

Submission on autistic Australians and Group Homes

to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

from *Autism Aspergers Advocacy Australia*

Introduction

Autism Aspergers Advocacy Australia, known as *A4*, appreciates the opportunity to provide a submission on group homes to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Our submission is specifically about autistic people, people with autism spectrum disorder (ASD).

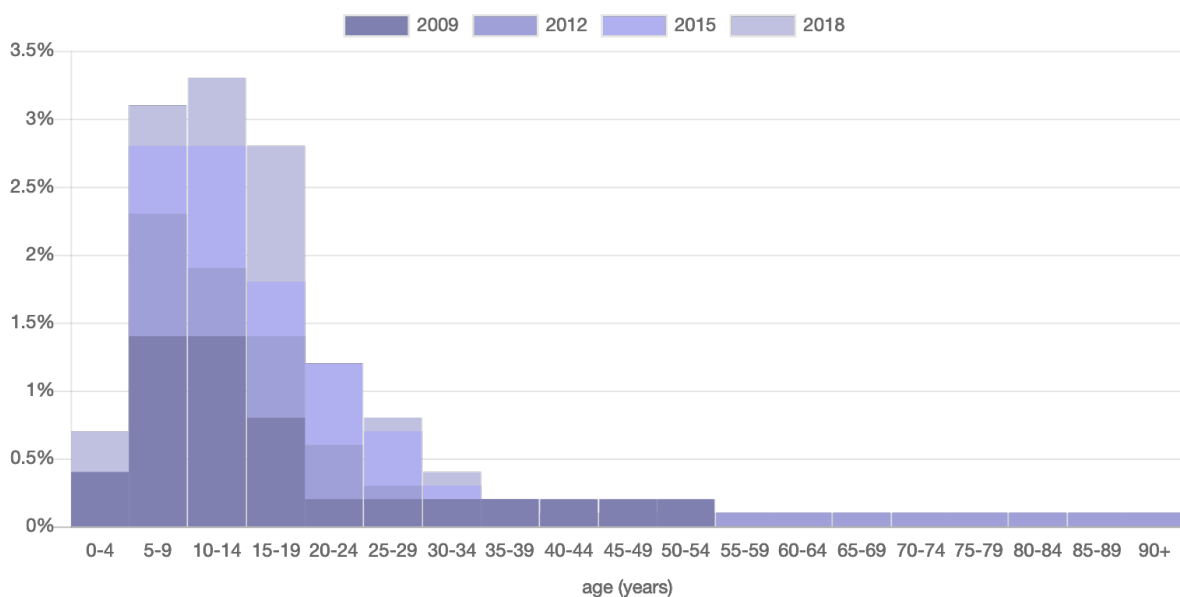
The challenge in preparing this submission is that we have very little information about autistic people in group homes.

Autistic Australians

Understanding of autistic Australians is relatively poor. Available data indicates that many autistic Australian adults remain undiagnosed.

In successive surveys, the Australian Bureau of Statistics estimated ASD diagnosis rates by age.

ABS SDAC Autistic Australians (percent estimate)



In addition to showing massive growth in the number of young autistic Australian in recent years, this chart indicates that diagnosis rates for adults are massively below diagnosis rates for children. The reason for this huge difference in diagnosis rates across age groups is not known. The reasons considered the most likely contributors to this difference are:

- a) chronic under-diagnosis of ASD in adults (and children in the past) contrasted with greatly improved awareness of ASD for children,
- b) shifts in how clinicians interpret¹ diagnostic criteria for ASD (mostly for children), and
- c) difficulty getting clinicians to diagnose ASD in adults.

The higher mortality of autistic Australians² may play a small part. It is not known whether underlying ASD prevalence is increasing.

Under-diagnosis of ASD results in neglect. And neglect leads to violence and abuse.

The result of under-diagnosis of ASD in adult Australians is that the support needs of many autistic Australian are unrecognised hence are mostly neglected/ignored.

