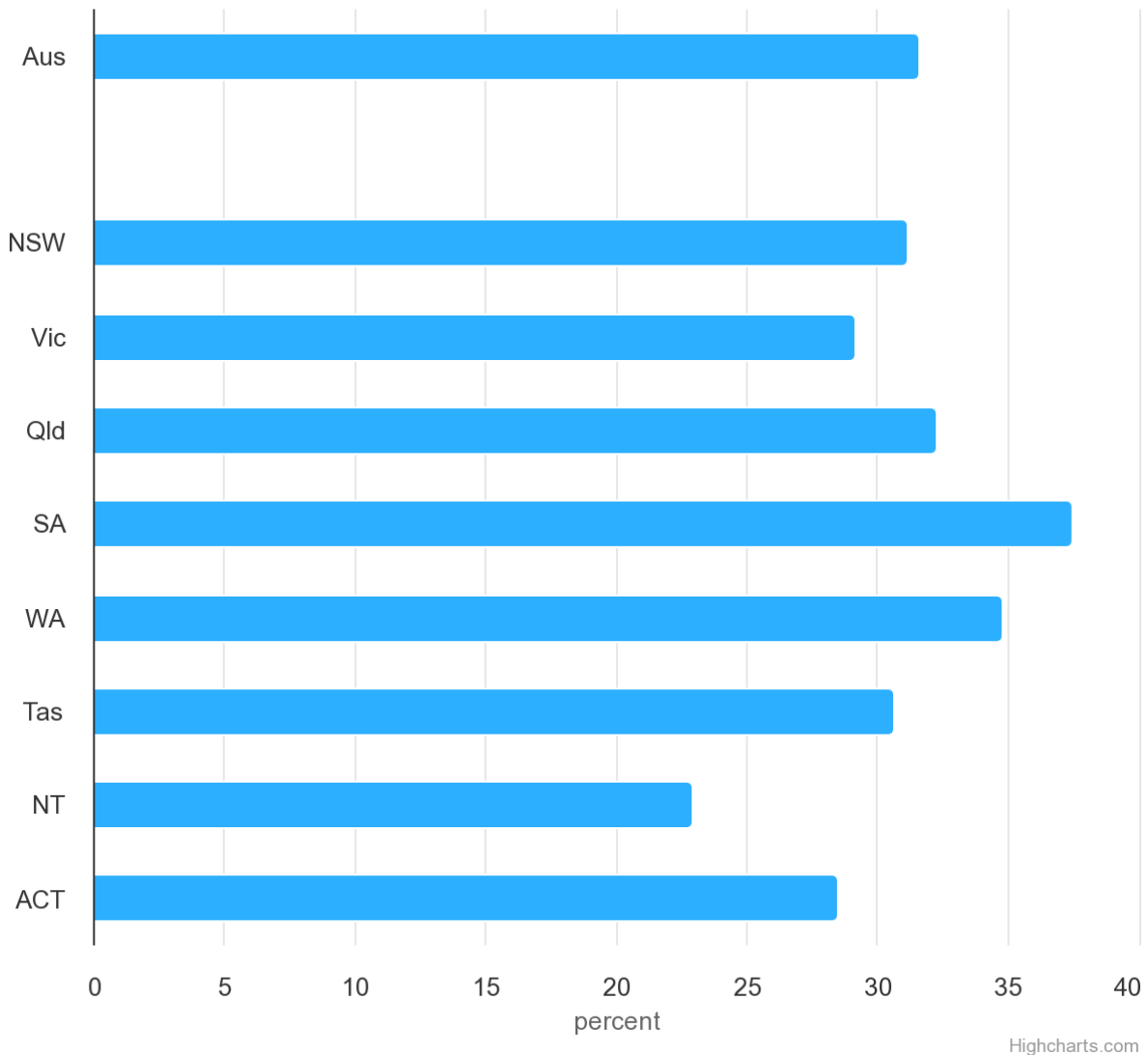


Figure 21. Percent of NDIS participants with primary disorder/condition is ASD.

