

In a class of their own

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

Education and Learning for Autistic Students

"Education is the most powerful weapon that you can use to change the world." Nelson Mandela "it's politicians who don't do their jobs, not children, who should be held in 'cages'." Arnold Schwarzenegger

2/2/2020

Autism Aspergers Advocacy Australia

Preface

Autism Aspergers Advocacy Australia, known as A4, welcomes this <u>Royal</u> <u>Commission into Violence, Abuse, Neglect and Exploitation of People with</u> <u>Disability</u>. A4 had been asking the Government to conduct a Royal Commission for some time (see <u>http://a4.org.au/node/1498</u>).

This submission focuses specifically on the education of autistic students. Autistic students are students who are diagnosed as having Autism Spectrum Disorder (ASD), a neurological disorder of unknown aetiology. The submission discusses who they are, their international rights, how they are treated in Australian schools and their education outcomes.

Previous inquiries and government reviews have considered policies and programs that affect people with disability including autistic Australians but these had relatively little effect and did not deliverer discernibly different outcomes. The education outcomes of autistic students remain poor because their rights are ignored, their needs are neglected and they continue to be abused.

A4 regards this Royal Commission as another opportunity for Australia to recognise and respect autistic students, and to act to improve their education outcomes.

A4 uses identity-first language throughout this report as we understand this is a preference that people with an Autism Spectrum Disorder diagnosis prefer.

About Autism Aspergers Advocacy Australia

Autism Aspergers Advocacy Australia, known as A4, started in 2002 trying to represent the diverse views and needs of autistic people in Australia and people associated with them, including family, friends and the ASD-related workforce.

A4 is a member of <u>Australian Federation of Disability Organisations (AFDO)</u> and <u>the Australian Autism Alliance</u>.

A4 is listed on <u>the DSS web page</u> as a National Disability Representative Organisation.

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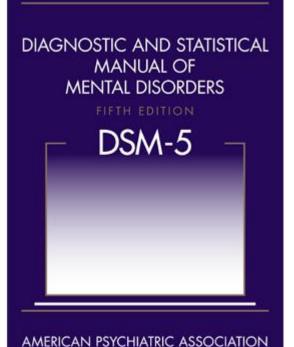
Autism Spectrum Disorder

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 Annex A below or <u>http://a4.org.au/dsm5-asd</u>.

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 <u>World Health</u> <u>Organization</u> published its ICD-11 criteria for <u>Autism Spectrum Disorders</u>.

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.

Survey year	Birth year	ASD per 1,000	range	rate
2000	1992	6.7	4.5 - 9.9	1 in 150
2002	1994	6.6	3.3-10.6	1 in 150
2004	1996	8.0	4.9-9.8	1 in 125
2006	1998	9.0	4.2-12.1	1 in 110
2008	2000	11.3	4.8-21.2	1 in 88
2010	2002	14.7	8.2-24.6	1 in 69
2012	2004	14.5	8.2-24.6	1 in 69
2014	2006	16.8	13.1-29.3	1 in 59

The US Centre for Disease Control and Prevention (CDC) <u>reports</u> that diagnoses of 8-year old children have increased substantially.



The method used in these surveys misses many autistic children so the rate of autistic children is likely to be an underestimate but the consistent method shows a substantial increase over the period.

<u>A carefully conducted epidemiological study in South Korea</u> from 2011 reported 2.64% or 1 in 38 children aged 7 to 12 years had autism. While this rate of ASD detection surprised many people, it now seems completely reasonable.

Increases are seen mostly in children but are now moving into young adults.

The word *spectrum* is essential in describing ASD. The diagnostic features of ASD vary substantially between autistic individuals. Autistic people have widely varied:

- language skills ranging from absent, minimal, dysfunctional, limited, reluctant or excessive.
- IQ scores from very low to very high.
- social skills and awareness.

Many autistic people say eye contact is difficult for them; some report that looking into someone else's eye is painful.

Autistic people often score especially poorly on *theory of mind* tests: they have a poor appreciation that what is in someone else's mind may not be the same as what they think and know. Autistic children may not learn to lie, or may be late starting, and their poor social skills means they are usually unsuccessful when they try to lie. Autistic people are notoriously honest, frank and forthright. Many autistics, though not all, regard lies and untruths as utterly unacceptable, abhorrent and repulsive.

The spectrum of symptoms seen among autistic students requires a spectrum of responses from educations systems. Bureaucrats and policy makers look for and prefer a simple universal approach for students with disability, but this strategy simply does not work for autistic students. Autistic students need a spectrum of services and supports to meet their individual and specific education needs.

The long-term prognosis for an autistic child is unpredictable. Many autistic children become very capable adults and live happy and fulfilled lives. The evidence also shows that many have poor outcomes. The DSM-5 says:

- ASD is not a degenerative disorder;
- it is typical for learning and compensation to continue throughout life;
- a small proportion of individuals deteriorate behaviourally during adolescence, whereas most others improve;
- only a minority of individuals with autism spectrum disorder live and work independently in adulthood, ...
- many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from the stress and effort of maintaining a socially acceptable façade;
- scarcely anything is known about ASD in old age.

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The DSM-5 emphasises the school years:

Symptoms are often most marked in early childhood and early school years, with developmental gains typical in later childhood in at least some areas (e.g., increased interest in social interaction).

The spectrum nature of autism means that Australia's educations systems need a spectrum of responses to autistic students. There is no "one size fits all" for autistic students. Unfortunately, education bureaucrats and administrators simply don't understand this.

ASD in Australia

While we would like to be able to describe comprehensively for you the experience of autistic Australians in detail, the data to do that simply is not available.

In the main, the experience of autistic Australians appears to resemble the experience of autistic citizens in other first-world countries.

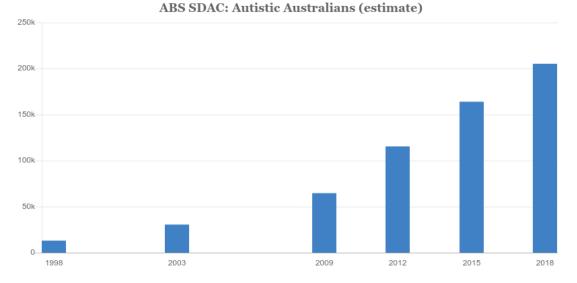
The number of Australians who are known to be autistic has increased substantially. The two main sources of national data are:

- the Australian Bureau of Statistic (ABS) Survey of Disability, Ageing and Carers (SDAC), and
- data that A4 collected from DSS on Carer Allowance (child) for children under 16 years of age

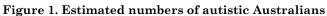
The number of autistic Australians (in thousands) estimated from ABS SDACs is shown in the following table:

	1998	2003	2009	2012	2015	2018
0-4 years	1.0	1.2	3.5	6.0	6.2	10.8
5-9 years		8.2	19.4	33.0	41.9	49.0
10-14 years	10.5	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			3.7	11.5	20.0	19.8
25-29 years			2.8	3.5	11.9	15.6
30-34 years		6.2		3.2	5.1	7.1
35-39 years			4.6	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

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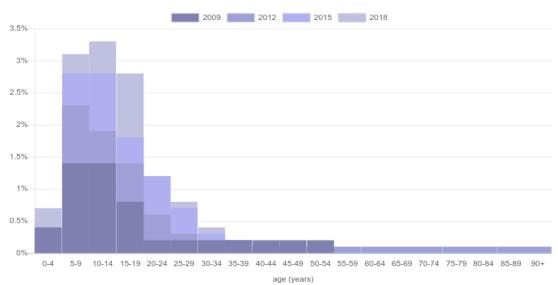
The following figure shows Australia's increasing autistic population estimates.



The following table and figure show the increasing diagnosis *rate* broken down by age. This reduces the effect of population increase over the same period.

age	2009	2012	2015	2018
0-4 years	0.2	0.4	0.4	0.7
5-9 years	1.4	2.3	2.8	3.1
10-14 years	1.4	1.9	2.8	3.3
15-19 years	0.8	1.4	1.8	2.8
20-24 years	0.2	0.6	1.2	1.2
25-29 years	0.2	0.3	0.7	0.8
30-34 years		0.2	0.3	0.4
35-39 years		0.1	0.2	0.2
40+ years		0.1	0.1	0.1





ABS SDAC Autistic Australians (percent estimate)

Figure 2. Age breakdown for autistic Australians from recent surveys

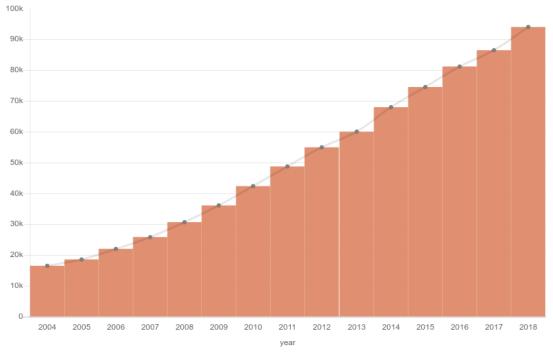
Notably, 3.3% or 1 in 30 of Australia's 10-14 year olds were autistic in 2018.

The drop off in older autistic Australians is far too big to be accounted for by increased mortality (see Hwang, 2019). Very few people spontaneously "recover" from ASD, so that does not explain the decrease. The mostly likely explanation is massive under-diagnosis of autistic adults.

The ABS is not the only source of data on the number of autistic children in Australia. Since 2006, A4 has collected and analysed data from the national Carer Allowance (child) database. These?? (*sentence structure*) data are for all autistic children in Australia who register; this is not a survey sample. Each child has a form signed by a health professional confirming their ASD diagnosis.

The following figure shows the growth in the number of autistic children who get (*got?*) Carer Allowance (child) for their autism from 2004 to 2018.





Autistic Australians aged 0-15 years Carer Allowance (child)

Figure 3. Autistic children in Australia - another dataset

The following figure shows both ABS SDAC estimates and Carer Allowance (child) figures for autistic children aged 5-14 years. Some families do not register for Carer Allowance (child) which may explain partially the difference between figures from the ABS and from Carer Allowance (child).

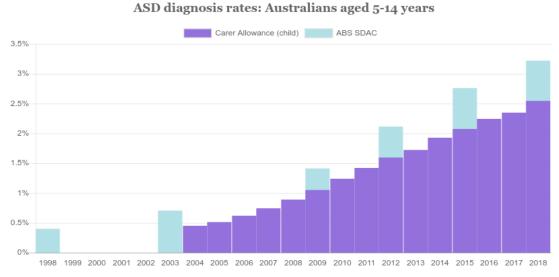


Figure 4. Comparison of autistic children from two datasets

Recently, the NDIS compared some of its autistic participants with the ABS SDAC data (see <u>http://a4.org.au/node/2084</u>). 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. Since then, the ABS data released showed a 25% increase from 2015 to 2018 (as seen above).

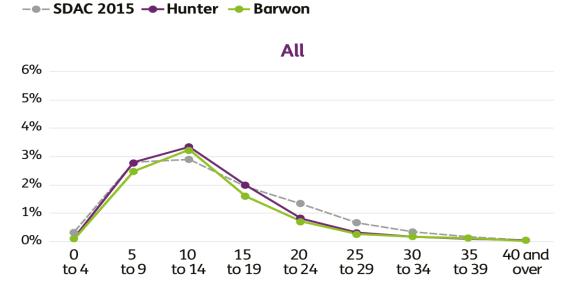


Figure 5. NDIS data from "mature" regions 2018 vs ABS SDAC data 2015 The shape and scale of the data are similar, however the shape of the NDIS data is closer to the shape of 2018 ABS SDAC data (see above) and the Hunter region has a similar scale.

Basically, we have a range of similar indicators of ASD diagnosis rates in Australia.

There is ongoing debate about whether the actual number of autistic people is increasing or whether increased diagnosis results from other factors.

ASD is now:

- Diagnosed more often the intellectual disability in school-age children in Australia.
- The biggest distinct disability type in the NDIS over 30% of NDIS participants have ASD as their primary disability.

Increasing diagnoses means increasing demand for services. Unfortunately, supports and services for autistic Australians have been seriously neglected; they simply have not kept pace with increasing ASD diagnoses.

The NDIS and governments do not recognise the growth in number of ASD diagnoses with the consequent demand for services for autistic Australians. They have no discernible plan to ensure the required services are available.

The pattern of ASD diagnosis in Australia is quite different from disability generally. The following figure (<u>from the ABS</u>) shows the number Australians with disability generally in 2018.

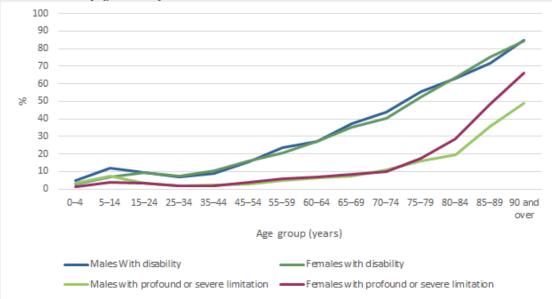


Figure 6. ABS SDAC 2018 disability generally by age

The numbers increase with age which is a distinctly different pattern from the number of autistic Australians.

The ABS reported that 68.9% of autistic Australians had severe or profound disability. Again, this is different from Australians with disability generally where only the population aged over 80 years has more than 50% with severe and profound disability.