These data indicate that the higher ASD diagnosis rate observed in younger Australians is progressing into the adult population. The number of autistic adults needing supported accommodation will increase substantially in coming years. Australia should plan to meet this need: the number of places and the quantity of trained staff providing supported accommodation for autistic adults needs immediate attention.

The progressive transition to for-profit service provision delivers inevitably increased exploitation and fraud in the disability service sector.

Autistic Australians and Group Homes

There is very little data describing autistic Australians living in group homes. A4 is not aware of any data collection or analysis showing how many autistic Australians live in group homes ... nor are we aware of information about the lives of autistic Australians in group homes.

The NDIS should be able to provide an analysis of autistic Australians in group homes but they did not include this information in their recent “deep dive” into their data (see <http://a4.org.au/node/2084>).

Anecdotally, many autistic adults remain in the family home until their parents die or are too old to support them. The apparent reason for this is that supported accommodation for autistic adults is considered largely unsatisfactory.

¹ Many commentators claim the diagnostic criteria have changed, but the changes that have occurred did not loosen diagnostic criteria for ASD – the change has been in how clinicians *interpret* diagnostic criteria for ASD more broadly.

² <https://onlinelibrary.wiley.com/doi/abs/10.1002/aur.2086>

Justifiably, group homes are considered inappropriate and unsafe for vulnerable autistic adults. Typically, service providers do not or cannot provide the support autistic people need because:

1. they don't know what supports autistic people need,
2. funding for essential supports is not part of the funding for an autistic person, and
3. even if the funding is provided the necessary clinical expertise is too limited or simply inaccessible.

Autistic people, like people with Intellectual Disability, are subject to neglect and abuse in group homes. Their health needs of both groups are often left undiagnosed. If the health needs of autistic people are identified, health systems often ignore those needs; too often autistic people are denied treatment (see <http://a4.org.au/node/1949> for example).

Basically, bureaucrats and government officials like putting autistic people in group homes. The advantages they claim include:

- use conventional housing so the cost of the physical setting is reduced or minimised, and
- the appearance of normalised living.

Bureaucrats, government officials and some disability service providers claim group homes are better than institutions but autistic people find group homes are as bad or worse than traditional institutions. Disadvantages of group homes are substantial.

- Group homes lack the economy of scale that brings access to specialist support services.
- Require cohabitation with a very limited group of other people, people who mostly have their own disabilities and challenges.
- Lack sufficient protection needed to ensure safety for group home residents with disability.

Group home settings often exacerbate distressed behaviour of autistic people. Distressed behaviour usually results from communications failure and frustration. But Australia trains very few behavioural clinicians, and does not register them (see <http://a4.org.au/node/1071>) to ensure clinical standards are maintained.

Issues with disability support in group homes have been raised before. [The Gallop Inquiry](#) in the ACT found major problems with inadequate support in group homes. Unfortunately, the ACT Government decided that protecting the reputation of ACT Government officials through its legal system was much more important than implementing the finding of the Inquiry so the needs of people with disability were not properly addressed. A4 is not aware that any Australian state has done any better.