At this stage, the NDIS has been rolled out for around 65% of Australians. The roll-out strategy may affect the distribution in some states.

The differences between states in the above figures deserve analysis.

Autistic women and girls

Concerns have been expressed about under-diagnosis of autistic women and girls. Figure mf-fig1. below shows the recent increase in ASD diagnoses for Australian women and girls. 20% female is a 1:4 female:male ratio.

A 1:3 female:male ratio, with over 25% of Autistic Australians are female, was exceeded for Autistic children aged 0-15 years by mid-2021.

The two main sources of ASD data sometimes includes this type of information.

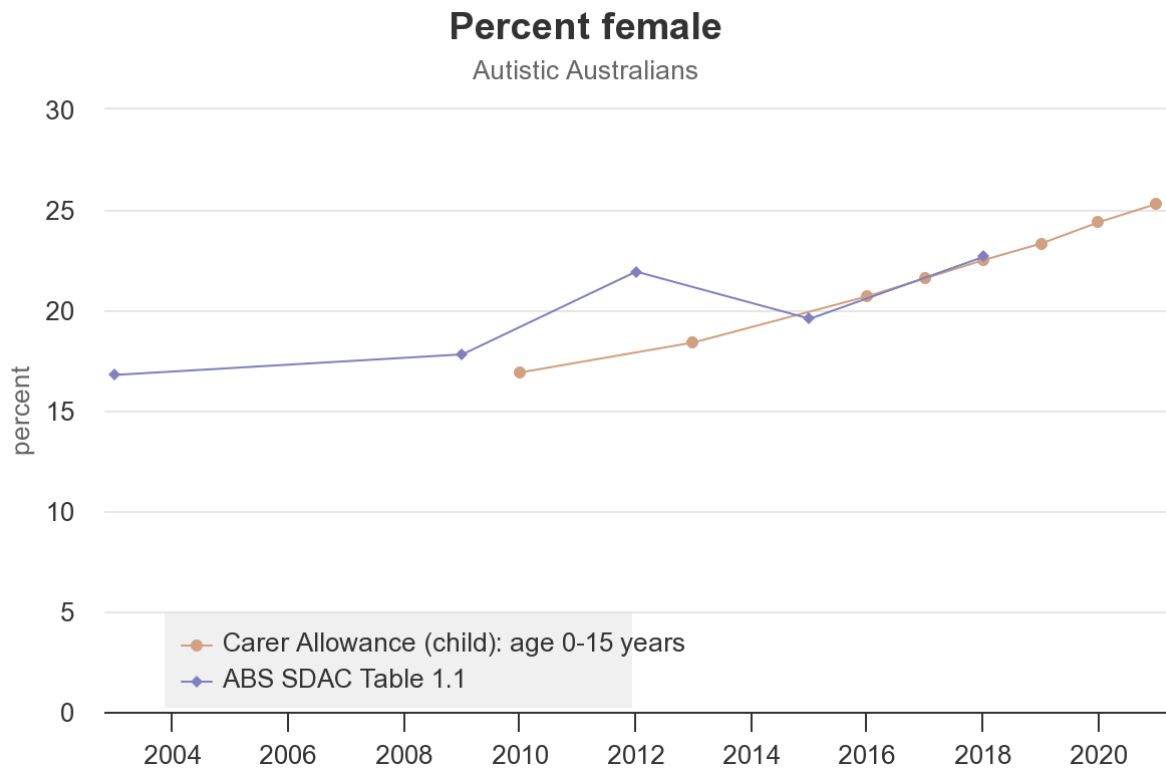


Figure 22. Percent Autistic female Australians – ABS SDAC vs Carer Allowance (child) by year.

Note: the apparently higher rate in the ABS SDAC data for 2012 looks anomalous.

Female percentage by state/territory.