But senior bureaucrats and administrators have expressed their belief (prejudice?) informally that families get their children diagnosed with ASD so they can access services that they don't really need. Senior officials think parents of borderline autistic children have nothing better to do than spend their time taking their children to hours of therapy each week.

Senior officials at the NDIS were very <u>keen to hear</u> that between 2012 and 2015 the increase in mild and moderate autism exceeded the increase in severe and profound disability due to ASD. Since then, the increased diagnosis rate has been observed to be due mainly to increases in autistic Australians with severe and profound disability, that is, people who need more intensive and specialised services.

At 30% of participants, autism rose to become the most numerous primary disability type in the NDIS. From the outset, the scheme actuary predicted 20% of participants would be autistic ... and has stuck with this prediction (see Annex C below) despite clear evidence that a) their initial guess was a substantial underestimate, and b) ASD diagnoses are increasing so the proportion of autistic NDIS participants will increase over time.

The cost of autism in Australia

Misguided and uninformed concern over cost is a primary cause of neglect of autistic Australians.

A4 is unaware of any government effort to analyse the cost-benefit of supports for autistic Australians. The consultancy, Synergies has published a report (see http://a4.org.au/node/1064).

The NDIS clings to a vain hope that autism will be 20 per cent of NDIS participants at final roll out (see Annex CAnnex C below).

The following figure shows the average cost of autistic NDIS participants in March 2019.

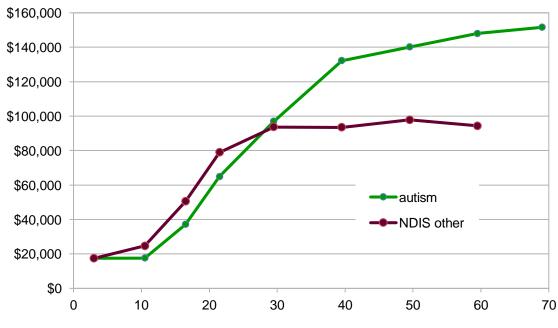


Figure 7. NDIS Plan costs - autistic vs other participants

Currently, the average support costs for an autistic NDIS participant from 0 to age 64 years is \$5,975,085 in 2019 dollars. The support cost for an adult between the ages of 20 to 64 years is \$5,498,285, and for the age range 20 to 85 years is \$8,529,845.

Repeated expert advice¹ to the government is that autistic children need and benefit from individualised intensive ASD-specific early intervention for best outcomes. At a cost of \$60K to \$100K per years for at least 2 years, some people regard this as prohibitive.

Evidence-based or best practice early intervention for autistic children is easily affordable. Australian governments have not considered the cost-benefit of evidence-based early intervention. If the average cost reduction for autistic adults is (a conservative) 10% and life-expectancy for autistic Australians is just age 65 years, then the break-even point for the cost of the early intervention for

¹The Government commissioned expert reports in 2006, 2011 and 2016. See Robert & Prior, 2006; Prior, Roberts, et. al., 2011, Roberts & Williams, 2016.

autistic children is \$549,828.50 which is substantially more than the current average NDIS plan for young autistic children of \$17,503 p.a. and substantially more than the cost of good practice in the form of evidence-based early intervention.

As best we can tell, the NDIS has so far neglected to do this analysis. Such an analysis is crucial for the proper operation of an insurance scheme. Despite being ask for it as evidence for AAT matters, the NDIA has not produced any such analysis of costs.

Senior NDIA officials told A4 that they regard evidence-based early intervention for autistic children as "contested". The NDIA contested the issue in AAT decision reviews (see <u>AATA 1480</u> and <u>AATA 1478</u>) where the AAT decided against the NDIA, but the NDIA still contests funding evidence-based early intervention for young autistic NDIS participants.

Effective early intervention also reduces the cost of effective education for autistic students. Autistic students who are better prepared for school need fewer supports and accommodations, and have substantially better education outcomes.

The cost of education for autistic students in Australia is unknown. We know exiting outcomes data show that current funding for autistic students fails to deliver effective education for most autistic students.

One piece of Australian <u>research</u> suggests that having an autistic child decreases average household income by \$35K per year.

Education outcomes for autistic Australians

A major measure of success in education for a subgroup of the Australian population is their employment rate. The employment rate shows how successful or not the group's education was in relation to their economic and financial outcomes.

The employment outcome for autistic Australians is abysmal. <u>The ABS</u> estimates that in 2018:

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%).

Basically, the education systems in Australia are failing autistic citizens. In relation to education, the ABS SDAC data show:

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%).

Unacceptable outcomes for autistic students and students with disability are an established features of education systems in Australia.

"Senator Birmingham said the federal government had forced universities to start training all student teachers to 'engage and teach' students with a disability." From <u>One in five students has a disability: confidential data (The Australian, 12/3/2016)</u>.

A4 is not aware of any measurable or otherwise discernible outcomes or improvement resulting from this program.

Bullying is a major issue in schools. Bullying causes major detriment for many autistic students. It is discussed below.

Autistic students and their "education" experience in Australia

Some autistic students do well in their education. Reports suggest that this is often despite the education systems. The available data on education outcomes for autistic students (see Education outcomes for autistic Australians above) show that most autistic students have particularly poor experiences in education.

Few autistic students in Australia are prepared for their education. Many autistic students fare especially poorly in mainstream and generic special education. Their education setting simply is not prepared for the student and the student is not prepared for education.

Key issues for autistic students include:

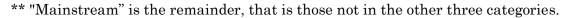
- Poor or absent preparation for school:
 - \circ $\$ delayed/late diagnosis too late to access ASD-specific early intervention
 - for those who do access early intervention, their early intervention is not "best practice" and does not prepare the student for education
- inadequate and/or inappropriate academic curriculum.
- unsuitable pedagogy for most autistic students
- lack of resources and adjustments
- neglect of behaviour strategies and supports sometimes involving abuse and violence
- rampant bullying of autistic students regrettably, many autistic students are damaged by their experience in education.

Data from the ABS SDAC shows that around 50% of autistic students attend mainstream school. The rate of education in mainstream settings dipped around 2012 and improved in the latest data (2018).



SDAC year	cannot attend*	special class	special school	Mainstream **	source	
2009	3.3%	24.2%	22.8%	<i>49.7%</i>	Table 1.5	<u>link</u>
2012	6.8%	24.9%	26.1%	42.2%	Table 1.5	<u>link</u>
2015	2.0%	21.7%	27.5%	48.8%	Table 5.3	<u>link</u>
2018	4.3%	19.9%	20.0%	55.8%	Table 5.3	<u>link</u>

* These data for "cannot attend" school have a high (25-50%) standard error. The number of autistic students who "cannot attend" school is alarming, no matter what the actual figure.



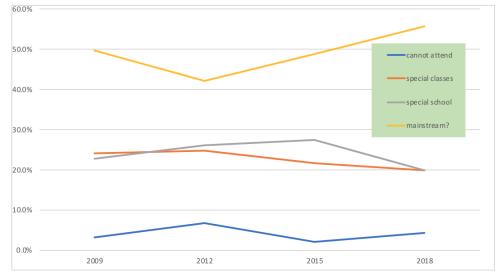


Figure 8. Autistic students school settings

These figures differ substantially from a report <u>published in an education journal</u> and <u>in the media</u> said to be based on the same data that suggests fewer than 18.8% in 2009 and just 3.3% in 2015 of autistic students are included in mainstream education. A4 questions the figures published in the journal article.

A4 is concerned <u>by a media report</u> that 50,000 students are just missing from Australian schools. <u>The university report</u> underpinning this news emphasises that:

It is almost incomprehensible that, in Australia, young people of all ages have been able to detach themselves from formal education and that we don't know who they are, where they are, how this has happened and why they remain largely hidden.

and

There is a tendency to use the word disengaged in an educational context to identify those students who are struggling at school, which is often related to issues such as poor attendance, anxiety, bullying, mental health issues, disability, family dysfunction, behavioural problems, suspensions and exclusions. These students need to have their educational challenges addressed before school disengagement turns into school detachment. This report acknowledges the prevalence of student disengagement across the nation as a serious barrier to achievement, however, we don't want to confuse the term disengaged with the even more devastating issue of school detachment.



Basically, education for students who do not attend school and who are not being home-schooled is neglected.

A4 is aware that a substantial number of autistic students simply leave school early (before school leaving age) and some never return. Some students are described as having "school refusal". Their "disengagement" or "school refusal" may result from bullying and/or anxiety, or from frequent suspension and exclusion. The National Census that provides the source data for the report neglects the need to identify disability types.

Some data is deeply puzzling. A media report says:

Nearly one in five students in government schools is classified as disabled — yet only 13.6 per cent are getting assistance and just 6.2 per cent attract additional funding.

The education systems in most states provided data² for the AIHW NMDS showing the number of students with disabilities in their schools. The 2016 report says 18.1% of students (almost1 in 5) had a disability ... and get support in school for their disability. Apparently, around 18% of students is the disability rate that education officials generally expected since everyone knows that 18% of Australians have a disability. Perhaps, education authorities expect this disability rate among school students.

The ABS reports that fewer than 10% of school-age children have a disability (see Figure 6. ABS SDAC 2018 disability generally by age). The difference between these two measures needs to be explained in full.

Early Intervention and school readiness

Evidence shows autistic students do very poorly in Australian schools. Research shows that best practice evidence-based early intervention for autistic children, as advised to governments and the community (Robert & Prior, 2006; Prior, Roberts, et. al., 2011, Roberts & Williams, 2016), frequently improves education outcomes for a substantial percentage of autistic students who access it.

The two key factors that prevent most autistic children from accessing best practice evidence-based early intervention for their ASD that could prepare them for school are:

- 1. Their late and/or delayed ASD diagnosis, and
- 2. The NDIA actively inhibiting or preventing autistic children from accessing effective (best practice evidence-based) early intervention for their ASD.

Few children are diagnosed with ASD in time to access best practice early intervention. Figure 9. Diagnosis age for children born in the 2002-3 Financial Year below shows the percentage of children diagnosed by age for children who were 15 years old at end June 2018. Under 0.91% of children were diagnosed by age 6 years but 2.69% were diagnosed by 15 years of age. In other words, 33.8%



 $[\]mathbf{2}$

http://www.educationcouncil.edu.au/site/DefaultSite/filesystem/documents/Report s%20and%20publications/ED17-

^{0046%20}SCH%20NCCD%20Report%202017 ACC.PDF

were diagnosed in time to access any government funded early intervention for their ASD.

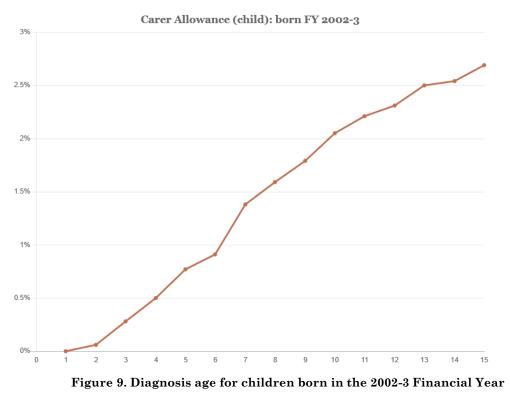


Figure 10. Diagnosis age for Carer Allowance (child) data below shows that this pattern of delayed ASD diagnosis persists for younger children in Australia. Carer Allowance (child) by birth year

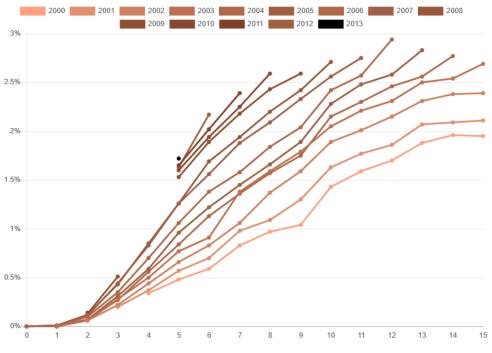


Figure 10. Diagnosis age for Carer Allowance (child) data



The Australian Government cuts access to early intervention for ASD when the child enters school or by age 7 years. With this restriction, 66.2% of autistic children in Australia are diagnosed too late to access effective early intervention.

Currently, bureaucrats with little or no knowledge of evidence-based early intervention decide government policy. NDIS bureaucrats decide to cut early intervention for autistic children when the child reaches school age, not when evidence says the student is ready for school or when the student no longer benefits from early intervention.

Then education officials decide many autistic children can only attend school part time because they are not school ready (or the school doesn't have sufficient resources to support/accommodate the student).

The officials do not recognise that a student that they prevent/prohibit from attending school full-time could continue early intervention. Nor do they recognise that some students need to continue early intervention as well as attending school. For some inexplicable reason, officials regard school and early intervention as mutually exclusive for autistic students.

Without essential early intervention to prepare them for school, most autistic children do poorly in their education.

Most autistic children in Australia enter school undiagnosed or without having accessed effective early intervention for their ASD.

The Australian Government should ensure autistic children are diagnosed early and access best practice early intervention. It should stop neglecting these basic needs of autistic Australians.

Teaching: Pedagogy and Curriculum

Even for students with a clear ASD diagnosis, schools rarely recognise and meet the specific needs of the individual student. Consequently, education simply fails most autistic students.

Often, autistic students do not learn the same way as non-autistic students. Some of them need different teaching strategies, a different pedagogy, to learn academic content. But instead of finding appropriate pedagogy for autistic students, many schools dismiss problem autistic children claiming they just can't learn. The schools neglect their education.

