



## **Pre-election 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. The number of Australians diagnosed with autism continues to increase. The Australia Bureau of Statistics (ABS) found that 2.8% of children aged 5-14 years had autism<sup>1</sup> in 2015. The number of children receiving Carer Allowance (child) for their ASD reached 2.94% for 11 year-old children in 2018. The substantial growth in ASD diagnoses continued from previous survey datasets.

At 2.8% of Australian children or more, ASD is now more prevalent than Intellectual Disability among Australian children. A4 expects 30-50% of autistic people also have Intellectual Disability. Autistic people have alarming levels of mental illness; their mental illness is often untreated or very poorly treated.

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 reason<sup>2</sup>.

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*.

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

<sup>2</sup> <http://a4.org.au/node/423>

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, ...

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

## **1. NDIS and Autism Spectrum Disorder (ASD)**

The latest (Y6Q2) 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”.

These statements are incorrect. The first is clearly incorrect because autism is currently the most numerous primary disability for NDIS participants. The second contradicts a large body of research. The NDIS does fund best practice early intervention for autistic children but in many instances, only if their family appeals NDIS decisions to the Administrative Appeals Tribunal (which is extremely difficult for families of children with disability).

So far, the NDIS failed/refuses to recognise A4’s concern over this matter. Families observe that NDIS eligibility and planning processes are badly uninformed, sometimes misinformed, about ASD and supports for it.

### **a) NDIS eligibility for autistic people**

The NDIS has ignored the ASD community over the eligibility issue: from the beginning, the NDIS eligibility criteria were *gobbledygook* (see <http://a4.org.au/node/794> and <http://a4.org.au/node/1056>). For a long time, the NDIS refused to even acknowledge this issue.

Then the NDIS had an alarming episode over its alleged “ASD eligibility mistake”<sup>3</sup> culminating in a letter 23/5/2018 from the Minister (your ref. [MS18-000877](https://www.a4.org.au/node/1056)).

Since the “mistake”, senior NDIA officials acknowledged the DSM-5 (which is not the DSM-V) description of an ASD diagnosis requires two, not one (as the

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<sup>3</sup> It was not a mistake.

NDIS List A indicates), severity levels. But the NDIA still has no proposed change to how it describes NDIS eligibility for ASD.

A4 raised numerous reports from families of NDIS representatives and intake officials making incorrect statements about the NDIS eligibility of autistic people and about acceptability or appropriateness of specific early intervention approaches for autistic children (see <http://a4.org.au/node/1580>; the issue was repeated in a letter to Mr De Natris on 1/8/2018). NDIS officials are yet to acknowledge this issue.

There is no discernible plan or action to improve or rectify the NDIS staff and representatives' knowledge and understanding of autism/ASD and the guidelines that they operate under.

### **b) NDIS funding for autistic participants**

The support that the NDIS provides for autistic participants is often inadequate. NDIS funding autistic participants is inequitable.

NDIS Quarterly reporting showed

- the NDIS's target, the "expected average annualised committed support", is about \$37K p.a.; and
- the NDIS only achieved about \$32K p.a. as its "actual average annualised committed support".
- After allowing for equitable funding for intellectual disability among autistic participants, the average NDIS support for ASD is at most \$7.4K p.a.

This level of support cannot provide the most basic needs of most autistic participants. Letters explaining this were sent to the Minister and NDIS officials; they can be downloaded from <http://a4.org.au/node/1977>.

### **c) Stakeholder engagement**

Following the alleged "eligibility mistake", the Minister promised A4 in his letter (see above) to ensure consultation about changes to the NDIS operation relating to ASD. The NDIS broke the Minister's promise within days<sup>4</sup> and the failure/refusal of the NDIS/NDIA to engage properly with ASD stakeholders continues.

A4's latest efforts to improve engagement with the NDIS failed (<http://a4.org.au/node/1975>): there were a number of meetings but no discernible progress on commitments the NDIA made in those meetings to address A4's concerns. For example, no progress was made on the agreed need to fix the NDIS's gobbledegook relating eligibility for autistic NDIS participants. A senior official told A4 that the CEO believed the issue had been "fixed". Either the NDIS CEO believed that he fixed it by doing nothing or he did not know that his NDIS had not done anything. Either option demonstrates failure to engage effectively from the highest level of the organisation.