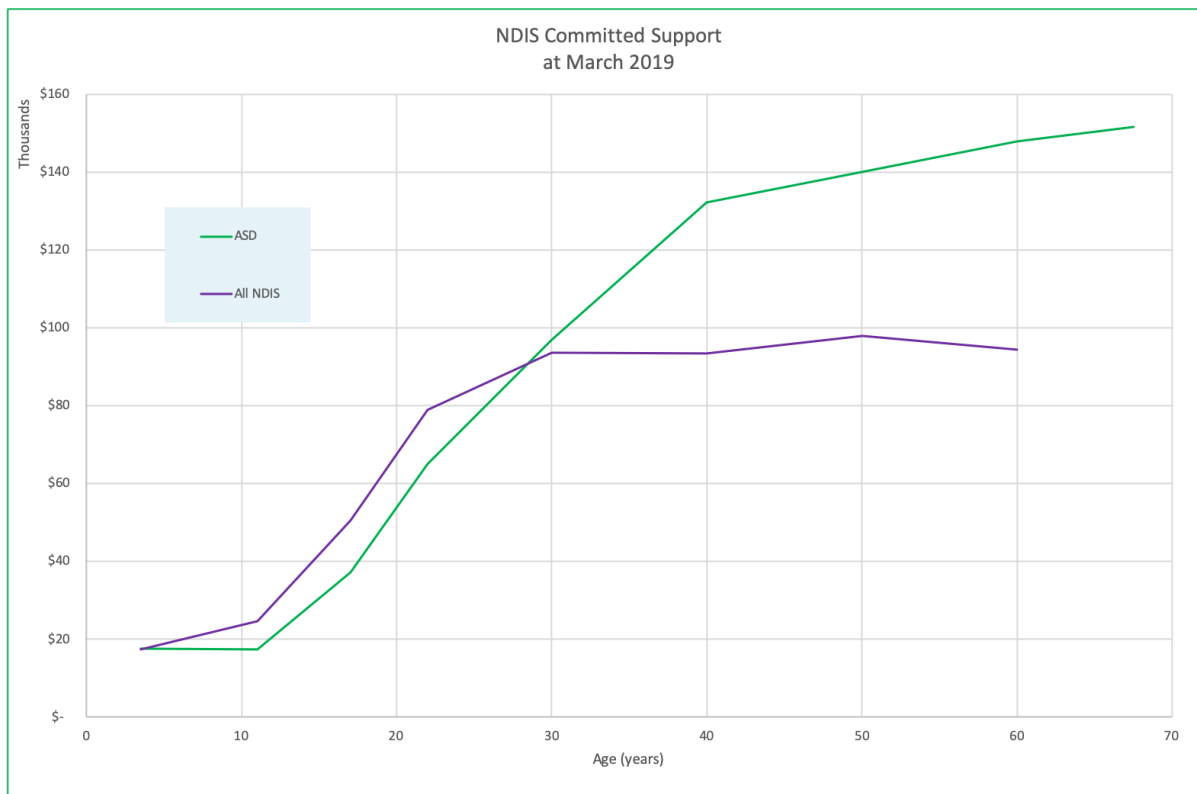
Autistic adults have higher rates of mental illness which often makes their accommodation difficult. Regrettably, mental health services routinely deny autistic people the mental health services they need.

Recently, the ACT Government tried to review services for autistic people, but ACT Health officials simply ignored autistic people and their distinct needs – see <http://sofasd.org.au/d7/node/232>. But instead, the review workgroup focused on “mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders where a service for people with Intellectual Disability that they deemed appropriate, in the ACT”. The review committee excluded services that are distinctly for autistic people, limiting the review to services for people with Intellectual Disability ... but possibly allowing autistic people access to a service if it might be appropriate. This fell well short of addressing the health and mental needs of autistic people.

This neglect of autistic Australians is also illustrated in the Health Minister’s recent [media release](#) promising greater support for people with Intellectual Disability, which we support and applaud, the Minister’s effort completely ignores unmet ASD-related health and mental health needs of autistic Australians.

Typically, support workers and service providers regard ongoing physical and chemical restraint as the appropriate response to distressed behaviour of their autistic clients. Restraint is not best practice and the NDIS Quality and Safeguards Commission may address individual situations as they increasingly become aware of them.

Currently, data from the NDIS (see the chart below) show support costs for autistic adults are relatively high across setting (the available data does not distinguish group homes). The reasons for cost increasing substantially with age are complex ... and not well understood.



Note that “autism” is the biggest distinct primary disability for NDIS participants. And the proportion of autistic NDIS participants is increasing over time, albeit slowly. The number of autistic NDIS participants is 50% more than the NDIS expected and planned for.

Questions from the Disability Royal Commission discussion paper

The following section tries to answer the questions asked in the [DRC's Group Homes Issues Paper](#).