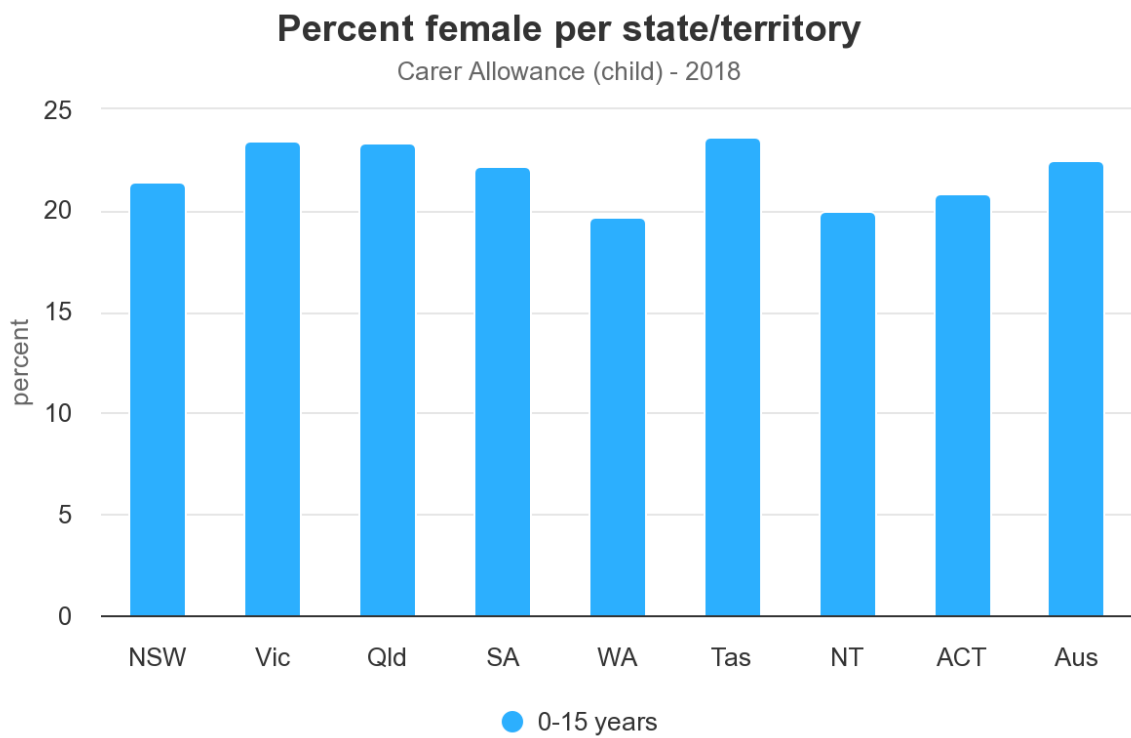


Figure 23. Percent Autistic females Australians by state - 2018.