The NDIS created an Autism Advisory Group (AAG), announced on 19<sup>th</sup> June 2018. That it took so long to create such a group, and needed substantial

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<sup>4</sup> See <http://a4.org.au/node/1762>

community response to the NDIS's "mistake", shows the Government's disinterest in engaging with the ASD community.

Anyway, by early February 2019 there was no discernible outcome from the AAG and its "agenda".

NDIS officials keep telling us about its trials of new or improved "pathways" for participants. Sometime it tells us in vague terms what it is doing in advance but it does not involve us in designing its experiments. It rarely tells us the outcomes.

#### **d) 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.

#### **e) 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.

#### **f) 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.

### **g) Getting advice about the NDIS**

Information on the NDIS website often does not answer people's questions.

Too often, the NDIS information call centre gives conflicting, confused or wrong advice about the NDIS.

Increasingly, people are turning to social media groups for advice and information about the NDIS.

## **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 a Royal Commission into abuse and neglect of people with disability. The disability sector is united and adamant over this.

Through its actions, the Government has demonstrated that it regards abuse and neglect of people with disability as a minor matter. The Government claims their NDIS Quality and Safety Commission will deal with the issue completely. But their NDIS Quality and Safety Commission addresses only part of the issue and simply is *not working* (just as we expected).

*They say a week is a long time in politics; there may be progress on this very soon. We are optimistic that the Government will agree to start a separate Royal Commission.*

## **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"<sup>5</sup>.

While there are Medicare items that help some families fund diagnosis of an autistic child, funding cuts out for adults. Many autistic adults are

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<sup>5</sup> See <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/autism-spectrum-disorder-and-adults>

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 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 or relinquished by their parents and families need much better support than is currently provided. For example, the death described in <http://a4.org.au/node/1575> would have been avoided had more appropriate support been in place.

## **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 that is often inappropriate for autistic people and their informal carers.

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 for most autistic children; it usually amounts to doing the same thing<sup>6</sup> and expecting a different result. Evidence shows outcomes for generic early intervention 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.

Currently, the Government prefers to fund generic disability advocacy. Generic disability advocacy demonstrably has failed to advocate for the growing number of autistic Australians, especially those with severe or profound disability who the process of generic disability advocacy excludes because of their disability.

Without support, systemic ASD advocacy in Australia have very limited ability to contribute to development of a new National Disability Agreement. A new NDA that does not address ASD is unacceptable.

## **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 the Burdekin Report increased awareness of issues for people with Intellectual Disability and mental illness starting in the mid-1990s, there has been little 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 (see <http://a4.org.au/node/1962>).

Possibly, the Productivity Commission inquiry into mental health will recognise the unmet need for mental health support for autistic people.

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<sup>6</sup> That is, putting the child back in mainstream setting where they already failed – and triggered their ASD diagnosis.

## **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.

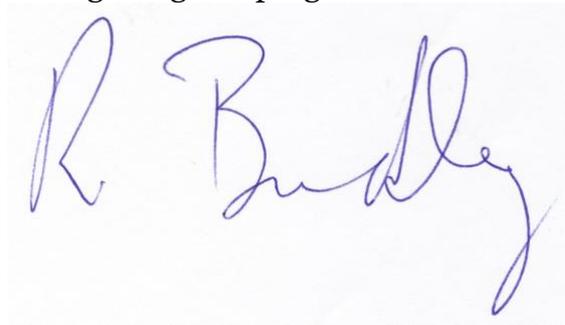
The disability sector needs substantially increased funding and something like the NHMRC or the ARC guiding disability research.

### **Conclusion**

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

Australian Governments continue to ignore largely the substantial needs of autistic citizens. The result in unacceptably bad outcomes for autistic Australians in disability support, health, education, employment, independent living and community participation.