Question 1: Have you, any member of your family, or anyone you care for, lived in group homes? Are you willing to share your experiences or those of another person with the Royal Commission?

A4 members have a range of experiences of autistic Australians in group homes, however, our experiences are limited.

Many autistic adults remain in the family home because people simply do not trust disability services to provide safe and comfortable living places for autistic Australians.

A4 representatives are willing to share our experiences of and concerns about group homes with the Royal Commission.

Question 2: What is your opinion of the quality of life for people with disability in a group home?

Varied. Most people consider group homes to be too risky for autistic adults.

Question 3: Are you aware of any violence, abuse, neglect or exploitation of people with disability in group homes? Are you willing to share your knowledge with the Royal Commission?

Yes, we are aware of violence, abuse, neglect and exploitation of autistic people in group homes. As well as our personal experiences, there are numerous reports in the media (see Autistic Australians and group homes in the media below).

Yes, we are prepared to share our knowledge with the Royal Commission.

Question 4: When violence, abuse, neglect and exploitation occurs in group homes, what do you think are the causes? What can be done to prevent violence, abuse, neglect or exploitation in group homes?

A number of things can trigger violence and abuse in the homes of autistic people. While relevant data is not available, experience suggests the following triggers:

- Lack of training and supervision for staff.
- Failure to properly accommodate autistic people.
- Poor communication – “behaviours of concern” usually relate to unsuccessful attempts to communicate.
- Frustration following failure to communicate ... often associated with lack/denial of independence and little or no self-determination for an autistic person
- Lack of training and skill development for management, clinical and supervising staff.
- Under-resourcing of group homes and supports for autistic people.
- Inadequacy of education and supports in early life.
- Trauma from past experience and frustration.
- Incompatible housemates.

The primary triggers for neglect and abuse are:

- Untrained and inadequately supervised staff
- Staff who are unsuited to the role
- Absence of respect for autistic people as human beings
- Denial of their human rights
- Inadequate funding
- Lack of safety and protection of autistic people.

Question 5: Do you consider the experiences of violence, abuse, neglect and exploitation in group homes different for particular groups of people with disability? For example, how does a person’s gender, age, or cultural or sexual identity impact on their experiences? What are the experiences of First Nations people in relation to group homes?

Autistic people are at substantially greater risk because:

- their social and communication skills are poor (by definition) and their needs are not recognised, respected and accommodated.
- behaviour supports are absent or inadequate.

Autistic First Nations people are rarely diagnosed with ASD, so we have very little information or experience with them. Diagnosis rates are especially low in the Northern Territory and Western Australia where First Nations people are a higher proportion of the population.

Question 6: Is there a continuing role for group homes in providing accommodation for people with disability? If so, what is the role? If not, what are the alternatives?

Group homes are rarely a best option for severely autistic people. The main reasons for this are:

- Some autistic people are “difficult” for many others to live with. Their communication and behaviour are not normal and many others find they cannot accommodate the differences for extended periods.
- Service providers are unable to recognise, respect and implement essential supports for autistic people in group homes.

Question 7: Are you aware of the use of restrictive practices in group homes that you can share with the Royal Commission? If so, what needs to change or happen to eliminate the use of restrictive practices in group homes?

Yes, autistic people are commonly subjected to “restrictive practices”. This is especially likely to occur for autistic people who live in group homes.

The first choice would be to not have autistic people in group homes.

If autistic people have to live in group homes, their supports need to be closely supervised by specialist professional behaviour clinicians. Group home settings need frequent independent monitoring and review from specialist inspectors. In some instances, constant video surveillance may be needed.

Any use of restrictive practices needs to be approved and must involve effective and enforced reduction over time.

Question 8: What barriers or obstacles exist for people with disability identifying, disclosing or reporting incidents of violence, abuse, neglect or exploitation? What should be done to encourage investigating and reporting of violence, abuse, neglect or exploitation in group homes when it occurs?