The learning gap for autistic students increases as students get older. In primary school, the apparent gap between a student with intellectual or learning disability and typical students appears to be smaller. And a teacher may be able to find and deliver a sufficient range of appropriate tasks for a diverse class. For example, while most of the class is learning about different classes of animals, a student with learning disability might learn to name some more animals and to colour-in pictures of them.

In high school, the wider gap makes it more difficult for a teacher to meet the needs of a student whose learning is substantially delayed compared to the body of the class. For example, a student who doesn't understand basic algebra cannot be included in a calculus class in any meaningful way. A student with minimal communication cannot get much benefit from a literature class. Some students are a long way behind the national curriculum.



Teachers are told that they should use the strengths and special interests of autistic students in their education. Schools often fail to put this into practice.

Kieran is quite autistic. He loves words and numbers. He loved playing with calculators. It turns out he learned to do arithmetic in his head. It's very impressive: he could multiply two 5-digit numbers before you could type them into a calculator.

His school said they were teaching to his strengths and special interests. When Kieran was 18 years old, his father wondered about the limits of his interest in arithmetic. Despite no prior exposure, he found that Kieran learned integer square roots after 3 examples. Clearly, his formal education did not explore his special interest – contrary to claims.

Later, Kieran worked out cube numbers for himself.

The school ventured into Kieran's interest in drawing and painting ... but avoided digital art which is Kieran's real interest.

What schools do is often a long way from what they say they do for autistic students.

For some autistic students, curriculum is no problem at all. They thrive on most of what they are asked to do academically but they often struggle socially, with sensory issues or with being organised.

Many autistic students have intellectual or learning disability. These are often undiagnosed or unreported. And they are poorly addressed in education settings.

Bullying

Bullying is an extremely prevalent and serious issue for autistic students.

"All forms of bullying, physical, verbal, social, and cyber, are prevalent among youth worldwide. An especially vulnerable population for involvement in bullying is students with an autism spectrum disorder (ASD). Although there are some studies that have investigated bullying in these students, many of these are beset by methodological issues. We surveyed 104 students with ASD on their bullying experiences in all 4 forms of bullying and examined their roles as victim, perpetrator, and bully-victim, comparing them with a group of typically developing students matched for age and gender. It was found that students with ASD reported significantly more traditional victimisation (physical, verbal, and social) than their typically developing peers. Cyberbullying victimisation was similar for the 2 groups. There were no differences between the groups on traditional bullying perpetration; however, typically developing students reported more cyberbullying perpetration behaviours. Implications for prevention and intervention are discussed."

Campbell, 2017

"Accumulating evidence suggests that the prevalence of bullying is significantly higher for students with Autism Spectrum Disorder (ASD) than for typically developing students." Recommendations of school students with autism spectrum disorder and their parents in regard to bullying and cyberbullying prevention and intervention 2017

A4 Autism Aspergers Advocacy Australia

<u>autism groups want bullying in schools fixed</u> – from A4, responses from some state/territory Ministers 2016

"Young people with Asperger Syndrome experience disproportionate levels of bullying in mainstream school. A survey of 169 students (aged 5-17 years) identified with ASD in South Australia identified 62 per cent of the students reported they were bullied once a week or more often (Slee, P., personal communication, 2013). This compares with between approximately 27 per cent of other students (Cross, et al. 2009)." https://www.ncab.org.au/bullying-advice/bullying-for-schools/asperger-sand-bullying/

"More than half—62%—of students with Autism Spectrum Disorder, for example, report being bullied once a week or more*. This is significantly higher than the 1 in 5 to 1 in 7 Australian students who report being bullied once a week or more**."

*2007 Channel 7 Children's research by Verity Bottroff and Phillip Slee, cited in Developing Inclusive School Communities: Addressing Bullying of Students with an Autism Spectrum Disorder. Paper presented at: Making sense of autism and strategies that succeed conference, 4-5 September 2008, The Children's Hospital at Westmead Educational Research Institute (CHERI): Sydney.

**As cited on the <u>Bullying. No Way! Website</u>. from <u>https://www.qld.gov.au/disability/children-young-people/bullying/bullying-</u> <u>disability-mental-health</u>

"Students with comorbid anxiety disorders were more likely to report face to face victimization and were more troubled by both face to face bullying and cyberbullying, while students with depression were more likely to report cyber victimization. Parental concerns included the impact of victimization on school attendance, self-esteem, mental health, social participation, academic performance, and behaviour. The significantly higher levels of worry about bullying and higher victimization rates reported by students with internalizing symptoms suggest that these students may be disproportionately at risk of psychological harm." How are students on the autism spectrum affected by bullying? Perspectives of students and parents 2018

"A survey of 169 students (aged 5-17 years) identified with ASD in South Australia identified 62 per cent of the students reported they were bullied once a week or more often. This compares with between approximately 27 per cent of other students". (see <u>https://www.ncab.org.au/bullying-advice/bullying-for-schools/asperger-s-and-bullying/</u>).

The media contains many reports of autistic students being bullied, including the following:

- <u>Study: Inclusion May Not Be Best After All</u>
- <u>Anxiety and bullying studies reveal startling findings</u>
- <u>Action Must Be Taken to Stop Bullying of Students with Disability</u>
- Bullying and ASD
- Bullying of autistic kids going unnoticed



- <u>Autistic students bullied with death threats, physical abuse:</u> <u>survey</u>
- <u>autism groups want bullying in schools gone</u>
- Bullying higher in teens with autism
- <u>SBS: Why children with autism often fall victim to bullies</u>
- <u>Autistic kids targeted by bullies</u>

Schools frequently fail autistic students who are bullied. Schools tell students to report bullying to a teacher but when autistic students report bullying the outcome for them is usually worse than if they said nothing. Things that happen to autistic students include:

- The student's experience is trivialised, dismissed as unimportant ... when the student's failure/inability to "read" the bully's intentions and behaviour is a massive concern for an autistic student.
- teachers don't believe autistic students because the autistic student cannot "look the teacher in the eye and tell the truth". Note: teachers are told that most autistic students struggle with eye contact. This means eye contact when stressed is even more difficult for an autistic student. Also, many autistic students have poor "theory of mind" which means they are less likely to lie.

The autistic student is left unsupported, often victimised, by how schools handle bullying. Experience proves very quickly that autistic students cannot trust school staff, that their advice to report bullying is completely wrong; autistic students learn quickly that teachers can't be trusted. This is a very bad outcome for a student with a disability, that is someone who depends heavily on extra supports.

Proponents of Inclusive Education dismiss the significant detriment from bullying for autistic students. A leading proponent said "It [bullying] is an issue for all students, not just those on the spectrum". Dismissing the bullying experience of autistic students because bullying "happens to all students, not just those on the spectrum" neglects major issues since autistic students:

- 1. experience more bullying and it is often worse than other students experience.
- 2. are often ignored or even further victimised by the school when they report it.
- 3. suffer more severe downstream consequences including stress, depression, anxiety, "school refusal", ...

Bullying happens more often for autistic students and can have an especially serious impact on them. This response is exactly like claiming we shouldn't be concerned about domestic violence against women as it affects people of all genders, not just women.

Schools and clinicians usually neglect the severe consequences of bullying for autistic students. Many autistic students are traumatised as a result: trauma isn't just from bullying; it also arises from subsequent treatment and victimisation when they report bullying. Rarely is their trauma recognised and addressed.

Hopefully, the Commission will recognise that mainstream schools have been trying to address the inclusion of autistic students in mainstream schools for



decades and they continue to fail. Governments need to recognise that existing approaches to education for autistic students do not work. More effective strategies are now needed.

Stressed behaviour

The treatment education authorities give to stressed behaviour is a major barrier to education for many autistic students.

Stressed behaviour is often called challenging behaviour, unwanted behaviour or behaviours of concern. Stressed behaviour is usually brought on through inadequate and inappropriate support for autistic students.

There is a slowly emerging awareness that stressed behaviour is a communication in most instances. However, few schools can access trained and registered clinicians with the necessary skills. They do not understand how little they know.

Inappropriate responses to stressed behaviour inhibit/prevent learning for many autistic students. Often, the school's response increases a student's stress which exacerbates the behaviour. The school blames the student; they fail/refuse to recognise their role in the growing problem. Most schools then escalate their response to restrictions, restraint, suspensions and expulsion.

Government responses to this issue are limited and fragmented. Nationally, the NDIS Quality and Safeguards Commission (Q&SC) aims to tackle the issue for NDIS-funded services.

Limiting the response to the Q&SC neglects the needs of autistic students. Different educations systems, one primary public education system in each state/territory and a plethora of private education systems, have minimal or inadequate approaches for autistic students.

The issue of stressed behaviour was raised previously: <u>Behavioural needs of</u> <u>autistic Australians must be met</u>.

Autism and Inclusive Education

Many people in the disability sector are extremely emphatic the "inclusive education" is essential for *all* students with disability.

Arguments and support for inclusive education generally are *not* evidence-based (Lindsay, 2007).

The evidence from this review does not provide a clear endorsement for the positive effects of inclusion. There is a lack of evidence from appropriate studies and, where evidence does exist, the balance was only marginally positive. It is argued that the policy has been driven by a concern for children's rights.

More recent reviews, such as Van Mieghem 2018, are no more helpful. They simply don't address the fundamental questions: does the evidence show inclusive education reliably and safely delivers better education outcomes for a) students with disability, and b) autistic students?

While most advocacy for students with disability strongly promote inclusive education, this is an issue that divides the autistic community. Some autistic advocates and advocacy organisations strongly favour inclusion for all autistic students. But there are many families and some autistic advocacy groups whose



experience with inclusive education resulted in some autistic children needing what they regard as safer education settings.

While inclusive education is appropriate and effective for many autistic students, there are some autistic students whose outcomes from inclusive education are completely unacceptable. They also need appropriate education that is not a so-called inclusive education.

There is no clear definition or explanation of what "inclusive education" is for autistic students. For example, Cologon's recent <u>Towards inclusive education: A</u> <u>necessary process of transformation</u> (Oct 2019) has a whole chapter called "Chapter 3 • Defining inclusive education" that doesn't define inclusive education. In relation to autistic students, proponents of "inclusive education" simply cannot explain what it is or how it is supposed to work. They tell us what it *isn't*: they say inclusion is not segregation, exclusion nor "integration".

The research literature does not show that inclusion is effective for autistic students. There may be evidence that many students with disability do better in mainstream inclusive setting but the evidence does not show that inclusive education is effective for all autistic students. Inclusion zealots ignore evidence that inclusive education seriously harms some autistic students. They claim that if it isn't effective, or if it causes harm, then the student was not getting inclusive education ... but they can only look back, they cannot ensure from the outset that an autistic student is getting functional and safe inclusive education from the start.

On its first day of hearings, the Royal Commission heard about an autistic student, a student with Asperger's Disorder, hiding in bins to avoid fellow students.

The response from inclusive education proponents is that if the student is traumatized, then it's not "inclusive education". This begs several key questions:

- Did the family know their child was being put into a non-inclusive school? And how would they have known or found out?
- Is (or was) the school described as "inclusive"? How do families find out which schools are inclusive and which ones aren't?

Basically, inclusion proponents expect that students with disability must be "included" in mainstream education. Students with disability are expected to be immersed totally in mainstream settings, never segregated or excluded. And integration is nowhere near sufficient. And it is the teachers' jobs to make this work.

Inclusion proponents have not explained how to include a student who has not yet understood algebra can be included in a class on calculus. They do not explain how inclusion can work where the difference in level of academic achievement is extremely broad.

Inclusion proponents support their argument with examples of students with a disability in early primary education. Their examples of inclusive education avoid showing upper primary and high school level examples where a wider gap between students with communication, intellectual and learning difficulties cannot keep up academically with their age peers.

They don't recognise that some autistic children do not follow a normal developmental trajectory through teenage years; that autistic student may not comprehend neuro-typical teenagers, and *vice versa*.



For autistic students, the consequences of "inclusive practice" are often severe, even life-threatening. On its first day, the Disability Royal Commission heard evidence of a young autistic woman who hid in garbage bins to avoid social inclusion with her peers. Autistic people have many similar stories to tell. No doubt, this Inquiry will hear a few of them as it progresses.

Autistic students are often stressed. They experience higher than normal mental illness and suicide.

The inclusive education model has major challenges to address for autistic students, including issues of:

- 1. Teaching: Pedagogy and Curriculum
- 2. Bullying
- 3. Stressed behaviour
- 4. Downtime time when an autistic student wants and needs to be separate/isolated from others.
- 5. Some teachers who are unable to accept/tolerate students with autistic difference.

When families cannot find a mainstream or inclusive education setting for their autistic child, the alternatives they try include:

- 1. "Special" school
- 2. Autism-specific school
- 3. Satellite classes or autism units within a mainstream school
- 4. Home schooling

Some older autistic students, when inclusive education fails them, simply withdraw from education.

Many schools ask autistic students to *not* attend school on NAPLAN test days. That is not inclusive. It neglects the needs of autistic students.

Some autistic students would be better served if they could avoid/skip social contact with neuro-typical teenagers and instead learn to socialise with adults who are the people they will socialise with for the rest of their life.

Basically, we've seen schools and education systems trying to use "special education" as the easy way out. Special education settings have allowed inadequate curriculum for students with disability.

Inclusion proponents claim that an education setting that doesn't working is not an inclusive education setting. This is unhelpful: it means you cannot tell whether an education setting is "inclusive" until it is too late, until after the damage is done and the education opportunity has passed.