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



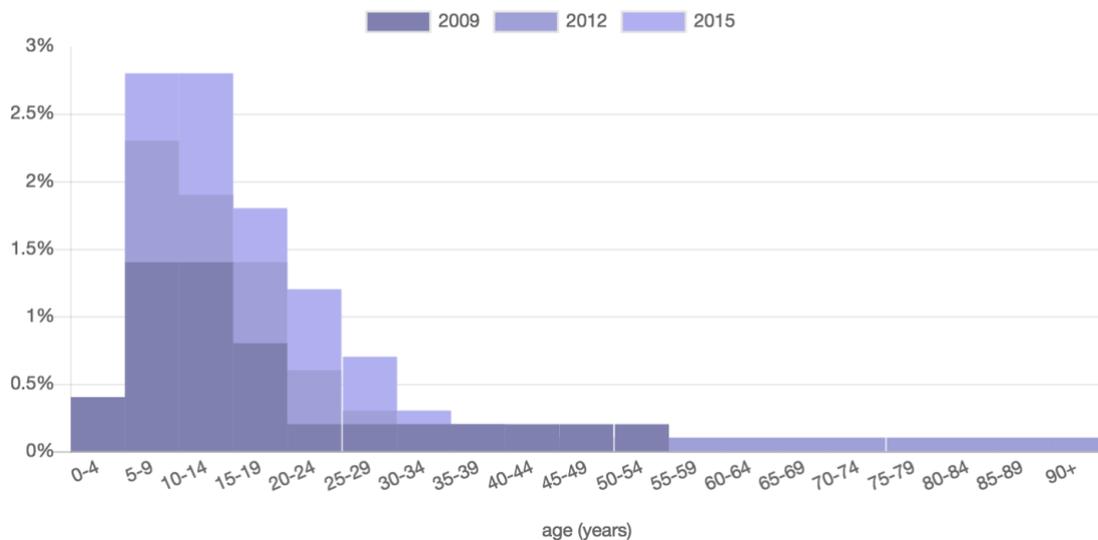
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16/02/2019

## Annex A – Data

The following figure shows:

1. “autism” diagnosis rates vary substantially between 2009 and 2015 ... as they have since these data were first collected,
2. “autism” diagnosis rates rose 42% between 2012 and 2015
3. have high rates among children, but much lower rates for adults (there is chronic under-diagnosis of autistic adults), and
4. resemble diagnosis rates observed in other countries.

**ABS SDAC Autistic Australians (percent estimate)**



Some researchers claim ASD prevalence is stable at around 1.1% of the population<sup>7</sup>. *If* this is so

1. 2.8% of children aged 5-14 years are being diagnosed with ASD, 2.55 times the claimed ASD prevalence, and
2. fewer than 1/10<sup>th</sup> of autistic adults have been diagnosed.

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

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

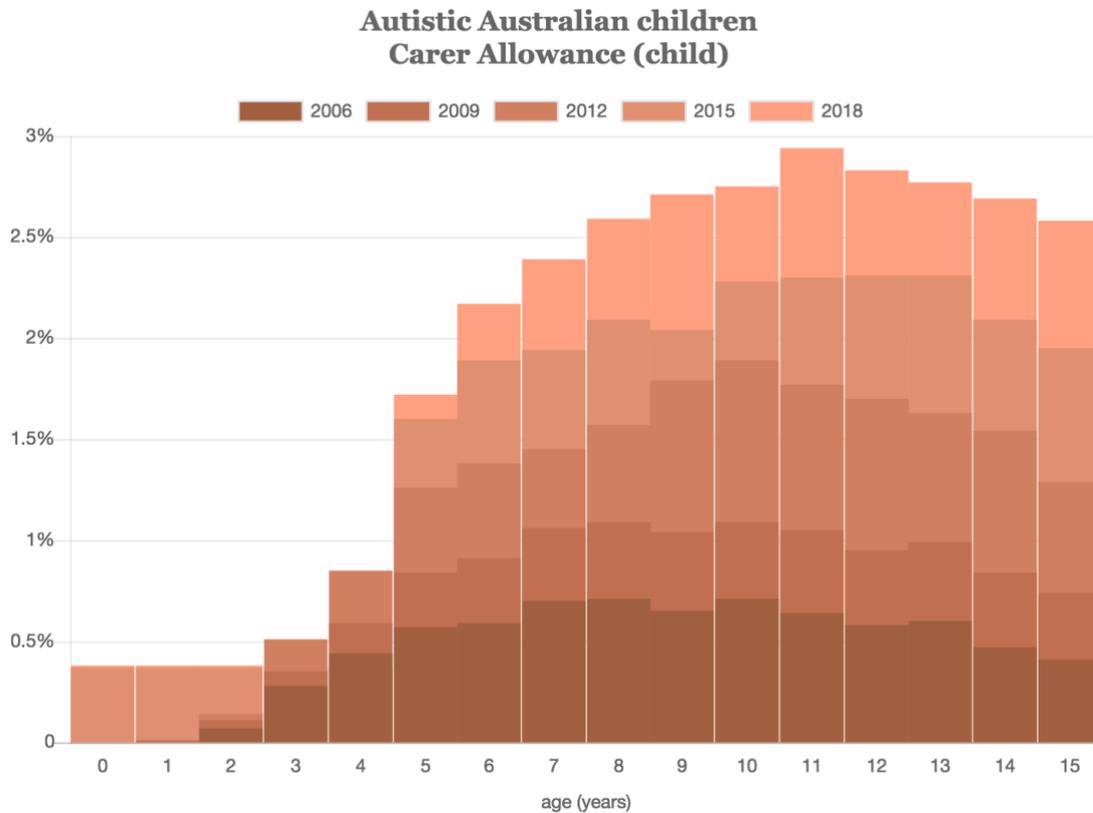
This study has shown that Centrelink [now described as DSS Carer Allowance (child)] is the most comprehensive single source of national information about the number of individuals seeking funding with a diagnosis of autistic disorder or Asperger disorder.