Reporting and complaints processes cannot be trusted. Most autistic adults have extensive experience of being further victimised when they report adverse treatment. Many of them are already traumatised through previous experience of complaint processes, especially in relation to bullying.

First, fix the issues of bullying of autistic children in schools and elsewhere in the community.

We need to recognise and address existing trauma for autistic adults.

The problems are widespread, not just in group homes.

Question 9: Should anything be done to improve or change staffing in group homes to better support the choices and potential of people with disability?

Yes, a lot needs to be done.

The need to properly registered behavioural clinician is paramount. These clinicians must be resourced to recruit, train and fully supervise support workers who support autistic people in group homes.

The additional training of workers needs to be respected. The industrial implications for these support workers need to be recognised and respected.

Government need to properly plan the disability workforce. The change that the NDIS is bringing cannot be left to market forces and the inherent exploitation and profiteering.

Question 10: What else should we know? Have we missed anything?

Autistic people are both victims and perpetrators of violence and abuse in group homes. However, when autistic people are violent or abusive it usually results from frustration, not from malicious intent.

For this reason, we prefer the term “stressed behaviour” rather than the other terms such as challenging or unwanted behaviour, or “behaviours of concern”.

Most autistic people are a-social some or all of the time. If their preference is not recognised and respected, an autistic person will be unsuited to any group home, especially where other residents are especially/excessively (annoyingly) social.

There are more males diagnosed autistic than females. Most males socialise differently from females. In the disability sector, females dominate the workforce and determine/impose their social expectation on autistic people. Too often, the social expectations imposed on autistic males are inappropriate for the individual. The resulting tension/conflict promotes violence and abuse of autistic people.

Australian Governments need to recognise that the disability sector is not prepared to accommodate growing numbers of autistic Australians. For example, the NDIS needs to recognise that even if 20% of NDIS participants being autistic was a reasonable estimate³ around 2013, the number of

³ A4 raised concern over the NDIS underestimate of autistic participants in its submission to the Disability Royal Commission on Education of autistic students (see <http://a4.org.au/node/2173> Annex C).

autistic NDIS participants has now increased to over 30%. The rate will continue to increase into the future.

ASD is neurological in nature: it relates to brain structure that does not change. The brain structure of an autistic brain is permanent – people do not grow out of it, so it is disappointing to hear people who should know better ask “hasn’t he/she grown out of it yet”?

The diagnostic criteria for ASD are entirely behavioural, so it should be no surprise that that behavioural approaches have the best evidence of efficacy. The lack of training and of a registration regime for behavioural clinicians in Australia shows the country is unprepared for increasing ASD diagnoses.

Currently, behaviour clinicians can register internationally with the Behavior Analysis Certification Board (BACB – see <http://bacb.com>) but this will not be possible after 2023. Australia needs to have proper professional registration for behaviour clinicians in place by 2023.

The Australian Government needs:

- Australian Universities that train behavioural clinicians, and
- that Australia develops and maintains a professional registration scheme for behavioural clinicians.

Hopefully, the efforts of the NDIS Quality and Safeguards Commission will improve clinical supports for autistic people, not just ion group homes.

However, the same protections are needed beyond the NDIS.

In particular, Australia needs to improve its culture of restraining autistic people in relation to both chemical and physical restraints. The naïve and widespread culture of adopting medications or chemical restraint for long term behaviour suppression must be deprecated.

There is too little data available about autistic people. Research and data collection must improve.

Autistic Australians and group homes in the media

Following are links to media items that relate in some way to autistic people and group homes.