Education and Learning Issues Paper

The following section is A4's response to the Royal Commission's *Education and Learning Issues Paper*.

Section 1 – Foundations

Human Rights and education for autistic students in Australia



The Issues Paper identifies that Article 24 of the *Convention on the Rights or Persons with Disability* (CRPD) says people with disability have the right to education and mentions "inclusive education".

The right to education is also described in:

- Articles 10, 13 and 14 of the *International Covenant on Economic, Social and Cultural Rights* (IESCR) describe the right of everyone, which includes people with disability, to education.
- Articles 28, 29, 32 and 19 of the *Convention of the Rights of the Child* (CRoC) also describes a child's right to education which applies equally to children with disability.

Australia's legal system, human rights and autistic students

The Issues paper says "The right to education is well established in international human rights law" but this is not the case for Australian law. There are particular problems around disability-related behaviour. Legal commentary says:

in practice, discrimination law has struggled to deal with people with disabilities who exhibit challenging behaviours

and

In *Purvis*, the High Court effectively shut down the future possibility of a successful direct discrimination complaint for a student excluded from school on the basis of challenging behaviour. *Purvis* has been applied in discrimination cases since to deny protection to people with disabilities, and it remains the most problematic and the most criticised of discrimination cases because of its narrow reading of direct discrimination law. It also reflects profound discomfort with the idea that individuals with a behavioural disability, particularly one that manifests in aggressive behaviour, should be fully included in mainstream public life.

from http://www.austlii.edu.au/au/journals/UNSWLJ/2015/55.html

Regrettably, Australian Law does not ensure children with disability have a right to education. Australian citizens, such as students with disability, are not protected by a *bill of rights* or any equivalent legal instrument. Australian Governments are extremely resistant to any such thing for its citizens.

This was tested and decided clearly in <u>Purvis vs NSW</u> which showed that any/every school can deny a student with "unwanted behaviour" access to education. There is no legal safety net for such a student, though state/territory education departments generally do not want to be seen to use this legal provision or to leave a student without an education setting. So, a significant (but unknown) number of autistic students find themselves without education or state support for their education.

The Walker vs Vic matter shows this issue affects autistic students.

At the state/territory level, <u>Woodbury and the ACT [2007] ACTDT 4</u> took 10 years to hear. The ACT Disability Discrimination Tribunal found that *not* providing education for an autistic student when education programs were provided for non-disabled students is *not* "discrimination". Given the time taken to hear the matter, there was **no** prospect of protecting any right to education ... even if part of Australia's legal system recognised an autistic student's right to education.



Australian law, specifically the *DDA 1992*, was meant to protect the right of a child with disability to be admitted on an equal basis to, but not the right to attend, any school. The *DDA 1992* fails to protect the Australian child's right to effective education

The Government claims "the Letters Patent establishing the Royal Commission recognise that people with disability have the right to the full and equal enjoyment of all human rights and fundamental freedoms and that Australia has international obligations to take appropriate legislative, administrative and other measures to promote the human rights of people with disability". The Letters Patent may try to recognise people with disability have rights, but Australian law does not ... and it is the law that matters. Australian law does *not ensure* these rights. "Promoting" rights is a long way short of "ensuring" rights.

The <u>United Nations Committee on the Rights of Persons with Disability</u> reminded Australian Governments in <u>their periodic reviews</u> of its concerns over Australia's

- 1. "insufficient harmonization of the domestic legal framework with the Convention".
- 2. "Legislation, policies and practices that permit the use of psychotropic medications, physical restraints and seclusion under the guise of "behaviour modification" and restrictive practices against persons with disabilities, including children, in any setting, including in justice, education, health, psychosocial and aged care facilities;" and
- 3. the whole section on Article 24 Education.

The Issues Paper discusses references discussions about "inclusive" education and tries to separate "inclusive education" from "segregation" and "integration". The aftermath of international swing to inclusive education has some of the strongest proponents admitting:

"Governments must come to recognise that, even if inclusion is an ideal for society in general, it may not always be an ideal for schools," she said. "I think it has gone too far. It was a sort of bright idea of the 1970s but by now it has become a kind of mantra and it really isn't working."

Pressure to include children with severe emotional and behavioural problems and those with conditions such as autism had caused confusion of which the children were the casualties, she said.

See http://a4.org.au/node/743

The autistic child's fundamental right is to education. Sometimes, the goal is a "least restrictive" setting, rather than "inclusion".

For some students, "inclusion" inhibits or prevents their education. For others such as Lucy, "inclusion" is simply impractical (see <u>Loving Lucy</u> – we recommend that you listen to the audio and/or read the transcripts) … but Lucy still has the right to an appropriate and effective education in the least restrictive setting possible.

A4's concern is that *all* autistic students should access effective and appropriate education. The best advice is that "no one size fits all"; autism is a spectrum and autistic students need a spectrum of educational approaches.



Hopefully, the Commission will recognise and respect that some autistic people do not want to be always "included"; many autistic people want to be sometimes on their own. Their preference must be recognised and respected.

Some inclusion proponents recognise that autistic children, and some other children, need withdrawal spaces. They now *allow* that a reasonable level of voluntary withdrawal³ is "inclusive practice".

As the issues paper suggests, education is a 'bridging' or 'multiplier' right. Education is the foundation for 'economic, social and cultural rights' which were the first and are the most fundamental of human rights.

Intersectional approach

Violence, abuse, neglect and exploitation of autistic people arise from numerous historical prejudices.

- 1. Autism or ASD is *not* "rare" ASD diagnosis rates have risen substantially and now over 3% of Australian children are now diagnosed autistic.
- 2. Autism is *not* due to poor or detached parenting parents of autistic children are often extremely effective parents for all their children, and parent training does not cure ASD.
- 3. Neither parents nor clinicians are trying to defraud the government by over-diagnosing ASD.
- 4. An ASD diagnosis usually means the autistic person has severe of profound disability ASD is *not* mostly mild or imagined disability as some politicians and senior bureaucrats believe.
- 5. There is serious government failure to recognise the need for and to develop services and supports for autistic Australians the service required are in short supply so deliberate action to develop the required services is needed.
- 6. Outcomes for autistic people are not inevitably poor. Better outcomes are likely through best practice services and supports.
- 7. Best practice for ASD is affordable when compared to the actual cost of doing little or nothing (or of funding ineffective supports).
- 8. Most autistic students *can* learn but they need to be taught in ways that meet their needs; they may not learn in the same way as neuro-typical students.
- 9. Autistic students *can/do* communicate albeit in different ways from other students. In particular, their distressed behaviour communicates with those who are open to such dialogue.



³ Be careful with terminology: involuntary "withdrawal" is segregation, seclusion or exclusion.

Section 2 – Issues and barriers

The unacceptable outcomes for autistic students in Australian education systems result from numerous issues and barriers. The following commentary is in categories from the Commissions discussion paper.

Delayed diagnosis is a major barrier to appropriate and effective education. An undiagnosed student usually cannot access essential supports for their education. At least 2.69% of children born in 2003 have been diagnosed autistic by age 15 years but just 0.91% were diagnosed with ASD by age 6 years when they start school. In other words, at most 33.8% of autistic children are diagnosed when they start school or 2/3 of autistic students do not have an ASD diagnosis.

2.1 Access to education and learning

Most autistic students are not diagnosed when they start school so most of them start school normally. Their need for autistic supports isn't recognised until they are diagnosed which often happens well into their time at school.

Autistic students cannot access education and learning when the resources required for their education are not available in the education systems. Initially, autism was considered rare and autistic students were considered unteachable.

ASD is now much more common. And some specialist teaching methods are known to be effective for autistic students.

Education Departments have not trained and employed enough staff to teach autistic students using best practice methods and have not managed demand for teachers who can deliver best practice for all the autistic students in their systems.

Governments have known about serious failures in education for autistic students. The <u>Parliamentary Inquiry into Education of students with disabilities</u> reported in December 2002. While the report said:

4.12 Autism is singled out in this report for particular mention because the full extent of its impact is only now being recognised.

But the "particular mention" did not extend to any mention in the Committee's 19 recommendations and nothing was done to address the educational needs of autistic students.

The report identified "the quite dramatic increase in the rate of [ASD] diagnosis, which has increased four or five time over the past decade" to 2002. The increase continues⁴: the ABS SDAC estimates autistic 5-14 year olds increased from 19,000 in 2003 to 59,300 in 2012 and 99,300 in 2018.

However, crucial parts of Australia's Government are in denial about increasing ASD diagnoses:

• In 2011, <u>the Health and Ageing Portfolio told the Senate Community</u> <u>Affairs Committee</u> the:

> The Department does not collect data on autism prevalence. The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.".

⁴ Though recent data indicates that the rate of increase may be dropping.

• In 2019, the NDIS told A4 that it did not expect the ABS's estimated number of autistic Australians would increase from 2015 to 2019 (as we indicated above).

Increasing numbers of autistic Australians need increased supports for their disability across all settings, including education.

There is little evidence of service and support development to meet the needs of autistic students. There was a brief flurry of activity with the introduction of the *Helping Children with Autism* (HCWA) package from 2008 but the NDIS that replaces HCWA avoids supporting students with disability, including ASD, in education settings.

While the number of autistic students increases, the few teachers with any meaningful training in autistic education get spread even more thinly. Autistic students lose more of their access to effective teaching staff.

Especially poor outcomes in education for autistic students, is a design feature of education systems in Australia.

The lack of resources for autistic students in schools means that schools cannot meet the needs of their autistic students. Schools turn autistic students into major problems and then exclude the students from education: <u>Constantly</u> <u>suspended autistic children being 'denied an education'</u>.

Accessibility of education facilities (all stages)

Access to education in Australia is problematic for many autistic children.

Generally, autistic student can physically access school settings though some school settings cause significant discomfort for some autistic students. Some autistic students have sensory discomforts that may be causes by sound, light, smell, etc. This can prevent of limit their attendance and attention in pre-school and school.

The *Purvis vs NSW* decision in the High Court means that all schools have the legal right to exclude any autistic student if they feel there is a risk of the student having "challenging behaviour". There is no safety net for students … though state/territory education departments seem reluctant to be *seen* to have denied a student access to education.

Administrative and cultural access to education services are discussed under Gatekeeping below.

Early childhood education

Research indicates that autistic children have substantially better outcomes if/when they access evidence-based ASD-specific early intervention before and as they enter school.

The necessity for early intervention for autistic students is discussed in Early Intervention and school readiness above.

Australia's especially poor education outcomes for autistic students are discussed in Education outcomes for autistic Australians0 above.

Gatekeeping



Parents report that many mainstream primary schools are reluctant (or basically refuse) to enrol autistic students. Lilley (2013) reports on experiences in Sydney, NSW:

- This paper documents the systemic failure of all sectors of the education system to meet the promises of stated policies of school inclusion, and the continuing stigmatisation of children with autism and their families.
- This paper contributes to knowledge of sustained and ongoing exclusion practices in education, especially the role played by school gatekeepers at the point of enrolment to primary school.

Parents report that many high schools refuse autistic students when students transition from primary to high school. Instead, many autistic students are directed to special schools.

The data shows that private schools rarely enrol autistic students.

Partial enrolment

Many parents report that their autistic child is only allowed partial attendance because their school does not have the resources needed for full school attendance.

Such an arrangement provides only partial education and is a breach of the student's right to education.

A4 is concerned by the lack of data or reporting describing partial enrolment of autistic students in Australian schools.

Segregation

Almost half of autistic students spend their education in segregated settings (see above). ABS SDAC data suggests that the rate of autistic students improved between 2015 and 2018 and 55.8% of autistic student attended mainstream education. This is a substantial improvement from 48.8% in 2015.

However, this level of segregation is alarming given that 2/3 of autistic students are not diagnosed when they start school so most of them start their education with a mainstream placement.

Exclusion from school activities

Many autistic students are excluded from (not taken on) school excursions, camps and outings generally.

Many schools prefer that autistic students with below average academic performance are absent for NAPLAN tests.

And a substantial number of older students self-exclude themselves from school for a range of reasons – mostly that schools do not meet their needs.

Suspensions and expulsions

<u>The media reports</u> that in 2018, NSW schools suspended 626 kindergarten students and Queensland schools suspended 1,067 prep students. Concerns were



expressed about the lack of diagnoses but the inability of schools to professionally address behaviour issues in students is a major concern.

The same report says 32,300 NSW school students were suspended in the year, 9,000 of them primary school students. The situation is similar in other states and territories.

The gross inadequacy of behaviour support in schools (and more generally) <u>has</u> <u>been raised</u> repeatedly. Political policy makers persistently neglect the issue.

Tertiary and further education

Education outcomes for autistic students in technical and further education are unacceptable. <u>The ABS reports</u> that:

People with autism are less likely than others to complete an educational qualification beyond school and have needs for support that differ from people with other disabilities. Of those with autism, 8.1% had a bachelor degree or higher, compared with 16.1% of those with a disability and 31.2% of those without disability. All people with disability and those with no disability were also more likely to have an Advanced Diploma, Diploma or Certificate III or IV than people with autism.

2.2 Appropriateness and adaptability of education and learning

Lack of reasonable adjustments

The ABS SDAC 2018 estimates (Table 5.3) that 45.7% of autistic school students need more support in school.