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

<sup>7</sup> See <http://a4.org.au/node/1449>

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.



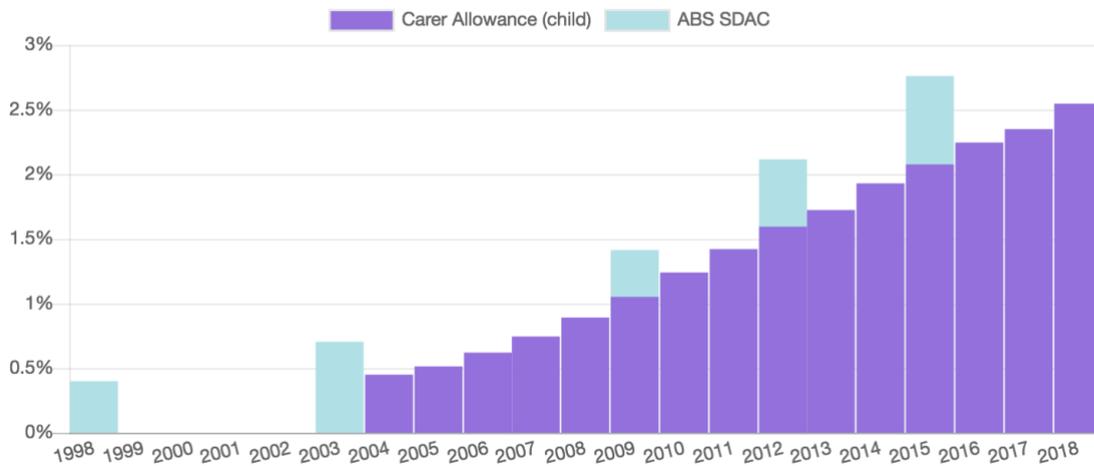
The figure shows the growth in the number of ASD diagnoses by age from 2006 to 2018. Diagnosis rate reaches 2.94% in 2018 for 11 year-olds. Growth in ASD diagnoses is ongoing.

These data show a lower diagnosis rate for any time period than the ABS data above. For example, the rate observed in these data in 2015 was consistently below 2.5%. The lower rate in these data *may* be due to:

1. some people not knowing they could receive this 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 finding registration for Carer Allowance (child) too difficult.