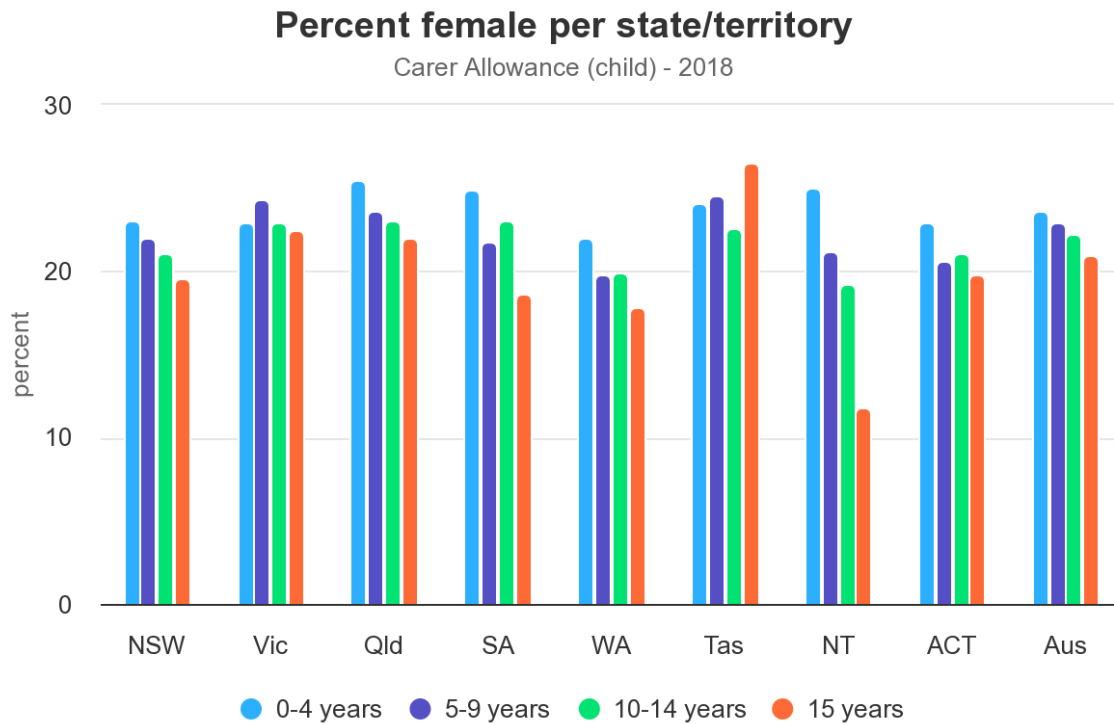


Figure 24. Percent Autistic females Australians by state and age band.

Figure 24 above suggests that most states/territories also see increasing diagnosis of girls over time - the percentage of younger girls is higher.

See also:

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4164392/>
- <https://www.autism.org.uk/about/what-is/gender.aspx>
- <https://www.autismawareness.com.au/could-it-be-autism/autism-and-girls/>

Autistic NDIS participants

At 34.77%, autism has surprised the NDIA by emerging as the most numerous primary disability type in the NDIS (Dec 2022).

Primary disability	Participants	rate
ABI	17385	3.03%
Autism	199367	34.77%
Cerebral Palsy	17468	3.05%
Developmental delay	56811	9.91%
Down Syndrome	11595	2.02%
Global developmental delay	13312	2.32%
Hearing Impairment	25615	4.47%

Intellectual Disability	87212	15.21%
Multiple Sclerosis	9938	1.73%
Other	7361	1.28%
Other Neurological	21811	3.80%
Other Physical	19633	3.42%
Other Sensory/Speech	2154	0.38%
Psychosocial disability	59512	10.38%
Spinal Cord Injury	5697	0.99%
Stroke	8592	1.50%
Visual Impairment	9877	1.72%
total	573340	100.00%