And an estimated 4.3% (with a high standard error) of school age autistic Australians can't attend school due to a lack of an appropriate setting.

Education departments around the country do not seem to have much idea of what they are doing to support autistic students. It seems that their data collection may be misguided and unreliable.

It is extremely concerning that state Education Departments provided data to the Commonwealth Government, that said "19.4 per cent of students nationally have a disability or learning difficulty — ranging from 25.3 per cent in Queensland to 17 per cent in Victoria and Western Australia, 18.6 per cent in NSW and 21 per cent in South Australia" (see <u>One in five students has a disability: confidential data</u>). The ABS estimates that on average 18% of Australians have a disability, but the rate for school-age children os under 10%.

Lack of individualised supports and planning

The section on Autistic students and their "education" experience in Australia above discusses the considerable lack of support for autistic students in school settings.

Few schools are able to plan and develop the individualised supports that autistic students need. Teaching staff lack appropriate training, and they have little or no access to clinical staff with the required training and experience.



Inflexible curricula

Typically, autistic students in mainstream classes are expected to follow the class curriculum. Class curriculum is inflexible: little or no effort goes into curriculum adjustment or accommodations for autistic students.

A high proportion of autistic students attend special classes. This usually means their education is *not* based on the national curriculum; hence these students do not sit standardised tests so they are excluded from typical qualifications.

They are supported to get individualised curriculum, but their education is rarely appropriate.

Lack of culturally responsive teaching

Very little is known about autism in different cultural elements of Australia's population.

A4 suspects that autism is relatively new to all cultures and responses are pretty similar; they are all only starting to become sufficiently aware of ASD for cultural responses to emerge.

Currently, families of autistic children tend to withdraw socially, becoming isolated from their communities and their families.

Schools and education systems do not recognise autistic culture. Any cultural response, either positive or negative, is due to individual teachers and their personal approach to their students.

This aspect of education needs substantially more research and development.

Workforce capability issues

As indicated above, education systems have not recognised and responded to rapidly growing numbers of autistic students. Schools do not have the skilled staff they need.

There is no discernible workforce planning for the education sector at either the state or federal level.

Behaviour management

A4 has repeatedly advised governments in Australia that <u>behavioural needs of</u> <u>autistic Australians must be met</u>. This matters for schools too. Governments have not heeded our advice.

Few schools are able to provide professional behaviour management plans for autistic students. Typically, the behaviour management plans that schools provide:

- Omit professional and clinical supervision;
- Lack modern behaviour science; they make little or no use of reinforcement (rewards) to promote preferred behaviour ... instead using aversives (penalties and punishment, often called "consequences") hoping to reduce unwanted behaviour;
- Fail to recognise or record antecedents of (precursors for) problem behaviour;



- Blame only the autistic students for unwanted behaviour; they do not recognise any lack or failure of appropriate accommodations;
- Neglect the need to practice, master and maintain calming and mitigation strategies; and
- Involve inappropriate segregation and restraints.

Their behaviour management plans are usually ineffective and the student is suspended or expelled. And may be traumatised in the process.

The widespread practice in schools of having untrained and unregistered people developing and implementing behaviour management plans is dangerous and detrimental for autistic students.

Primary Concerns of the Royal Commission

The title of the Royal Commission identifies four specific areas of concern. The following addresses those issues.

Violence

Many autistic students experience violence at school.

Too often, parents report that their autistic children come home from school bruised and traumatised. Some of these students cannot communicate what happened to them. Typically, the school does not have an incident report, or the incident report is inconsistent, impossible or quite different from the child's account (which mean that it's fabricated).

Autistic students report high levels of violent bullying from other students. Few schools have effective ways to prevent bullying of students with disability. Autistic students learn quickly that reporting bullying usually makes their situation worse.

School staff say they can't believe what an autistic student says because the student won't look them in the eye and tell them what happened. The school staff regard poor eye contact as evidence that the autistic student lying about what happened when many autistic people have difficulty with eye contact, it's part of their disability. School staff use the autistic student's disability against the student. School staff complain that autistic students don't tell them quickly and clearly what happened — ignoring that poor communication is a key part of their ASD diagnosis. And the school staff ignore the fact that autistic students have delayed or reduced theory of mind — which means they don't really know how to lie.

Most autistic students learn very quickly that reporting bullying does not work for them. They become reasonably frustrated and anxious about their safety in school. Some are traumatised by their experience.

Autistic students also experience violence at the hands of school staff. There is a significant risk that students with distressed behaviour will be subject to violence from school staff. Sometimes pictures and videos of staff hitting children and physically dragging them around emerge.



The child is blamed and parents are accused of lying unless clear pictures or video of incidents is made public. This example shows a school principal dragging an autistic boy through a playground⁵.

And even with clear pictures as evidence, violence against autistic students is "acceptable" to and implicitly condoned by many in the community⁶.



Relatively recent media reports of violence against autistic students include:

- <u>Disabled boy 'punched' by staff at special school, court documents show</u>
- <u>Students grabbed, wrestled to the floor and strapped to chairs three or</u> <u>more times a day</u>
- Sophie's bruises appeared after a day at school but the Victorian education department won't say why

Abuse

Autistic Australians suffer persistent verbal, physical, sexual and legal abuse.

In schools, autistic students suffer constant verbal and physical abuse from both staff and other students. When staff do it, it is called "policy and procedure". When other students do it, they call it bullying.

Verbal abuse is ubiquitous. It varies across a spectrum from subtle to blatant.

Violent physical abuse is discussed above.

Reports of autistic students being restrained inappropriately in schools abound.

A4 recognises that situations arise where some form of restraint of an autistic student may be the only practical option. However, A4 also believes that schools too often fail to prevent or minimise the need for restraint which means they resort to restraint far too easily.

The education departments in Australia and their schools reject the need for trained and registered behavioural clinicians; instead, they prefer a range of untrained amateurs practice a wide range of abusive methods on autistic students.

A clear example of the lack of appropriate behavioural expertise is the repeated installation of cages for autistic students made out of heavy pool fencing.

Not so long ago, an ACT school made news with its cage for an autistic student. This is some of the media attention it got:



⁵ Media reports of the event include <u>Principal stood down after vision emerges of</u> <u>him dragging pupil along the ground</u>

⁶ See <u>Melbourne school principal who dragged boy across playground keeps his</u> job and <u>Hundreds Of Parents Back Principal Who Dragged Student By The Arm</u>

- Delays in investigation into Canberra boy locked in school cage angers
 <u>parents</u>
- <u>Autism cage details emerge as United Nations investigates abuse of children</u>
- Cage for autistic child at Canberra school a shocking wake-up call
- Image of cage in Canberra school a 'wake-up call', says disability advocate
- <u>Photo of cage used to restrain boy with autism at Canberra school</u> <u>becomes public</u>
- <u>Cage used to contain boy with autism described by staff as 'sanctuary' in</u> <u>Canberra classroom sign</u>
- <u>Boy, 10, pictured sleeping inside an 'autism cage' built to separate him</u> <u>from others in the classroom - and which teachers referred to as a</u> <u>'sanctuary'</u>
- <u>Little cause for optimism in school cage inquiry outcome</u>
- <u>ACT Government releases report in response to 'boy in cage' incident</u>
- <u>School principal loses her job over student cage inquiry</u>
- Autism group passes no confidence motion against Joy Burch over boy in cage
- <u>DPP did not advise investigators about criminal charges over autism cage</u> <u>incident in Canberra school</u>
- <u>Shock and sadness at 'cage' for Canberra school boy with autism: Ricky</u> <u>Stuart</u>
- <u>School cage scandal reforms beset by failed deadlines</u>

Despite the extensive coverage of this "incident", schools in Australia did not learn from the experience. Since then there have been more examples of this kind of abuse. Other schools have confined students and even built similar cages since the one in the ACT school.

- <u>Watchdog looking into fenced-off classroom used to isolate teen</u>
- Hobart high school 'cage' for teenagers with autism 'akin to Risdon jail'
- <u>School puts autistic boy in 'cell-like' room</u>
- <u>Family seeks damages amid allegations boy with autism locked in 'cage' at</u> <u>Sydney school</u>
- Boy with autism locked in 'cage', NSW school being investigated
- <u>Dodgy report clears Victoria's schools to cage special needs students</u>
- <u>ABC 7.30 Report: Mum 'gobsmacked' at school's response to autistic son</u> <u>being tied to restraining chair</u>
- Parents pull kids from school
- Autistic kids 'tied to chairs' at school, Senate inquiry told
- <u>Victoria Teachers banned from restraining students with straps</u> and <u>Victorian education department to investigate claims disabled children</u> <u>were locked in cages at schools</u>



• <u>Students grabbed, wrestled to the floor and strapped to chairs three or</u> <u>more times a day</u>

Because autistic students are often misunderstood, misinterpreted, restrained and inappropriately punished, autistic students experience high levels of frustration, stress and anxiety. Typically, this abuse and the associated stress for the student results in increasing distressed behaviour ... which schools usually describe as challenging or unwanted behaviour, or behaviours of concern.

Schools refuse to recognise that the student's distressed behaviour is due to the school's abusive treatment of the autistic student. The school often escalates the abuse which increases the distressed behaviour and results in exclusion, expulsion or school refusal.

Schools and education departments completely ignore the antecedents and deny their role in such adverse outcomes.

For autistic female students, the risk and actual occurrence of sexual abuse is so high that some parents regard sterilisation as an acceptable or preferred practice.

Australia's laws and its legal system⁷ abuse autistic people in relation to their education. The *Purvis vs NSW* decision denies autistic Australians the right to education.

Autistic people are ignored and mistreated in legal processes. They are denied their voice. Most of the research and commentary relates to people with intellectual disability; it neglects autistic people who typically have similar or worse experiences (because they often have more problematic distressed behaviour) in the Australian legal system.

Neglect

The Australian Governments neglect autistic citizens as much as they can.

We've shown above that education outcomes for autistic Australians are abysmal. The abolition of the education aspects of the *Helping Children with Autism* package and the lack of any discernible replacement to improve education outcomes for autistic Australians shows the Government's clear, current and pervasive neglect of autistic Australians.

Federally, successive Ministers for Disability have refused to meet with the A4, the Disability Representative Organisation for autistic Australians, for the last 4 terms of government. A4 had one meeting with an Assistant Minister but all the commitments given in that meeting failed to eventuate.

The Government ignores systemic advocacy and most or all the issues raised. For example, neither the Minister, the Assistant Minister, the Department nor the Agency responded (other than auto-reply emails) to <u>the contents of A4's letter on 4/12/2017</u>.

A Disability Minister said (see <u>http://a4.org.au/node/1761</u>):



⁷ Australia famously does not have a *Bill or Right* that ensures justice for its citizens, hence Australia has a legal system; Australia does not have a justice system.

I can assure you that no changes will be made to the NDIA's operational guidelines ... unless those changes are informed by research, evidence and extensive consultation with stakeholders and the community.

This empty assurance was abandoned within days – see <u>http://a4.org.au/node/1762</u>.

Neglect of autistic Australians is even stronger in the Commonwealth Government's Education and Health policy and planning.

And the fact that so little is known about what autistic Australians need and how policy and programs fail them, shows autism research is minimal, and largely neglected. The ABS has reported abysmal outcomes for autistic students in its SDAC report on autism since 2009 but the issue was omitted from policy development, most notably the National Disability Strategy 2010-2012.

With each survey (2009-2018), the ABS reported that

Almost half the young people with autism aged 5 to 20 years (45.9%) indicated they needed more support or assistance at school then they were receiving.

The following table shows some of the school age autistic children who are recognised in various schemes.

ABS SDAC 2018	Carer Allowance (child)	NDIS Sep-2019
5-14 years old	June 2019	age 7-14
99,300	83,429 - 5-14 yo 71,066 - 7-14 yo	49,015

The differences in these data suggest that a significant number of autistic children may have their disability support needs neglected.

Apart from the failure of the education systems, anecdotal evidence and NDIS aggregated data indicate that autistic Australians of school age have some of their important needs neglected by the NDIS.

Exploitation

Perhaps the best news in all this is that A4 does not have extensive tales of exploitation of autistic children.

The main form of exploitation is schools getting special needs funding for autistic students but using the funds for other purposes. This malpractice is especially the case when autistic students have partial attendance, sometimes on a regular basis, sometimes through exclusions, expulsion and school-refusal. In this case schools are funded for education that they are not even attempting to provide.

Mostly, schools are funded annually for their autistic students. Funding is not tied to the student so a school is funded even if the child moves school, is suspended, expelled or just does not attend. And there is no accountability for special needs funding so it is easy to exploit.



Education experiences of autistic students

A few autistic students do well in school, though this is generally due to the student and their parents. Very occasionally, a school can be credited with a good outcome for an autistic student.

The predominantly abysmal education results for autistic students show that many students are simply left behind in the mainstream settings.

Many autistic students are meant to have an Individual Education Plan (IEP). Schools start each school year with an education plan in place for typical students, but education plans for an autistic student are prepared later in the year so autistic students miss out on accessing planned education in the first part of their year. Sometimes, their plan is not in place until the second half of the year.

Schools should start each year with the IEP already in place for each student who needs one. Education planning for autistic students must not be neglected.

Schools have low expectations for many autistic students, so little or nothing is done if they fall behind their IEP. Schools just let them fall further behind. Much more care is needed in the monitoring and reporting of education outcomes for autistic students.

