



Brief on Autism Spectrum Disorder for federal politicians

ASD-related issues for Commonwealth Government

Autism Spectrum Disorder (ASD) is biggest distinct disability among NDIS participant – see Annex below. Generally, the number of people diagnosed with autism continues to increase. The Australia Bureau of Statistics (ABS) found that 2.8% of children aged 5-14 years had autism¹ in 2015. The substantial growth in autism numbers continued from previous survey datasets.

At 2.8% of children, ASD is now more prevalent than Intellectual Disability among Australian children. A4 expects 30-50% of autistic people also have Intellectual Disability.

Other data sources, for example Carer Allowance (child) data from DSS (see the Annex below), also show comparable growth in ASD diagnoses.

The overall cause of growing numbers of ASD diagnoses is unknown. Some of the growth is due to increased awareness of ASD. But this may not be the only reason².

The ABS data suggest chronic underdiagnoses of autistic adults also continues. Under-diagnosis of adults means that many autistic adults do not get the support they need; support that would substantially improve their outcomes and their contribution to the community.

ASD is a distinct disability: it presents quite differently from other disability types. It is not a subtype of intellectual disability. Hiding ASD in a “complex needs” category does not help improve outcomes.

Data shows most autistic Australian experience abysmal outcomes. Most autistic people need supports that address their specific ASD-related needs. Mostly, ASD-specific supports cannot be accessed simply because they do not exist ... and the arrival of the NDIS has eliminated some of the supports that previously existed, for example *Autism Asperger ACT*.

In the past, “autism” was regarded as rare so ASD-specific services didn’t exist. Increasing ASD diagnoses has not resulted in funding for increased ASD-specific services. ASD is not included in much of the disability sector, e.g. Paralympics, funding for peak body, ...

¹ See <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>

² <http://a4.org.au/node/423>

Following are twelve issues that especially affect autistic people. They are not in any particular order. The first step is to recognise issues. Recognising an issue costs nothing.

1. NDIS and Autism Spectrum Disorder (ASD)

The latest NDIS Quarterly Report shows that 29% of NDIS participants nationally have “autism” as their primary disability. Senior NDIA officials tell Government that they expect “autism” will drop to 20% of NDIS participant by full roll-out ... but the NDIS “autism” rate hasn’t decreased through the roll-out.

NDIS officials underestimated the number of autistic NDIS participants from the outset. They choose to ignore advice that their modelling under-estimates significantly ASD diagnosis numbers. They have yet to recognise the ongoing growth in ASD diagnoses and how it affects the NDIS’s future.

NDIS staff and their workforce have a poor understanding of ASD. Families have reported NDIS officials and representative telling them:

- “the NDIS doesn’t support autism anymore”
- “[evidence-based or best practice] early intervention for ASD doesn’t work”, or
- “the NDIS does *not* fund [evidence-based or best practice] early intervention for autistic children”.

Families observe that NDIS eligibility and planning processes are badly uninformed, sometimes misinformed, about ASD.

a) NDIS eligibility for autistic people

The NDIS has ignored the ASD community over the eligibility issue from the outset: the NDIS eligibility criteria are gobbledygook. For a long time, the NDIS refused to acknowledge the issue.

Then the NDIS had an alarming episode over its alleged “ASD eligibility mistake” culminating in a letter from the Minister (your ref. [MS18-000877](#)).

Since the “mistake”, senior NDIA officials acknowledged the DSM-5 (not the DSM-V) description of an ASD diagnosis requires two, not one (as the NDIS List A indicates), severity levels. But the NDIA still has no proposed change to the NDIS eligibility for ASD, and no discernible progress towards change. The NDIA has not proposed any alternative wording to its existing gobbledygook.

A4 has advised the NDIA of numerous reports from families of incorrect statements about NDIS representatives and intake officials about the eligibility of autistic people. Again, there is no discernible activity or change to improve or rectify the NDIS’s eligibility criteria for autistic people.

b) Stakeholder engagement

Following the alleged “eligibility mistake”, the Minister (at the time) promised to ensure consultation about changes to the NDIS operation relating to ASD. The NDIS broke the Minister’s promise within days³.

³ See <http://a4.org.au/node/1762>

A4 would like to know whether the new Minister remains committed to consultation with the ASD community.