1. [Darkest moments: Why two mothers are considering giving up their children](#)
2. [Training first responders to recognize autism may avert tragedies](#)
3. [Down syndrome man’s case upheld on appeal after ‘shocking’ slight by judge](#)
4. [Family fears NDIS can't help autistic man facing eviction from group home](#)
5. [Mum demands answers after death in care](#)
6. ['I can't change what happened to Matty': family of disabled man sues state over rape](#)
7. [In search of truce in the autism wars](#)
8. [Concerns raised about a 'culture of cover-ups' in group homes](#)

9. [Children in group homes face criminal charges for breaking coffee cups, says report](#)
10. [Disability carer recorded saying 'I just wanna f***ing beat these kids without risk'](#)
11. [Waiting for the eruption: Why our autistic son had to leave to save our family](#)
12. [Families ask government to shut down Autism Plus following damning Ombudsman report](#)
13. [People with intellectual disabilities locked away under cloak of suburbia](#)
14. [Allegations of violence, abuse in ACT disability homes not referred to police](#)
15. [Carers of hard cases fear private future under NDIS](#)
16. ['It's a horror story': Carers, family speak out on NDIS regional care](#)
17. [The missing generation](#)
18. [Disability services slammed for Vic rapes](#)
19. [Mother branded mentally ill after complaint](#)
20. [FaCS worker Lennard Michael Downes faces court accused of assaulting disabled boy, 9, at government-run home in the Illawarra](#)
21. [Young people with high needs shut out of Canberra respite care under NDIS](#)
22. [The struggle for care](#)
23. [Stress, despair in care of children with autism](#)
24. [Autistic boy being held in adult mental health ward in Launceston](#)
25. [Fighting the System](#)
26. ["It's like a five-year-old wrote it": disability advocates slam NDIS care plans](#)
27. [Residents bearing the brunt of disability care in their street](#)
28. [a personal letter to NDIA CEO](#)
29. [In care for 17 years, Centrelink still told Andrew to prove he deserved pension](#)
30. [TasWeeked: A different way of being](#)
31. ['Shocking' abuse of Victorians with disabilities](#)
32. [Medication](#)
33. [Senate committee calls for royal commission into disability abuse](#)

Annex A. About Autism Spectrum Disorder

The following repeats information provided in A4's submission to the Commission on education – see A4's [In a class of their own](#). See that submission for a more comprehensive description of autistic Australians generally.

Autism Spectrum Disorder

The APA's *Diagnostic and Statistical Manual of Mental Disorder, 5th edition (2013)*, known as the DSM-5, describes the diagnostic criteria for Autism Spectrum Disorder (ASD). The full text is available at **Error! Reference source not found.** or <http://a4.org.au/dsm5-asd>.

The DSM-5 classifies ASD as a neurological disorder though the nature of autistic neurology is not known. There is no physiological or biochemical test for ASD; diagnosis is based on observed behaviour.

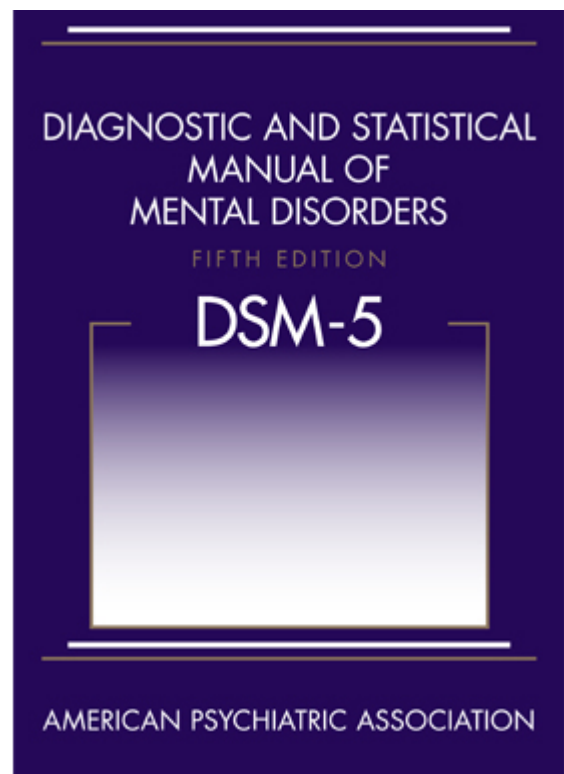
More recently, the [World Health Organization](#) published its ICD-11 criteria for [Autism Spectrum Disorders](#).