Jack's story

Jack had severe autism - "had" because <u>Jack died in out-of-home care</u>.

When Jack started school, he was in a class in a "special school" with other students with disability. His school did not have an individualised program for his education and he wasn't learning anything. Following unsuccessful discussion about Jack's education with the education authority, Jack's mother lodged a Disability Discrimination complaint with the ACT Disability Discrimination Tribunal.

In response, the ACT Education Department put Jack in a classroom on his own in a mainstream school with just a "teacher's aide" to teach him.

One day, early in the school year, Jack came home from school with severe bruising on his back and on the back of his limbs. His mother immediately took him to the police station. Initially, the school said it wasn't them; that it must have happened after school. It was clear to the police that such a timeline wasn't possible.

The school and its staff said they don't know what happened. Despite clear evidence of severe bruising and an undisputed timeline, the police said they could not pursue the matter because Jack could not tell them what happened – the ACT police decided Jack was not a credible witness. Jack was subject to violence and abuse at his school but no one from the school would admit anything.

Jack's mother refused to allow Jack to return to that classroom. The teacher's aide was "redeployed".

The ACT Education Department created its first autism-specific Learning Support Unit starting in the second half of the school year.

It took the ACT Discrimination Tribunal 10 years to hear Jack's disability discrimination complaint about the initial lack of an appropriate education



program. The delay in the legal system neglected Jack's need for education and denied Jack any prospect of an outcome that would benefit Jack. Evidence and court transcripts show:

- a) Jack was not given an appropriate education program/plan until after the discrimination complaint was lodged,
- b) Government representatives lied⁸ to the tribunal and proved to be unreliable witnesses.

In the end, <u>the ACT Discrimination Tribunal decided</u> that failure/refusal to provide Jack an appropriate and effective program for his education was *not discrimination*; that is, the Tribunal rejected the claim that *having* education for non-autistic students but *not having* effective education for an autistic child is *not* different/discriminatory treatment of an autistic child. The ACT Discrimination Tribunal failed/refused to recognise the lack of any functional education for Jack as an issue of human rights. Nor did the ACT Discrimination Tribunal even mention any of the proven falsehoods in the ACT Government's evidence, or any of the ACT Government representatives' other breaches of its model litigant obligation, when it wrote up its decision.

As with the aftermath of <u>the Gallop Inquiry</u>, governments and their legal system in Australia protect government officials who give false evidence in legal actions about the people with disability. The ACT Government vigorously defended a government official who the Gallop Inquiry described as unreliable witnesses. The same witness lied in Jack's matter. Clearly, ACT authorities wanted to avoid another public criticism of its public service.

The ACT Education Department improved Jack's education during and after the legal process, though it was far from plain sailing (Jack spent another year out of school because there was no suitable placement for him).

Jack didn't finish his education. Jack was left to drown in a bath in short-term disability accommodation. He was left alone in a bath despite his well-known seizures. The ensuing coronial inquest was characterised by lost and missing government records and officials with chronic memory loss. The inquest's focus, as usual, was to protect the images of NSW and ACT Governments rather than to learn from the tragedy and improve outcomes for autistic Australians.

It must be recognised that Jack was *abused* by the ACT and NSW legal systems over his right to education and his safety in out-of-home care.

Suggestions

1. Recognise that education outcomes for autistic Australians are unnecessarily poor, and that better outcomes must be achieved.

⁸ Previously, the Gallop Judicial Inquiry into fatal disability supports in the ACT had criticised an ACT Government witness as unreliable; subsequently, the ACT Government concentrated on using legal loopholes to defend its staff rather than recognise the need to improve disability supports. The same witness lied in Jack's tribunal hearings. Two other Government witnesses also lied. Governments do not conduct themselves as *model litigants* in these legal matters ... and Attorneys-General ignore complaints that governments' legal representatives are not model litigants.

- 2. Ensure Australian law protects the right of autistic Australians to appropriate and effective education.
- 3. Diagnosis of autism spectrum disorder should be as early as possible in a person's life. Australia needs to bring the age of diagnosis much lower. It could start by getting waiting lists for diagnosis down to days rather than months or even years as is now the case.
- 4. Autistic children should have ready access to complete programs of bestpractice early intervention for their ASD.
- 5. Governments need to recognise that diagnosis rates for ASD have risen substantially. Such growth has major workforce implications that need to be addressed.
- 6. The education workforce is not trained to educate autistic children in the numbers now seen in the Australian population. Major changes are needed in the workforce structure, their initial and ongoing training to adequately support autistic students.
- 7. Education outcomes for autistic students need to be fully monitored and reported within the education systems. Education systems ignore education outcomes for autistic students when they are only reported by the ABS.
- 8. Bullying in schools is a problem that is acute for autistic students. Governments need to recognise and address this major issue. It cannot be regarded as "affecting everyone" because it does not affect everyone in the same way.
- 9. Autistic students need specialist behaviour support from registered professionals both in and outside school.



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Annex A. Autism Spectrum Disorder (ASD) in the DSM-5

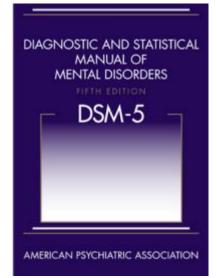
Following is the full description of Autism Spectrum Disorder (ASD) from the *Diagnostic and Statistical Manual of Mental Disorder*, *5th edition* (DSM-5) https://doi.org/10.1176/appi.books.9780890425596.dsm05.

Autism Spectrum Disorder Diagnostic Criteria 299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.



3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

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3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor (Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition)

(**Coding note**: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)



Recording Procedures

For autism spectrum disorder that is associated with a known medical or genetic condition or environmental factor, or with another neurodevelopmental, mental, or behavioral disorder, record autism spectrum disorder associated with (name of condition, disorder, or factor) (e.g., autism spectrum disorder associated with Rett syndrome). Severity should be recorded as level of support needed for each of the two psychopathological domains in Table 2 (e.g., "requiring very substantial support for deficits in social communication and requiring substantial support for restricted, repetitive behaviors"). Specification of "with accompanying intellectual impairment" or "without accompanying intellectual impairment" should be recorded next. Language impairment specification should be recorded thereafter. If there is accompanying language impairment, the current level of verbal functioning should be recorded (e.g., "with accompanying language impairment no intelligible speech" or "with accompanying language impairment-phrase speech"). If catatonia is present, record separately "catatonia associated with autism spectrum disorder."

Specifiers

The severity specifiers (see Table 2) may be used to describe succinctly the current symptomatology (which might fall below level 1), with the recognition that severity may vary by context and fluctuate over time. Severity of social communication difficulties and restricted, repetitive behaviors should be separately rated. The descriptive severity categories should not be used to determine eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets. Regarding the specifier "with or without accompanying intellectual impairment," understanding the (often uneven) intellectual profile of a child or adult with autism spectrum disorder is necessary for interpreting diagnostic features. Separate estimates of verbal and nonverbal skills are necessary (e.g., using untimed nonverbal tests to assess potential strengths in individuals with limited language).

TABLE 2 Severity levels for autism spectrum disorder			
Severity level	Social communication	Restricted, repetitive behaviors	
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/ difficulty changing focus or action.	

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TABLE 2 Severity levels for autism spectrum disorder			
Severity level	Social communication	Restricted, repetitive behaviors	
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/ or difficulty changing focus or action.	
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.	

To use the specifier "with or without accompanying language impairment," the current level of verbal functioning should be assessed and described. Examples of the specific descriptions for "with accompanying language impairment" might include no intelligible speech (nonverbal), single words only, or phrase speech. Language level in individuals "without accompanying language impairment" might be further described by speaks in full sentences or has fluent speech. Since receptive language may lag behind expressive language development in autism spectrum disorder, receptive and expressive language skills should be considered separately.

The specifier "associated with a known medical or genetic condition or environmental factor" should be used when the individual has a known genetic disorder (e.g., Rett syndrome, Fragile X syndrome, Down syndrome), a medical disorder (e.g. epilepsy), or a history of environmental exposure (e.g., valproate, fetal alcohol syndrome, very low birth weight).



Additional neurodevelopmental, mental or behavioral conditions should also be noted (e.g., attention deficit/hyperactivity disorder; developmental coordination disorder; disruptive behavior, impulse-control, or conduct disorders; anxiety, depressive, or bipolar disorders; tics or Tourette's disorder; self-injury; feeding, elimination, or sleep disorders).

Diagnostic Features

The essential features of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criteria C and D). The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment. Core diagnostic features are evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence, the term spectrum. Autism spectrum disorder encompasses disorders previously referred to as early infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder.

The impairments in communication and social interaction specified in Criterion A are pervasive and sustained. Diagnoses are most valid and reliable when based on multiple sources of information, including clinician's observations, caregiver history, and, when possible, self-report. Verbal and nonverbal deficits in social communication have varying manifestations, depending on the individual's age, intellectual level, and language ability, as well as other factors such as treatment history and current support. Many individuals have language deficits, ranging from complete lack of speech through language delays, poor comprehension of speech, echoed speech, or stilted and overly literal language. Even when formal language skills (e.g., vocabulary, grammar) are intact, the use of language for reciprocal social communication is impaired in autism spectrum disorder.

Deficits in social-emotional reciprocity (i.e., the ability to engage with others and share thoughts and feelings) are clearly evident in young children with the disorder, who may show little or no initiation of social interaction and no sharing of emotions, along with reduced or absent imitation of others' behavior. What language exists is often one-sided, lacking in social reciprocity, and used to request or label rather than to comment, share feelings, or converse. In adults without intellectual disabilities or language delays, deficits in social-emotional reciprocity may be most apparent in difficulties processing and responding to complex social cues (e.g., when and how to join a conversation, what not to say). Adults who have developed compensation strategies for some social challenges still struggle in novel or unsupported situations and suffer from the effort and anxiety of consciously calculating what is socially intuitive for most individuals.

Deficits in nonverbal communicative behaviors used for social interaction are manifested by absent, reduced, or atypical use of eye contact (relative to cultural



norms), gestures, facial expressions, body orientation, or speech intonation. An early feature of autism spectrum disorder is impaired joint attention as manifested by a lack of pointing, showing, or bringing objects to share interest with others, or failure to follow someone's pointing or eye gaze. Individuals may learn a few functional gestures, but their repertoire is smaller than that of others, and they often fail to use expressive gestures spontaneously in communication. Among adults with fluent language, the difficulty in coordinating nonverbal communication with speech may give the impression of odd, wooden, or exaggerated "body language" during interactions. Impairment may be relatively subtle within individual modes (e.g., someone may have relatively good eye contact when speaking) but noticeable in poor integration of eye contact, gesture, body posture, prosody, and facial expression for social communication.

Deficits in developing, maintaining, and understanding relationships should be judged against norms for age, gender, and culture. There may be absent, reduced, or atypical social interest, manifested by rejection of others, passivity, or inappropriate approaches that seem aggressive or disruptive. These difficulties are particularly evident in young children, in whom there is often a lack of shared social play and imagination (e.g., age-appropriate flexible pretend play) and, later, insistence on playing by very fixed rules. Older individuals may struggle to understand what behavior is considered appropriate in one situation but not another (e.g., casual behavior during a job interview), or the different ways that language may be used to communicate (e.g., irony, white lies). There may be an apparent preference for solitary activities or for interacting with much younger or older people. Frequently, there is a desire to establish friendships without a complete or realistic idea of what friendship entails (e.g., one-sided friendships or friendships based solely on shared special interests). Relationships with siblings, co-workers, and caregivers are also important to consider (in terms of reciprocity).

Autism spectrum disorder is also defined by restricted, repetitive patterns of behavior, interests, or activities (as specified in Criterion B), which show a range of manifestations according to age and ability, intervention, and current supports. Stereotyped or repetitive behaviors include simple motor stereotypies (e.g., hand flapping, finger flicking), repetitive use of objects (e.g., spinning coins, lining up toys), and repetitive speech (e.g., echolalia, the delayed or immediate parroting of heard words; use of "you" when referring to self; stereotyped use of words, phrases, or prosodic patterns). Excessive adherence to routines and restricted patterns of behavior may be manifest in resistance to change (e.g., distress at apparently small changes, such as in packaging of a favorite food; insistence on adherence to rules; rigidity of thinking) or ritualized patterns of verbal or nonverbal behavior (e.g., repetitive questioning, pacing a perimeter). Highly restricted, fixated interests in autism spectrum disorder tend to be abnormal in intensity or focus (e.g., a toddler strongly attached to a pan; a child preoccupied with vacuum cleaners; an adult spending hours writing out timetables). Some fascinations and routines may relate to apparent hyper- or hyporeactivity to sensory input, manifested through extreme responses to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects, and sometimes apparent indifference to pain, heat, or cold. Extreme reaction to or rituals involving taste, smelt texture, or appearance of food or excessive food restrictions are common and may be a presenting feature of autism spectrum disorder.

A4 Autism Aspergers Advocacy Australia

Many adults with autism spectrum disorder without intellectual or language disabilities learn to suppress repetitive behavior in public. Special interests may be a source of pleasure and motivation and provide avenues for education and employment later in life. Diagnostic criteria may be met when restricted, repetitive patterns of behavior, interests or activities were clearly present during childhood or at some time in the past, even if symptoms are no longer present.