The major stakeholder engagement relating to ASD is the Autism Advisory Group (AAG) announced on 19th June 2018. That it took so long, and needed substantial community response to the NDIS's "mistake", shows the Government's disinterest in engaging with the ASD community.

As yet, there is no discernible outcome from the AAG and its agenda.

A4 has also been working with the NDIA towards improving engagement. There have been a number of meetings. But again, there is no discernible outcome. Senior NDIA officials asked for "trust and respect" from A4. However, this is difficult for A4 when our concerns remain unaddressed and the NDIS often provides incorrect information.

c) Lacking support for severe and profound ASD

The lack of appropriate disability services for autistic people is most notable for autistic people who are severely or profoundly affected by their autism.

Some notable issues and examples include:

- A family resorting to crowd funding support for their son
- Ongoing and unsupervised restraint of a young man in a regional NSW hospital for more than 200 days.
- massive cuts to funding for an extremely challenging autistic child in the ACT because the funding was "outside the statistical norm".
- lack of recognition of behaviour supports for autistic NDIS participants.

d) Poor training in ASD means poor understanding and inadequate plans

A4 has reports of massive inconsistency in how NDIS officials plan for autistic NDIS participants.

We had reports that an NDIS representative met an access request with the claim that "the NDIS doesn't support autism any more" ... which is clearly wrong.

e) Early Intervention

NDIS officials show poor understanding of early intervention for autistic children.

Despite numerous promises, the NDIS has not shown us any new pathways for autistic children trying to access best practice, evidence-based or appropriate early intervention for their ASD.

Families of vulnerable autistic children are often unwilling to challenge officials. The NDIS shut down the Autism Advisors so few families can access accurate and comprehensive advice about evidence-based practice for autistic children. Many families simply accept seriously inadequate early intervention plans because they are not prepared to ensure the review processes.

The NDIA claims it adheres to "insurance principles" yet it resists funding best practice early intervention for autistic children that substantially reduces life-long costs for autistic people.

The pathway to best-practice for autistic children is via the AAT's conciliation process that precedes an AAT review of NDIS planning.

Families who seek review of uninformed NDIS planning decisions are subject to unreasonable and detrimental delays that typically deny children essential early intervention. And they are made targets and victims by the adversarial and acrimonious legal process.

A4 was promised an AAT review of delays in their process. That did not happen. It is another broken promise.

2. Behaviour support

Behaviour support is a major issue for autistic people and their families.

Australia does not train its clinicians appropriately in behavioural practices. And there is no formal registration regime for behavioural clinicians.

Monitoring the use of restraint is meant to be a responsibility of the new NDIS Quality & Safety Commission ... however, A4 reported that a young autistic man is being restrained in a NSW regional hospital. The NDIS Quality & Safety Commission wrote back saying that the hospital told them they are looking after the young man. This is a *very* inadequate response.

Lack of support in mental health for people with ASD.

3. Inquiry into abuse and neglect of people with disability

Autism Aspergers Advocacy Australia is deeply disappointed that the Government refuses to conduct an inquiry into abuse and neglect of people with disability.

The Government's NDIS Quality and Safety Commission is *not working* and seeks to address only part of the issue.

4. Lack of diagnosis and support for autistic adults

Data suggests ASD is massively under-diagnosed in Australian adults (see Annex below): "it is not unusual for people on the autism spectrum to have reached adulthood without a diagnosis"⁴.

While there are Medicare items that help some families fund diagnosis of an autistic child, funding cuts out for adults. Yet the evidence shows that many autistic adults are undiagnosed. Which means they cannot access the services and supports they need for their ASD.

5. Supporting autistic mothers and parents

There is emerging evidence that autistic mothers are especially likely to be undiagnosed.

Autistic mothers report that they do not get the support they need. Clearly, this is a growing part of the disability sector, yet there is no discernible response from Government to the needs of autistic mothers.

There are reports of authorities targeting autistic mothers. Authorities expect that autistic mothers are not competent instead of offering the supports

⁴ See <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/autism-spectrum-disorder-and-adults>

autistic mothers need to succeed as mothers and generally in the community. Many authorities disrespect autistic women.

6. Out-of-home care for autistic children

Autistic children who are removed from their parents and families need much better support than is currently provided.

7. Disability Supports for autistic NDIS non-participants

The NDIS operational guidelines expect that autistic people with Level 1 severity (but an ASD diagnosis has 2 severity levels) will be subject to further “functional assessment”.