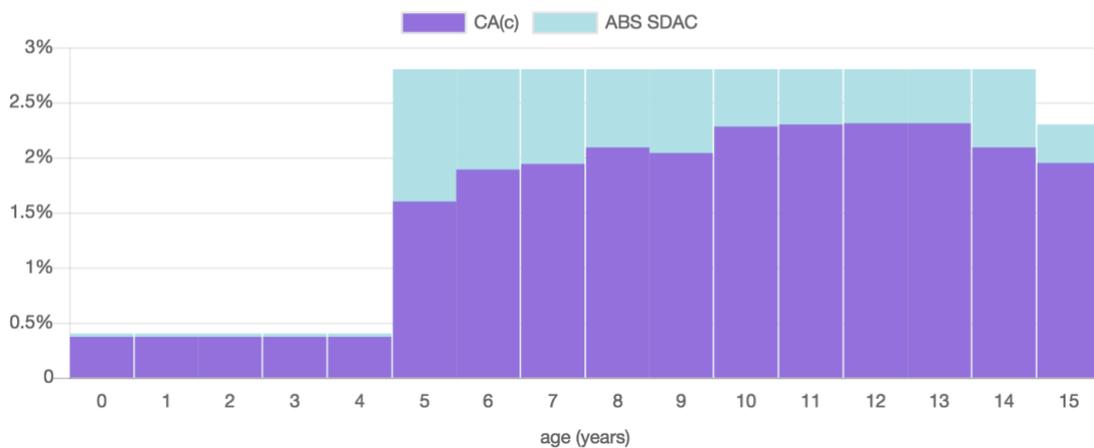
The following figure shows the diagnosis rates for children 5-14 years from two data sources. The two data sources show comparable growth patterns.

**ASD diagnosis rates: Australians aged 5-14 years**



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

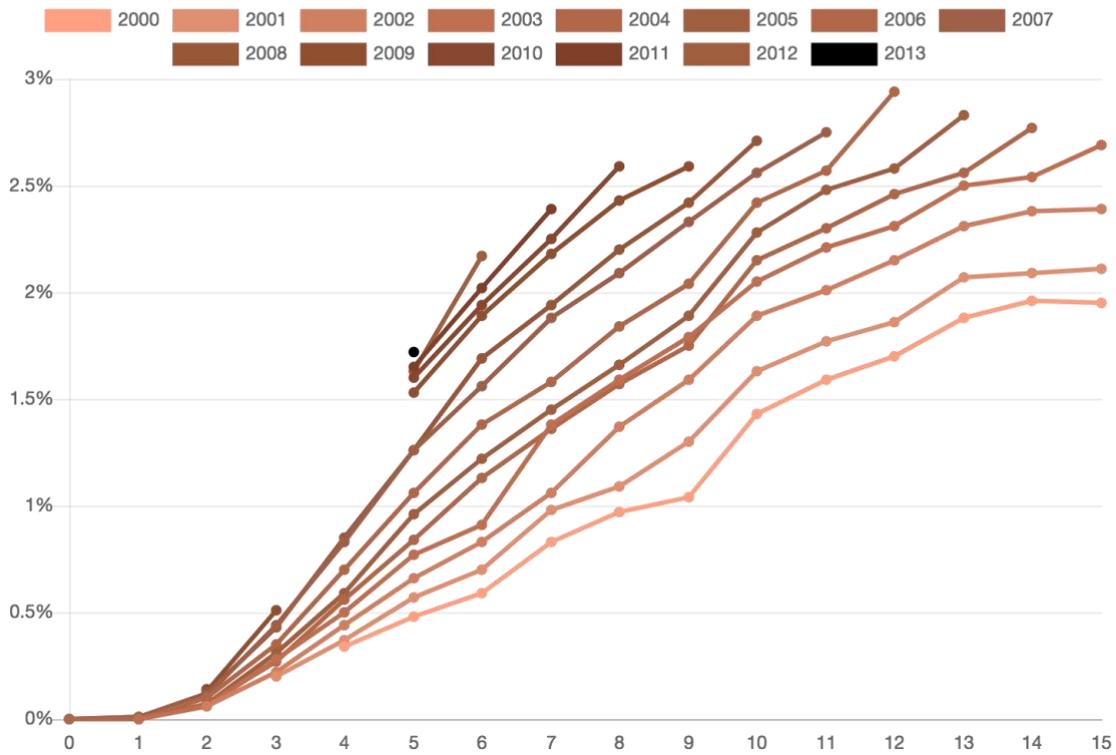
**Autistic Australian children  
2015**



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 its ECEI funding when the child enters school at age 5

or 6 years, whether or not cutting off the funding for the child is appropriate or advisable.

**Carer Allowance (child) by birth year**



By 2018, more than 1.72% of Australian children (1 in 58) aged 5 years were diagnosed formally with ASD. In 2018, 2.71% of children (1 in 37) aged 10 years and 2.94% (1 in 34) children aged 12 years were autistic with their diagnoses recorded formally in DSS's database.