Table 7. NDIS participants - primary disability - December 2022

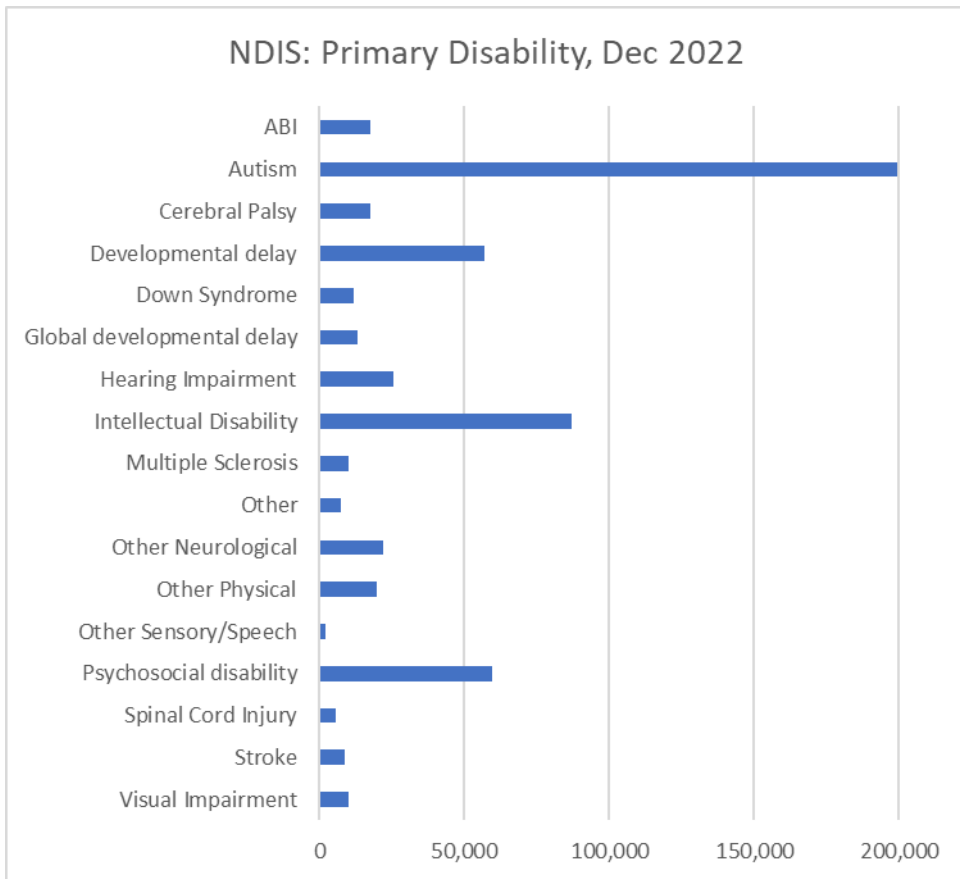


Figure 25. NDIS participants - primary disability - December 2022

While autism is the biggest primary disability type in the NDIS, it is not the biggest contributor to overall NDIS Plan commitment in dollar terms. Table 1 below contrasts participant numbers with their NDIS Plan budgets for the two biggest disability types in the NDIS.

	participants	Plan Budgets
Autism	34.8%	19.2%
Intellectual Disability	15.2%	24.1%

Table 8. Participant numbers vs Plan Budget

The remarkable difference between the share of NDIS participants and their plan budgets is due to differences in the age profile and costs of plans at the different ages.