The NDIS rejects expert opinion from the diagnosing clinician who typically has substantially more expertise in ASD than NDIS representatives and, by diagnosing ASD, indicates the diagnosed autistic person needs support for their ASD.

The NDIS uses the PEDI-CAT to do the “further assessment”. The PEDI-CAT is widely reported as inappropriate for assessing autistic people yet the NDIS insists on its continued use for autistic applicants.

Supports for autistic people who are ineligible for the NDIS are under stress. The NDIS ended *Autism Asperger ACT*. Other state autism groups are under stress.

Government expects mainstream services to meet the needs of autistic people who are not eligible for the NDIS. Government ignores the fact that no such services exist: mainstream services like health, education, employment, etc. do not address the needs of autistic people. The Government refuses to engage in sector development so autistic people, more than most, are denied the services and supports they need.

8. ASD-specific advocacy

The Government’s National Disability Advocacy Program does not provide any advocacy services for autistic people. Instead, it offers generic advocacy.

Unfortunately, advocates in the program have little actual knowledge of autistic people and their needs. For example, they advocate for early intervention aimed at generic disability rather than best practice early intervention for a child’s ASD. Generic early intervention for disability is ineffective most autistic children; evidence shows its outcomes are well short of best practice early intervention for autistic children. Time spent on generic early intervention is a detriment to an autistic child as they are not getting essential services for their ASD.

While Government funds a number of disability peak bodies, it has never funded a national peak body for autism/ASD ... even though autism is the biggest distinct disability in the NDIS.

9. Education support

Reports of the education outcomes for autistic students remain especially poor. Continued refusal to ensure autistic students can access properly trained and registered behaviour specialists in school ensures many autistic students have particularly poor education outcomes.

Most schools are reluctant to accept specialist advice. Those that do often reject the advice or are just unable to implement it.

10. Employment support

The ABS has reported repeatedly that autistic adults, those who are diagnosed, have especially poor employment outcomes.

Disability employment programs do not address the needs of autistic people for employment services and supports.

11. ASD, health and mental health

Parents of autistic children often report that their children experience difficulty accessing health services. Services are not set up to provide health services generally for autistic people. Parents are encouraged to take their children home early.

While there was an increased awareness of issues for people with Intellectual Disability and mental illness starting in the mid-1990s, there has been no recognition that autistic people with mental illness need services for their mental illness. Many mental health services simply refuse to admit or treat autistic patients.

12. Autism research

Research funding for the disability sector is grossly inadequate. Given the cost to Government and the community, more effort needs to go into improving the cost/benefit model for the whole sector.

The disability sector needs substantially increased funding and something like the NHMRC or the ARC guiding disability research.

Conclusion

Autistic people a major part of the disability sector. The number of people diagnosed with ASD continues to increase substantially. Services for autistic people were never adequate and continued growth in numbers stretches the limited services further.

Governments continue to ignore the substantial needs of autistic people. The result in unacceptably bad outcomes for autistic people in health, education, employment and community participation.

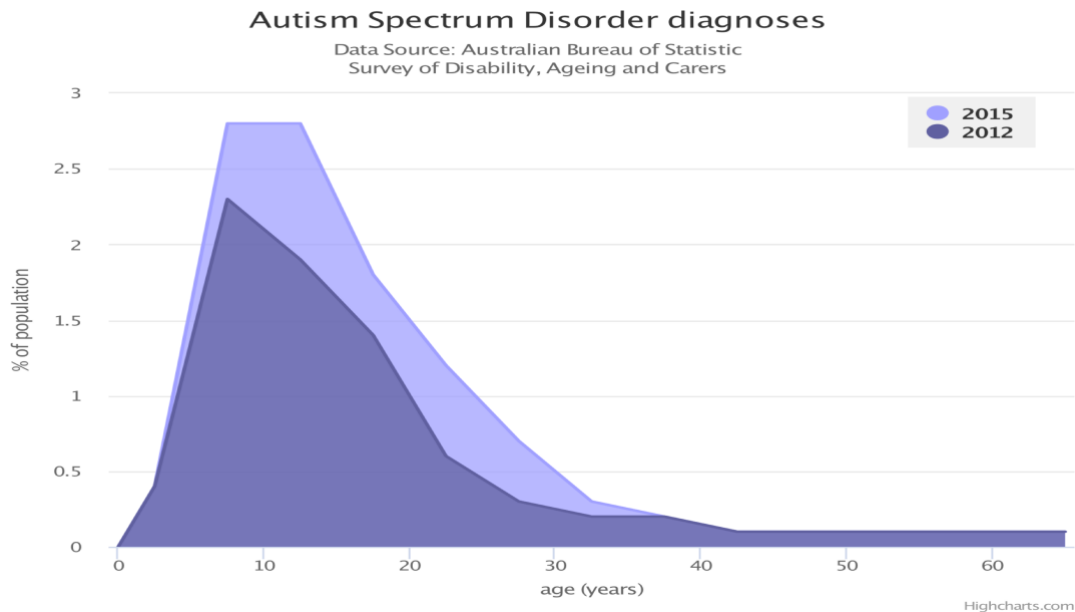
Government must recognise that autistic people need better outcomes through targeted programs.