ASD is not a marginal condition, as some people believe. The diagnostic criteria for ASD require that there be “clinically significant impairment in social, occupational, or other important areas of current functioning”.

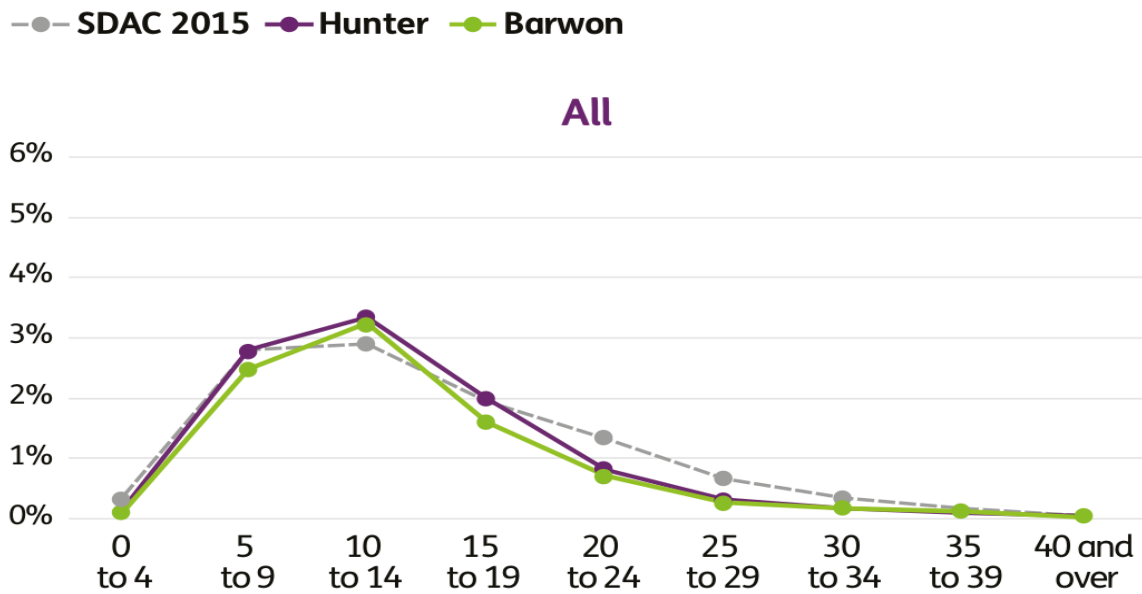
Diagnosis rates for ASD are increasing around the world. ASD diagnosis rates in numerous first world countries have risen to over 2% of children though the rate for adults remains quite low. ASD was thought to be rare: in 1994, the DSM-IV described prevalence as 4 people with Autistic Disorder per 10,000 people and 1 per 1,000 people were thought to be on the autism spectrum.

ASD in Australia

Recently, the NDIS compared some of its autistic participants with the ABS SDAC data (see <http://a4.org.au/node/2084>). The NDIS figures are for 2018 while the ABS estimates were from 2015. At the time, ABS data for 2018 was not available. NDIS officials said there was no reason to assume ABS SDAC estimates for 2018 would be different from 2015 estimates despite all previous surveys having shown substantial increases in



numbers from the previous survey. Since then, the ABS data released showed a 25% increase from 2015 to 2018 (as seen above).



The scale of the data from both the NDIS 2019 data and the ABS 2015 survey are comparable, however the shape of the NDIS data is closer to the shape of 2018 ABS SDAC data (shown above in the body of this submission). The NDIS considers its Barwon and Hunter regions as “mature” sites for the NDIS.

Both datasets show similar patterns of ASD diagnoses. The similarity between these data, and their consistency with other data (see A4’s previous submission) improve confidence in analyses of these data.