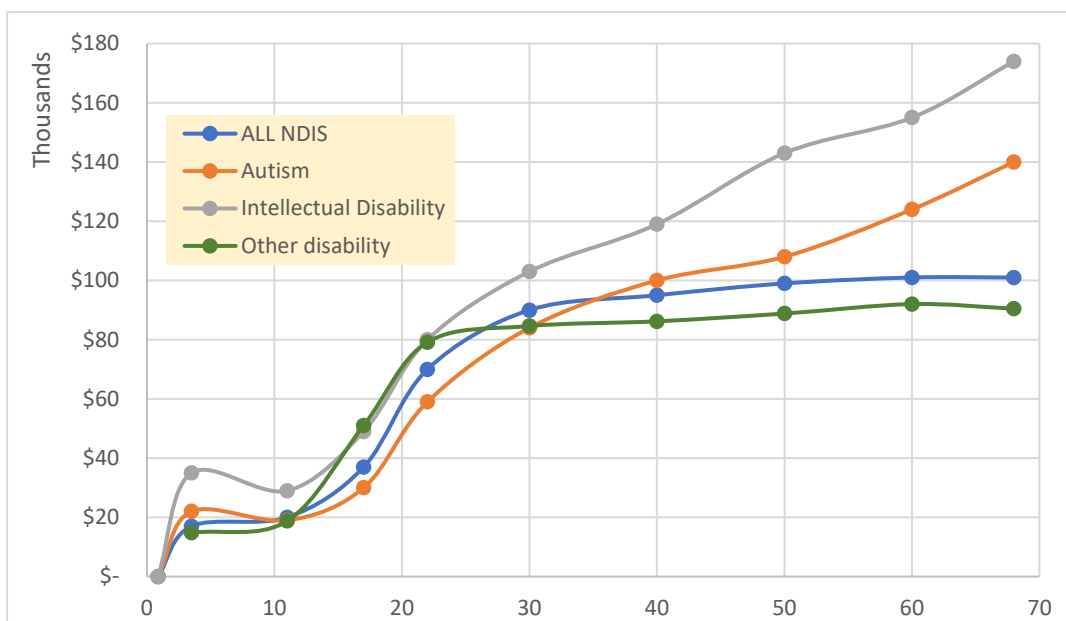


Figure 26. NDIS Plan budgets by age (years) December 2022

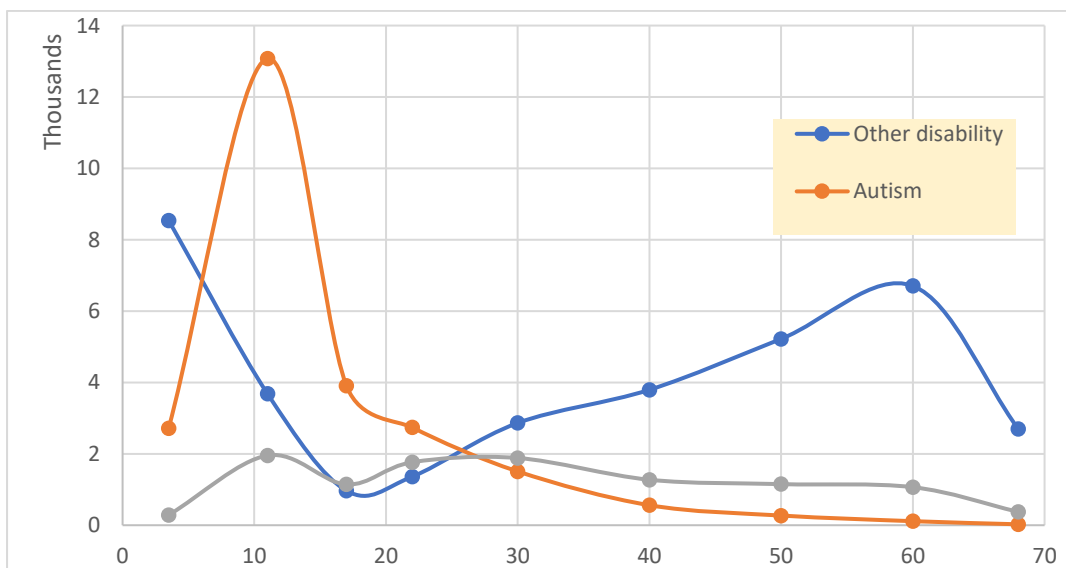


Figure 27. NDIS participant numbers by age (years), December 2022

A4 expects that:

- around 30% of autistic NDIS participants also have an intellectual disability;
- there are autistic people who list other disabilities as their primary disability; and
- a significant percentage of adults with intellectual disability are undiagnosed autistics.

The large numbers of young ‘other’ disability types is due to the Developmental Delay (DD) and Global Developmental Delay (GDD) categories that are only applicable up to ages 6 and 5 years respectively.

These data suggest that most children diagnosed initially with DD or GDD are subsequently diagnosed as autistic. This suggests that more effort put into early diagnosis would achieve better outcomes.

The proportion of autistic NDIS participants varies between states.