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10/12/2018

Annex A – Data

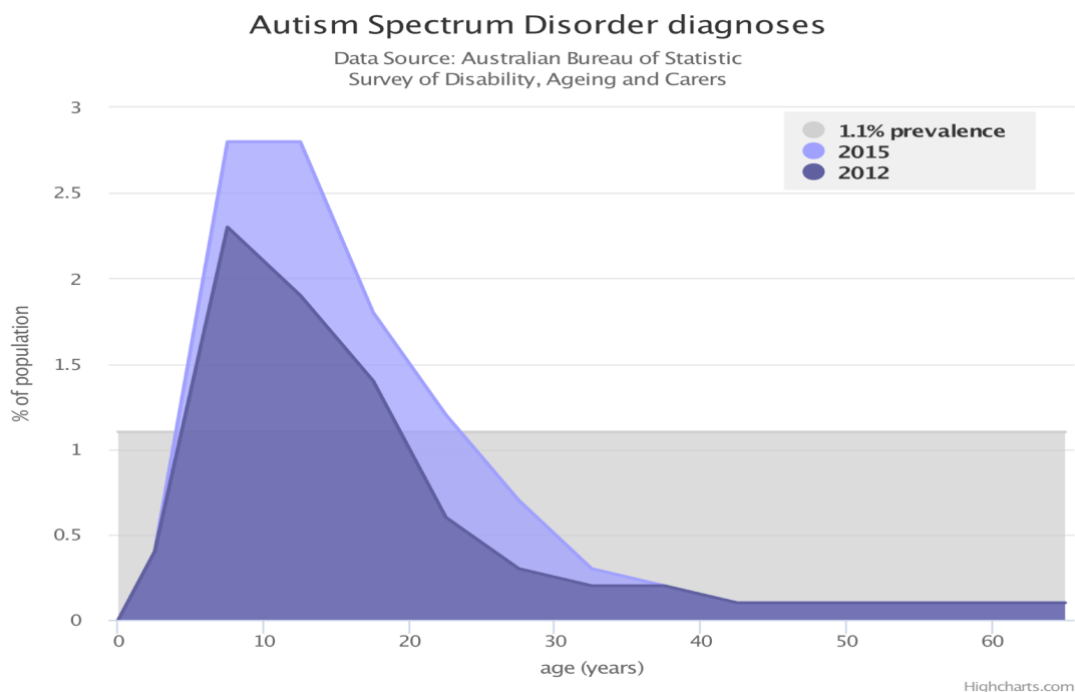
The following figure shows:

1. “autism” diagnosis rates vary substantially between 2012 and 2015 ... as they have since these data were first collected,
2. have high rates among children, but much lower rates for adults (there is chronic under-diagnosis of autistic adults), and
3. resemble diagnosis rates observed in other countries.



Some researchers claim ASD prevalence is stable at around 1.1% of the population. *If* this is so