Criterion D requires that the features must cause clinically significant impairment in social, occupational, or other important areas of current functioning. Criterion E specifies that the social communication deficits, although sometimes accompanied by intellectual disability (intellectual developmental disorder), are not in line with the individual's developmental level; impairments exceed difficulties expected on the basis of developmental level. Standardized behavioral diagnostic instruments with good psychometric properties, including caregiver interviews, questionnaires and clinician observation measures, are available and can improve reliability of diagnosis over time and across clinicians.

Associated Features Supporting Diagnosis

Many individuals with autism spectrum disorder also have intellectual impairment and/ or language impairment (e.g., slow to talk, language comprehension behind production). Even those with average or high intelligence have an uneven profile of abilities. The gap between intellectual and adaptive functional skills is often large. Motor deficits are often present, including odd gait, clumsiness, and other abnormal motor signs (e.g., walking on tiptoes). Self-injury (e.g., head banging, biting the wrist) may occur, and disruptive/challenging behaviors are more common in children and adolescents with autism spectrum disorder than other disorders, including intellectual disability. Adolescents and adults with autism spectrum disorder are prone to anxiety and depression. Some individuals develop catatonic-like motor behavior (slowing and "freezing" mid-action), but these are typically not of the magnitude of a catatonic episode. However, it is possible for individuals with autism spectrum disorder to experience a marked deterioration in motor symptoms and display a full catatonic episode with symptoms such as mutism, posturing, grimacing and waxy flexibility. The risk period for comorbid catatonia appears to be greatest in the adolescent years.

Prevalence

In recent years, reported frequencies for autism spectrum disorder across U.S. and non-U.S. countries have approached 1% of the population, with similar estimates in child and adult samples. It remains unclear whether higher rates reflect an expansion of the diagnostic criteria of DSM-IV to include subthreshold cases, increased awareness, differences in study methodology, or a true increase in the frequency of autism spectrum disorder.

Development and Course

The age and pattern of onset also should be noted for autism spectrum disorder. Symptoms are typically recognized during the second year of life (12-24 months of age) but may be seen earlier than 12 months if developmental delays are severe, or noted later than 24 months if symptoms are more subtle. The pattern of onset



description might include information about early developmental delays or any losses of social or language skills. In cases where skills have been lost, parents or caregivers may give a history of a gradual or relatively rapid deterioration in social behaviors or language skills. Typically, this would occur between 12 and 24 months of age and is distinguished from the rare instances of developmental regression occurring after at least 2 years of normal development (previously described as childhood disintegrative disorder). The behavioral features of autism spectrum disorder first become evident in early childhood, with some cases presenting a lack of interest in social interaction in the first year of life. Some children with autism spectrum disorder experience developmental plateaus or regression, with a gradual or relatively rapid deterioration in social behaviors or use of language, often during the first 2 years of life. Such losses are rare in other disorders and may be a useful "red flag" for autism spectrum disorder. Much more unusual and warranting more extensive medical investigation are losses of skills beyond social communication (e.g., loss of self-care, toileting, motor skills) or those occurring after the second birthday (see also Rett syndrome in the section "Differential Diagnosis" for this disorder). The essential features of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities.

First symptoms of autism spectrum disorder frequently involve delayed language development, often accompanied by lack of social interest or unusual social interactions (e.g., pulling individuals by the hand without any attempt to look at them), odd play patterns (e.g., carrying toys around but never playing with them), and unusual communication patterns (e.g., knowing the alphabet but not responding to own name). Deafness may be suspected but is typically ruled out. During the second year, odd and repetitive behaviors and the absence of typical play become more apparent. Since many typically developing young children have strong preferences and enjoy repetition (e.g., eating the same foods, watching the same video multiple times), distinguishing restricted and repetitive behaviors that are diagnostic of autism spectrum disorder can be difficult in preschoolers. The clinical distinction is based on the type, frequency, and intensity of the behavior (e.g., a child who daily lines up objects for hours and is very distressed if any item is moved).

Autism spectrum disorder is not a degenerative disorder, and it is typical for learning and compensation to continue throughout life. Symptoms are often most marked in early childhood and early school years, with developmental gains typical in later childhood in at least some areas (e.g., increased interest in social interaction). A small proportion of individuals deteriorate behaviorally during adolescence, whereas most others improve. Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from the stress and effort of maintaining a socially acceptable facade. Scarcely anything is known about old age in autism spectrum disorder.

A4 Autism Aspergers Advocacy Australia

Some individuals come for first diagnosis in adulthood, perhaps prompted by the diagnosis of autism in a child in the family or a breakdown of relations at work or home. Obtaining detailed developmental history in such cases may be difficult, and it is important to consider self-reported difficulties. Where clinical observation suggests criteria are currently met, autism spectrum disorder may be diagnosed, provided there is no evidence of good social and communication skills in childhood. For example, the report (by parents or another relative) that the individual had ordinary and sustained reciprocal friendships and good nonverbal communication skills throughout childhood would rule out a diagnosis of autism spectrum disorder; however, the absence of developmental information in itself should not do so.

Manifestations of the social and communication impairments and restricted/repetitive behaviors that define autism spectrum disorder are clear in the developmental period. In later life, intervention or compensation, as well as current supports, may mask these difficulties in at least some contexts. However, symptoms remain sufficient to cause current impairment in social, occupational, or other important areas of functioning.

Risk and Prognostic Factors

The best established prognostic factors for individual outcome within autism spectrum disorder are presence or absence of associated intellectual disability and language impairment (e.g., functional language by age 5 years is a good prognostic sign) and additional mental health problems. Epilepsy, as a comorbid diagnosis, is associated with greater intellectual disability and lower verbal ability.

Environmental. A variety of nonspecific risk factors, such as advanced parental age, birth weight, or fetal exposure to valproate, may contribute to risk of autism spectrum disorder.

Genetic And Physiological. Heritability estimates for autism spectrum disorder have ranged from 37% to higher than 90%, based on twin concordance rates. Currently, as many as 15% of cases of autism spectrum disorder appear to be associated with a known genetic mutation, with different de novo copy number variants or de novo mutations in specific genes associated with the disorder in different families. However, even when an autism spectrum disorder is associated with a known genetic mutation, it does not appear to be fully penetrant. Risk for the remainder of cases appears to be polygenic, with perhaps hundreds of genetic loci making relatively small contributions.

Culture-Related Diagnostic Issues

Cultural differences will exist in norms for social interaction, nonverbal communication, and relationships, but individuals with autism spectrum disorder are markedly impaired against the norms for their cultural context. Cultural and socioeconomic factors may affect age at recognition or diagnosis; for example, in the United States, late or underdiagnosis of autism spectrum disorder among African American children may occur.



Gender-Related Diagnostic Issues

Autism spectrum disorder is diagnosed four times more often in males than in females. In clinic samples, females tend to be more likely to show accompanying intellectual disability, suggesting that girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties.

Functional Consequences of Autism Spectrum Disorder

In young children with autism spectrum disorder, lack of social and communication abilities may hamper learning, especially learning through social interaction or in settings with peers. In the home, insistence on routines and aversion to change, as well as sensory sensitivities, may interfere with eating and sleeping and make routine care (e.g., haircuts, dental work) extremely difficult. Adaptive skills are typically below measured IQ. Extreme difficulties in planning, organization, and coping with change negatively impact academic achievement, even for students with above-average intelligence. During adulthood, these individuals may have difficulties establishing independence because of continued rigidity and difficulty with novelty. Many individuals with autism spectrum disorder, even without intellectual disability, have poor adult psychosocial functioning as indexed by measures such as independent living and gainful employment. Functional consequences in old age are unknown, but social isolation and communication problems (e.g., reduced help-seeking) are likely to have consequences for health in older adulthood.

Differential Diagnosis

Rett Syndrome. Disruption of social interaction may be observed during the regressive phase of Rett syndrome (typically between 1-4 years of age); thus, a substantial proportion of affected young girls may have a presentation that meets diagnostic criteria for autism spectrum disorder. However, after this period, most individuals with Rett syndrome improve their social communication skills, and autistic features are no longer a major area of concern. Consequently, autism spectrum disorder should be considered only when all diagnostic criteria are met.

Selective Mutism. In selective mutism, early development is not typically disturbed. The affected child usually exhibits appropriate communication skills in certain contexts and settings. Even in settings where the child is mute, social reciprocity is not impaired, nor are restricted or repetitive patterns of behavior present.

Language Disorders And Social (Pragmatic) Communication Disorder. In some forms of language disorder, there may be problems of communication and some secondary social difficulties. However, specific language disorder is not usually associated with abnormal nonverbal communication, nor with the presence of restricted, repetitive patterns of behavior, interests, or activities.

When an individual shows impairment in social communication and social interactions but does not show restricted and repetitive behavior or interests, criteria for social (pragmatic) communication disorder, instead of autism spectrum disorder, may be met. The diagnosis of autism spectrum disorder supersedes that of social



(pragmatic) communication disorder whenever the criteria for autism spectrum disorder are met, and care should be taken to enquire carefully regarding past or current restricted/ repetitive behavior.

Intellectual Disability (Intellectual Developmental Disorder) Without Autism Spectrum Disorder. Intellectual disability without autism spectrum disorder may be difficult to differentiate from autism spectrum disorder in very young children. Individuals with intellectual disability who have not developed language or symbolic skills also present a challenge for differential diagnosis, since repetitive behavior often occurs in such individuals as well. A diagnosis of autism spectrum disorder in an individual with intellectual disability is appropriate when social communication and interaction are significantly impaired relative to the developmental level of the individual's nonverbal skills (e.g., fine motor skills, nonverbal problem solving). In contrast, intellectual disability is the appropriate diagnosis when there is no apparent discrepancy between the level of social communicative skills and other intellectual skills.

Stereotypic Movement Disorder. Motor stereotypies are among the diagnostic characteristics of autism spectrum disorder, so an additional diagnosis of stereotypic movement disorder is not given when such repetitive behaviors are better explained by the presence of autism spectrum disorder. However, when stereotypies cause self-injury and become a focus of treatment, both diagnoses may be appropriate.

Attention-Deficit/Hyperactivity Disorder. Abnormalities of attention (overly focused or easily distracted) are common in individuals with autism spectrum disorder, as is hyperactivity. A diagnosis of attention-deficit / hyperactivity disorder (ADHD) should be considered when attentional difficulties or hyperactivity exceeds that typically seen in individuals of comparable mental age.

Schizophrenia. Schizophrenia with childhood onset usually develops after a period of normal, or near normal, development. A prodromal state has been described in which social impairment and atypical interests and beliefs occur, which could be confused with the social deficits seen in autism spectrum disorder. Hallucinations and delusions, which are defining features of schizophrenia, are not features of autism spectrum disorder. However, clinicians must take into account the potential for individuals with autism spectrum disorder to be concrete in their interpretation of questions regarding the key features of schizophrenia (e.g., "Do you hear voices when no one is there?" "Yes [on the radio]"). 11

Comorbidity

Autism spectrum disorder is frequently associated with intellectual impairment and structural language disorder (i.e., an inability to comprehend and construct sentences with grammar), which should be noted under the relevant specifiers when applicable. Many individuals with autism spectrum disorder have psychiatric symptoms that do not form part of the diagnostic criteria for the disorder (about 70% of individuals with autism spectrum disorder may have one comorbid mental disorder, and 40% may have two or more mental disorders). When criteria for both ADHD and autism spectrum disorder are met, both diagnoses should be given. This same principle applies to concurrent diagnoses of autism spectrum disorder and developmental coordination



disorder, anxiety disorders, depressive disorders, and other comorbid diagnoses. Among individuals who are nonverbal or have language deficits, observable signs such as changes in sleep or eating and increases in challenging behavior should trigger an evaluation for anxiety or depression. Specific learning difficulties (literacy and numeracy) are common, as is developmental coordination disorder. Medical conditions commonly associated with autism spectrum disorder should be noted under the "associated with a known medical/genetic or environmental/acquired condition" specifier. Such medical conditions include epilepsy, sleep problems, and constipation. Avoidant-restrictive food intake disorder is a fairly frequent presenting feature of autism spectrum disorder, and extreme and narrow food preferences may persist.

from https://www.autismnj.org/document.doc?id=20



Annex B. Autistic Students in the Media

Following are links to some of the media report describing violence, abuse, neglect and exploitation of autistic students in recent years.