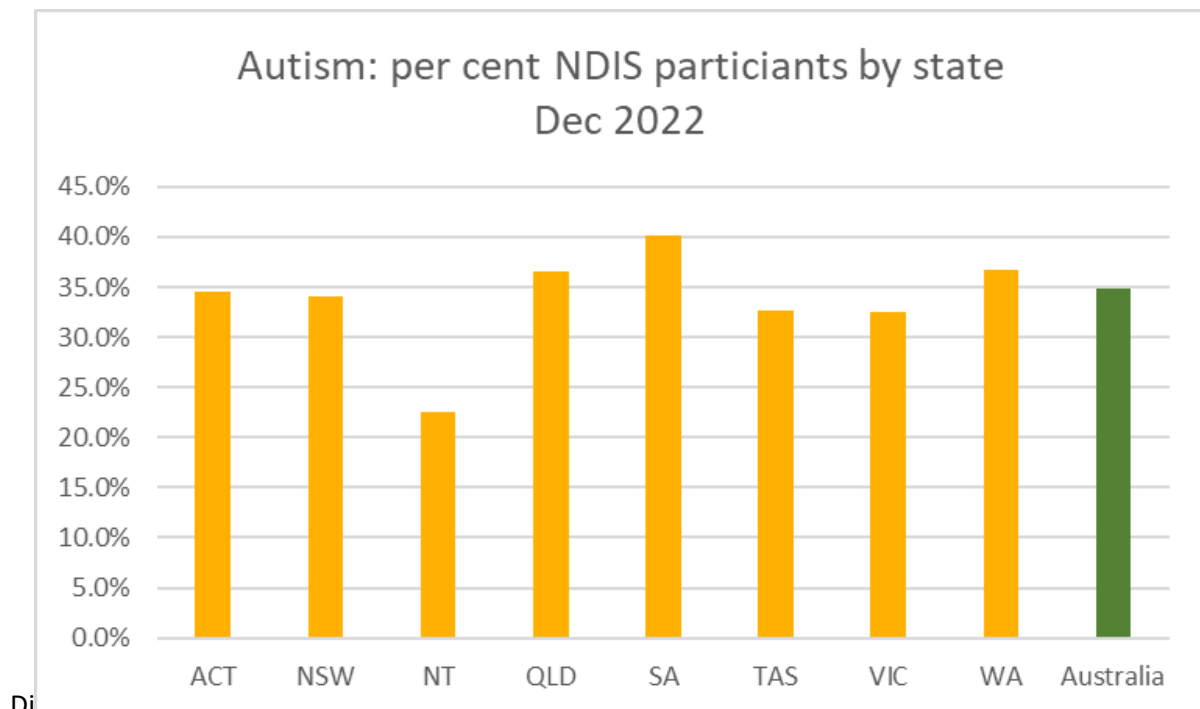


Figure 28. Autistic NDIS participants by state, December 2022

Autism prevalence research and commentary

The research literature contains various reports on the prevalence and incidence of autism. The methods used to collect data vary. Few provide population data.

If one accepts that autism is associated with a person’s neurology, then it does not change through the person’s life. If the neurology were known and could be identified (perhaps through genetic indicators), then theoretical incidence is just the birth rate needed to achieve the prevalence of autism in the population.

Australia

In addition to the information above, reports of autism prevalence in Australia are variable.

There are other data sources described in the research literature.

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Gaps in understanding autism

The above material does not provide adequate information on the health, well-being, and life outcomes for Autistic Australians. There is insufficient information about where Autistic Australians live, what happens to them in Australia's when they are embroiled in Australia's injustice systems, or in emergencies. Information given to the Disability Royal Commission suggest that outcomes in all these areas are unsatisfactory.

Education and employment policy and programs might be improved though more detailed understanding of how autistic people are affected in those contexts. Basically, better data is likely to contribute to better policy and programs.

The developing National Disability Data Asset (NDDA) faces a substantial challenge to report on the lives of Autistic Australians and to fill in the gaps in existing data sources.

Conclusions

In Australia:

- numerous sources of data describing an Autistic population. There is a level of agreement between some of the data sources.
- autism diagnosis rates are increasing significantly.
- diagnosis rates for adults are much lower than for children.
- average age of autism diagnosis in children is above 6 years of age.
- diagnosis rates observed vary substantially with time and differ by age, gender and state/territory. Estimating a single figure for autism prevalence in Australia's population is misleading: such a figure ...
 - does not represent prevalence in either children or adults and
 - will be out of date quite quickly.
- gaps in data describing autistic lives need to be addressed so that policy and programs to improve well-being are shown to be effective.