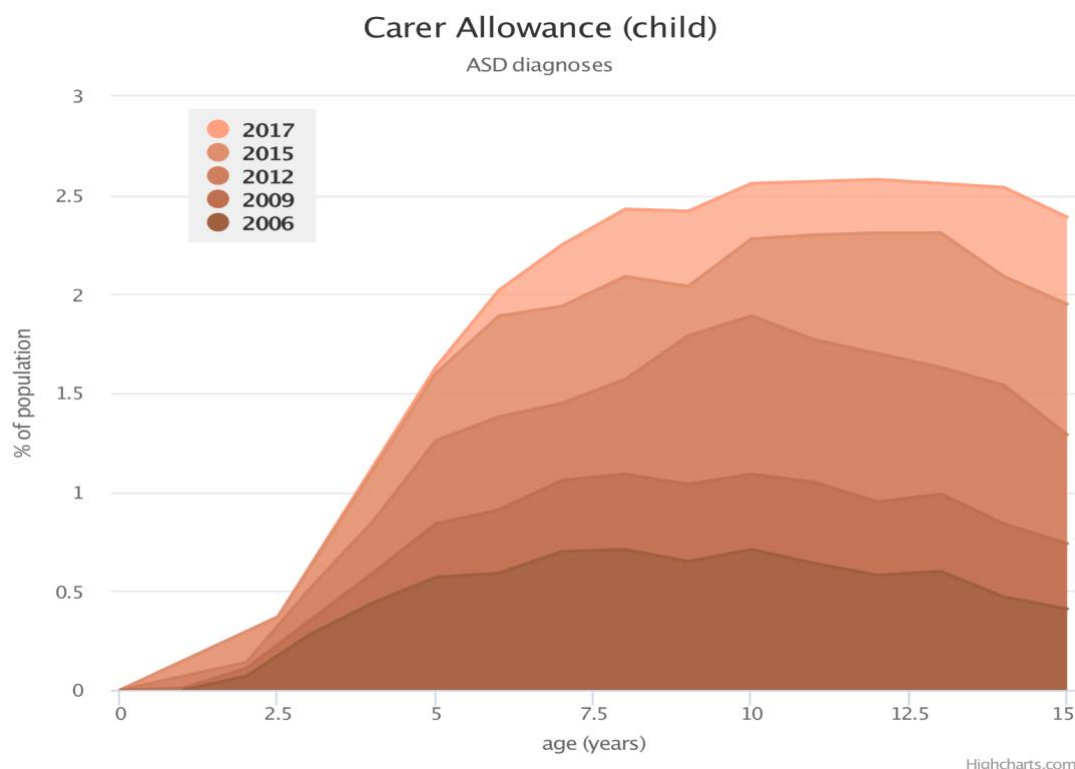
1. children are being diagnosed with ASD at more than twice the actual prevalence, and
2. fewer than 1/10th of autistic adults have been diagnosed.



The ABS data above is an estimate based on a carefully constructed statistical sample.

The following figure shows the number of Australian children who have a formal diagnosis of Autistic Disorder, Asperger's Disorder or Autism Spectrum Disorder and have registered to receive Carer Allowance (child) for their autism.

These are population data, not a sample.