- 1. <u>School puts autistic boy in 'cell-like' room</u> 3/2019
- 2. <u>'Minimal progress': State sued for 'abandoning' autistic boy's education</u>
- 3. <u>'It doesn't make sense': More than 600 kindy kids suspended last year</u>
- 4. <u>'Something is wrong': Inquiry hears harrowing school violence stories</u>
- 5. <u>a short list of recent "isolated incidents"</u>
- 6. Mother accuses school of restraining autistic son
- 7. Hobart high school 'cage' for teenagers with autism 'akin to Risdon jail'
- 8. <u>Prestigious school forced to apologise to autistic girl's family</u>
- 9. Psychologist accused of assaulting student with autism tried to calm boy, court told and WA: Former Christ Church Grammar school psychologist Agni Angelkovska 'simply lost the plot' in attack on autistic student
- 10. Boy with autism locked in 'cage', NSW school being investigated
- 11. More Victorian students diagnosed with severe behaviour disorders
- 12. ABC 7.30 Report: Mum 'gobsmacked' at school's response to autistic son being tied to restraining chair
- 13. <u>Concerns raised after girl with autism placed in cardboard 'box' enclosure in classroom</u>
- 14. <u>'Like a jail sentence': Teen with special needs isolated at school</u>
- 15. <u>Family seeks damages amid allegations boy with autism locked in 'cage' at Sydney</u> <u>school</u>
- 16. <u>Sophie's bruises appeared after a day at school but the Victorian education</u> <u>department won't say why</u>
- 17. <u>School left teen with autism outside on a beanbag for a whole term to control difficult behaviour</u>
- 18. <u>Report on school suspensions</u>
- 19. Autism: Queensland schools still expelling children despite review
- 20. Autistic boy deemed 'too wordy' for special school
- 21. <u>Use of cage for boy with autism at Canberra school prompts call for national</u> <u>education standard and Child reportedly contained in cage-like structure at ACT</u> <u>primary school and School cage disgrace: Eight staff reprimanded but not a single</u> <u>person sacked for building a steel enclosure to lock up an autistic boy</u>
- 22. <u>Mother claims her autistic son, eight, was locked in a plywood box with only</u> <u>PEEPHOLES by school teachers to 'calm him down' - before he was expelled for 'bad</u> <u>behaviour'</u>
- 23. Autistic kids 'caged' at school
- 24. Outrage over Seven Hills West Public School putting autistic children in cage
- 25. <u>School refusal: Anxious kids miss months, even years of class</u>
- 26. <u>Melbourne boy with autism attacked by spanner-wielding teens outside Northcote</u> <u>school</u>
- 27. 'My son with Asperger's received a petition at school telling him he's disgusting'



- 28. <u>Aspect Macarthur School denies locking autistic boy into cage-like structure</u>
- 29. 'Ready to try anything': Parents say education is failing autistic kids
- 30. <u>Autistic teen found gagged and tied up in toilet block at Croydon Special</u> <u>Developmental School</u>
- 31. Parents pull kids from school
- 32. <u>Disabled student's family launches human rights complaint against Balnarring</u> <u>Primary School</u>
- 33. School sends students to 'naughty classroom'
- 34. Autistic five-year-old suspended from Prep school
- 35. 'Intolerant' parents push special needs child out of Knox school
- 36. <u>Mum claims she was kept in the dark after out of school hours carer allegedly</u> <u>attacked her autistic son in fast food restaurant</u>
- 37. School accused of locking kids in cages
- 38. <u>Probe ordered into claim primary school held student with autism in small plywood</u> <u>room</u>
- 39. Disabled victims of abuse in school 'failed' by education department
- 40. Autistic kids 'tied to chairs' at school, Senate inquiry told
- 41. Watchdog looking into fenced-off classroom used to isolate teen
- 42. <u>School boy with autism stranded in Dural</u>
- 43. Disabled boy 'punched' by staff at special school, court documents show
- 44. Children with disability are being excluded from education
- 45. Irate dad says his disabled daughter was bound on a school bus
- 46. <u>'Massive pressure': special needs classes clustered in Sydney's west</u>
- 47. <u>Widespread bullying and abuse of children with disability at school: report to federal</u> <u>senate inquiry</u>
- 48. School locked autistic children in dark room, parents claim
- 49. <u>Outrage as autistic boy is chained to a chair using a weighted belt and ankle straps</u> <u>during school lessons to 'keep him under control'</u>
- 50. Too costly to help disabled at school
- 51. Child with autism allegedly locked in Kotara South Public School cupboard
- 52. <u>School Attendance Exemptions for Special Needs Students</u>
- 53. <u>Strapped in and locked up: Shocking photos reveal how autistic children are treated</u> <u>in Australian schools</u>
- 54. <u>Caleb has autism, needs dialysis and a new kidney but Canberra Hospital says it</u> <u>can't help him</u>
- 55. Dodgy report clears Victoria's schools to cage special needs students
- 56. How schools avoid enrolling children with disabilities
- 57. <u>Education Victoria and "martial arts therapy" for "special students"</u>
- 58. <u>Staffing boost for young autistic man confined to a dingy room</u>
- 59. <u>Victorian education department to investigate claims disabled children were locked</u> <u>in cages at schools</u>
- 60. Autism Queensland: Mum fights Brisbane Boys' College over expulsion



- 61. Family to pay discrimination case costs
- 62. <u>Ivanhoe Girls' Grammar reaches confidential settlement with 10-year-old autistic</u> <u>girl over discrimination claims</u>
- 63. Disability carer recorded saying 'I just wanna f***ing beat these kids without risk'
- 64. Dismay at report on locking up children with disabilities
- 65. Minister calls for probe into claims autistic student left alone in classroom
- 66. <u>Children with disability face deep-seated discrimination in Victorian schools,</u> <u>Monash University report shows</u>
- 67. <u>'Courtney had a knife out in public but she didn't deserve to die'</u>
- 68. Disability inclusion practices failing some families, says experienced WA educator
- 69. <u>'It is a lonely experience': the students barred from camps and excursions</u>
- 70. Parents in disabled kids fight
- 71. Damning report into NSW schools finds 'unacceptable' mistreatment
- 72. <u>Maitland mum calls for better support for children with disabilities in mainstream</u> <u>schools</u>
- 73. Mother of autistic child speaks out for Tasmania's disabled children
- 74. <u>Students grabbed, wrestled to the floor and strapped to chairs three or more times a day</u>
- 75. <u>Schools telling disabled children to stay at home</u>
- 76. <u>Parents forced to homeschool autistic children because of lack of understanding in</u> <u>mainstream schools, advocates say</u>
- 77. Government investigates 246 reports of abuse of disabled children in NSW schools
- 78. Autistic boy told to seek 'alternative education' after axing of program
- 79. Desperate parents in classroom-support fight for children with disabilities
- 80. Autistic kids under siege
- 81. Disabled children shut out of private schools
- 82. <u>Mothers tell of horror at home</u>
- 83. <u>Kids incarcerated in Australia have 'alarming' levels of neurodevelopmental</u> <u>impairment</u>
- 84. Police who shot teen made 'good choices' to protect themselves, Commissioner says
- 85. Autism and schools there's a long way to go
- 86. to Victorian Education official: "every word you wrote is inaccurate".
- 87. Vic Education says too many donuts cause failure to learn
- 88. Couple forced to give up son
- 89. Boy with severe autism 'threatened with fake gun' outside Dickson shops
- 90. Students with autism and emotional disorders exiled for disorderly conduct
- 91. Parents' exhausting battle with education system
- 92. Constantly suspended autistic children being 'denied an education'
- 93. Multiple mistakes admitted by Education Department
- 94. Taskforce says schools 'fail' on disability with full Gonski funds needed
- 95. Schools quicker to suspend autistic children, says report



- 96. Rocketing autism numbers met with education shortfall
- 97. <u>Disabled students pursue neglect claims</u>
- 98. <u>UN asked to investigate 'abuses' of disabled students in Australian schools</u>
- 99. Disabled youth more abused than others
- 100. Autistic boy, 7, expelled from Mosman's The Kids Cottage after-school care via email
- 101. Opinion: NSW public schools receive an 'F' for disabled kids
- 102. <u>Report of the Select Committee on access to the South Australian education system</u> <u>for students with a disability</u>
- 103. The teachers using physical force to manage autistic children.
- 104. 'Special Schools' Can Only Do So Much
- 105. 'No discrimination' of Asperger's boy
- 106. Schools treating children with autism like terror suspects
- 107. Petition, Victoria: stop restraint/abuse of disabled children in schools
- 108. Students with disabilities subjected to 'harmful' control measures at schools
- 109. Disabled boy wins secret payout from Victorian Government
- 110. Parents of disabled children rebel against suspensions
- 111. Autism restraints 'not uncommon': Disability advocates
- 112. Death of autistic boy at Kyneton a 'tragic accident', coroner rules
- 113. <u>Schools failing students with disabilities, teachers need more training: Senate committee finds</u>
- 114. 'We almost lost him': Canberrans with special needs turned away from hospital
- 115. Autistic boy's family appeals to Scott Morrison
- 116. <u>Schools need more support for children with autism</u>
- 117. Some parents and doctors faking autism diagnosis to get help for kids
- 118. Children with autism 40 times more likely to die from injury, study says
- 119. A mother chained up her autistic son. And I understand why.
- 120. <u>Education minister responds to allegations of boy with autism being locked in cupboard</u>
- 121. <u>Capped funds for pupils with disabilities</u>
- 122. <u>Beau Abela wants \$300,000 compo from Education Department because he can't</u> <u>read properly</u>
- 123. destruction of a family
- 124. Funds call as autism students numbers triple
- 125. Schools fail to cope with explosion in autism diagnoses
- 126. letter: need to act on NDIA's mad transport/travel policy
- 127. Australian Governments don't educate children with autism
- 128. Autistic pupils unfairly treated
- 129. Family forced to head to UK for autistic son's sake
- 130. Psychologist warns funding needed to avoid special needs 'mess'
- 131. Children in group homes face criminal charges for breaking coffee cups, says report



- 132. A bright boy forced to jump through hoops
- 133. Girls with autism or ADHD symptoms not taken seriously
- 134. 'Padded cells' at Perth schools reports among calls to disability abuse hotline
- 135. Boy, 16, found chained up in Blacktown home
- 136. Victoria Teachers banned from restraining students with straps
- 137. Dozens of NSW teachers investigated for alleged assaults against students with <u>autism, data shows</u>
- 138. The missing generation
- 139. Magician pleads guilty to unlawful death of autistic boy left to freeze in shed
- 140. Disabled Students Are Spanked More
- 141. <u>Attorney General reply to open letter</u>
- 142. Michael Ormsby, the boy who died because we didn't do enough



Annex C. Extract from Senate Estimates

<u>Senator WATT:</u> Does the NDIA have concerns about the number of people with autism entering the scheme?

Mr De Luca: Does it have any concerns with it? Our focus is to make sure that those eligible for the scheme get into the scheme. At the moment, 29 per cent of our active participants have a primary disability of autism. The Productivity Commission's expectation at full scheme was around 20 per cent. So it's not materially different to what the Productivity Commission's expectations were.

Senator WATT: I would have thought 10 per cent is a pretty big—

Mr De Luca: Yes, and the slight difference is that the way the bilateral agreements were put in place was based on different participants across the country getting in at different times. In South Australia, for example, children were first. A large proportion of the children in the scheme have autism. So it really depends on where we are in the phase of the rollouts. Over time, we would expect the numbers to be broadly in line with what the Productivity Commission estimated, but we continue to monitor that to understand any variances and differences to those assumptions.

<u>Senator WATT:</u> Do you think that the number of people entering the scheme with autism poses a risk to the sustainability of the scheme?

Mr De Luca: In itself?

Senator WATT: Yes.

Mr De Luca: I think the key focus for us from a sustainability perspective is a number of things we need to continue to monitor, including making sure we've got the right people in the scheme with the right packages. That's really core to what we need to focus our attention on. Whether it's autism or other disabilities, we monitor that in line with the expectations.

<u>Senator WATT:</u> So autism numbers are no greater threat to the sustainability of the scheme than many other factors?

Mr De Luca: Well, I think each of them is different in its own situation. Depending, obviously, on the total number of people in the scheme, if you have a large proportion of one cohort, you need to have a look at whether that cohort's cost of their packages varies from the expectations. So it's not just about the number; it's about the package and then the tenure of how long they would be in the scheme based on exit assumptions as well.

Ms Rundle: It's also important to make the point here that we've been within budget every single year of operation and remain within budget. Whilst we monitor carefully, as Mr De Luca has just said, we haven't exceeded our scheme envelope year on year.

Mr Lye: The intention here is not based around concern that autism is out of control or is that it's too high a proportion of scheme costs. The concern here is



around an area of disability which, relative to other areas, is not as well understood. The interventions that work aren't as well documented, and I think we have a lot of work to do in policy terms to say, 'Okay, what's a fair way what's the best way—to work out who comes into the scheme, what they might need and what's the most effective intervention?' For autism, relative to other areas, we don't know as much, and we have to pay attention to that—most importantly because it's an insurance based scheme, and we want to actually get better at devising interventions that work and then maximise the outcomes for people who have the benefit of the scheme. This isn't coming at it from a view that it's a problem that we need to contain or where we need to restrict access. It's around understanding better what the needs of people are out there in the community and how we can help them.

<u>Senator WATT:</u> What does your actuarial evidence say, Mr De Luca, about the cost impact on the scheme if the levels of entry to the scheme for autism go on the way they are?

Mr De Luca: I'm trying to understand the question. What do our actuarial insights tell us if the current trajectory of those with autism get into the scheme?

<u>Senator WATT:</u> Correct—if that continues into the future.

Mr De Luca: In terms of being at 29 per cent versus 20 per cent?

<u>Senator WATT:</u> Yes. Let's start with: would you anticipate further growth beyond 29 per cent over the next five or 10 years if changes aren't made?

Mr De Luca: Obviously, estimates are estimates, and the Productivity Commission did some work on the estimates of the scheme. But everything that we've been seeing to date broadly supports those estimates and the PC's recent review acknowledged that, basically, in terms of the cost view that we had, based on our current experience of the scheme, the 2020 estimates is the best estimates that exist. Therefore, there's nothing materially different, at this point in time, based on experience, that gives us concern. Obviously, as Ms Rundle and Mr Lye alluded to, it's an insurance scheme, and an insurance scheme allows us then to look at and monitor experiences and recognise whether there are other interventions that are required at any point in time. Where we sit today, the 2020 estimate for the scheme is that that the Productivity Commission put in play, based on our experience.

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