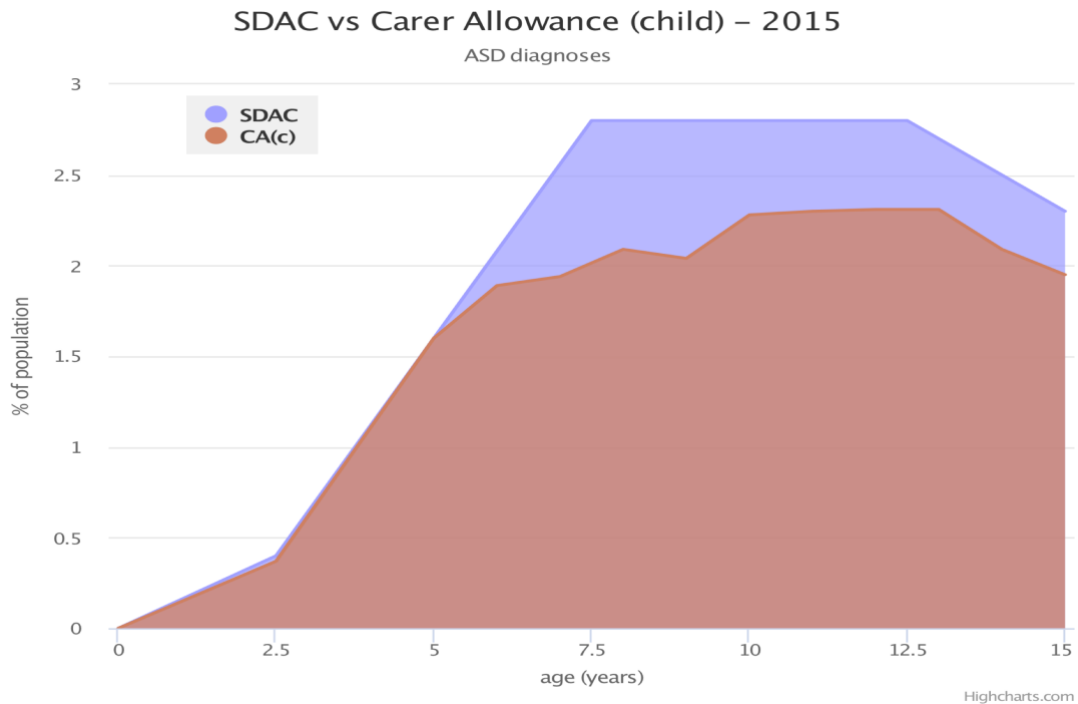


The figure shows the growth in numbers by age from 2006 to 2017.

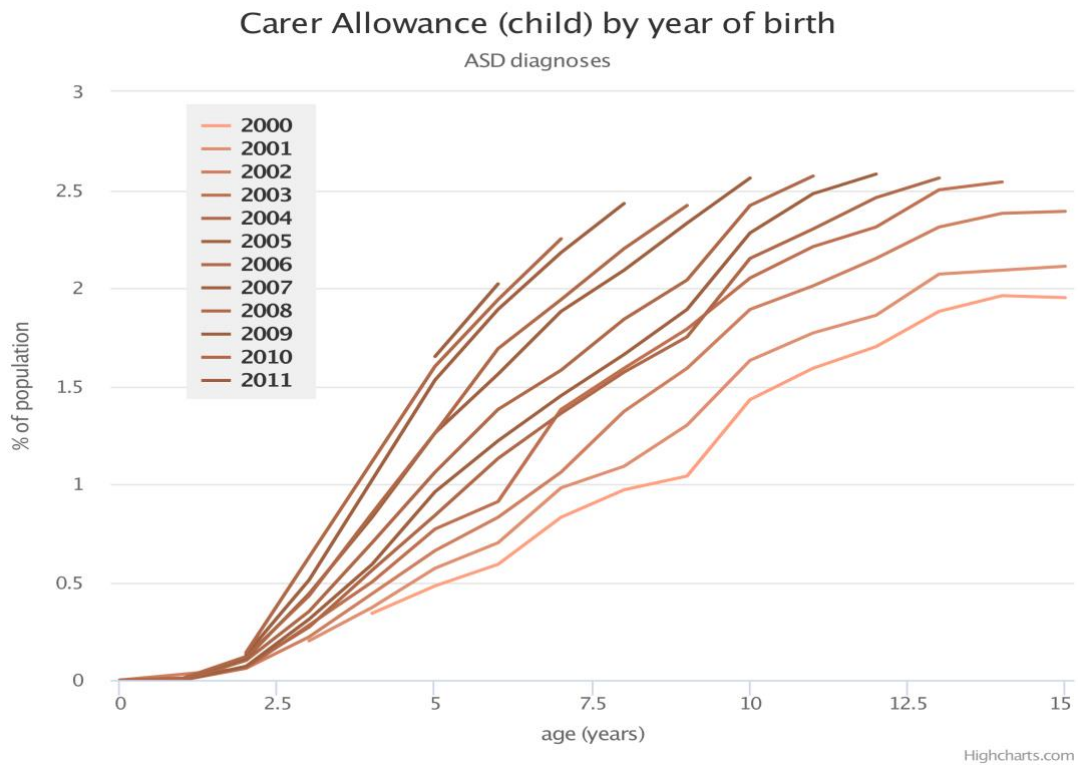
These data show a lower prevalence than the ABS data. For example, the rate observed in these data in 2015 was consistently below 2.5%. This lower rate *may* be due to:

1. some people not knowing they could receive the allowance,
2. a more rigorous requirement for documenting children's ASD diagnoses,
3. people who *choose* to not claim this allowance, and
4. some people find registration for Carer Allowance (child) too difficult.

The following compares the rates of ASD diagnoses reported from these two sources in the age range 0-15 years.



The following figure shows that a small fraction of autistic children is diagnosed in time to access NDIS funding for early intervention ... that the NDIS typically cuts off at age 5 or 6 years when the child enters school.



By 2015, more than 1.6% of Australian children (1 in 62) aged 5 years were diagnosed formally with ASD. In 2017, 2.56% of children (1 in 39) aged 10 years were autistic.