

***A submission on health
care for autistic
Australians***

*responding to
the Royal Commission's
Health care for people with cognitive
disability Issues Paper*

20/3/2020

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Introduction

Autism Aspergers Advocacy Australia (A4) appreciates that the Royal Commission includes “autism” in its list of cognitive disabilities.

5 We also appreciate the opportunity that the Royal Commission provides for us to respond to its [Health care for people with cognitive disability Issues paper](#) and to describe health care for autistic Australians. It is a matter of grave concern to us that there are major flaws evident in health and mental health services for autistic Australians.

10 The following submission focuses on experiences of autistic people in health-care systems around the country. A4 does not represent or speak for people with other types of disability.

About Autism Spectrum Disorder

15 The *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (2013), known as the DSM-5, sets current criteria for diagnosing Autism Spectrum Disorder (ASD). The full criteria and the associated commentary are [available from A4’s website](#).

20 Previous editions of the diagnostic manual, DSM-IV (1994) and DSM-IV-TR (2000), separated pervasive developmental disorders into five sub-types:

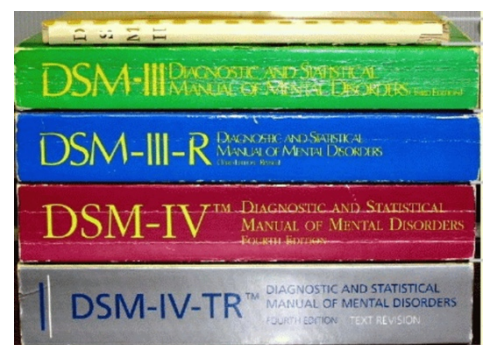
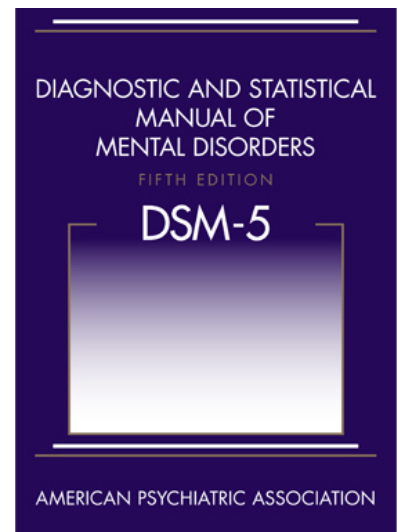
- Autistic Disorder
- Asperger’s Disorder
- Pervasive Developmental Disorder – not otherwise specified (PDD-NOS)
- 25 • Rett’s disorder
- Childhood disintegrative disorder (CDD)

Since then:

- 30 • The DSM-5 merged Autistic Disorder, Asperger’s disorder, PDD-NOS and CDD into a single disorder, Autism Spectrum Disorder, which it classes as a neurological disorder;
- The genetics of Rett’s disorder have been identified, which moves it to a “genetic disorders” category.

35 The World Health Organisation essentially followed the lead of the DSM-IV and DSM-5 in relation to autism in its ICD-10 and emerging ICD-11 classification systems.

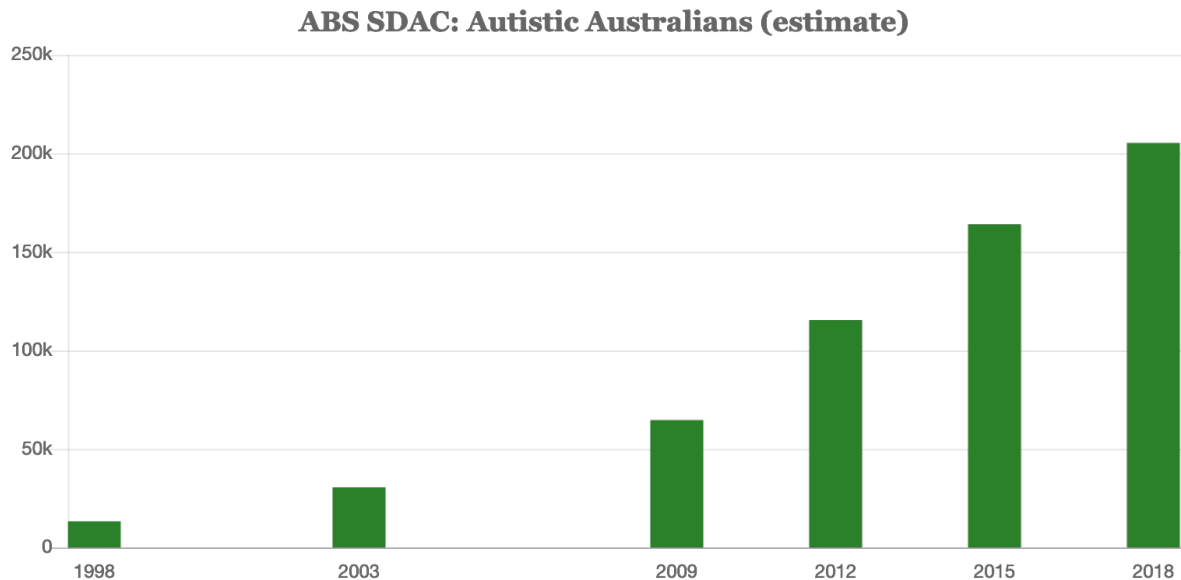
40 Please note that the following information uses identity-first language, which is the stated preference of autistic people (see pages on the [ASAN-AUNZ](#) and [Amaze](#) websites).



ASD in Australia

The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), conducted periodically, collects data about autistic Australians.

5 The overall number of Australians known to be autistic has increased substantially over the past 20 years.



These data show substantial increases in numbers that contradict advice that there is no “major shifts in prevalence of autism in Australia” that the Health Department gave to [Senate Estimates in 2011](#):

10 The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.

15 A4 is not aware that the Health Department has revised its view since then, even though the ABS published a series of reports ([2009](#), [2012](#), [2015](#) and [2018](#)) documenting continued increases in ASD diagnoses. The Health Department’s lack of awareness represents alarming *neglect* of autistic Australians and their growing needs for health-related services.

Since 2009, the ABS has reported specifically on autism in Australia. [The latest ABS report on autism in Australia \(2018\)](#) is available online.

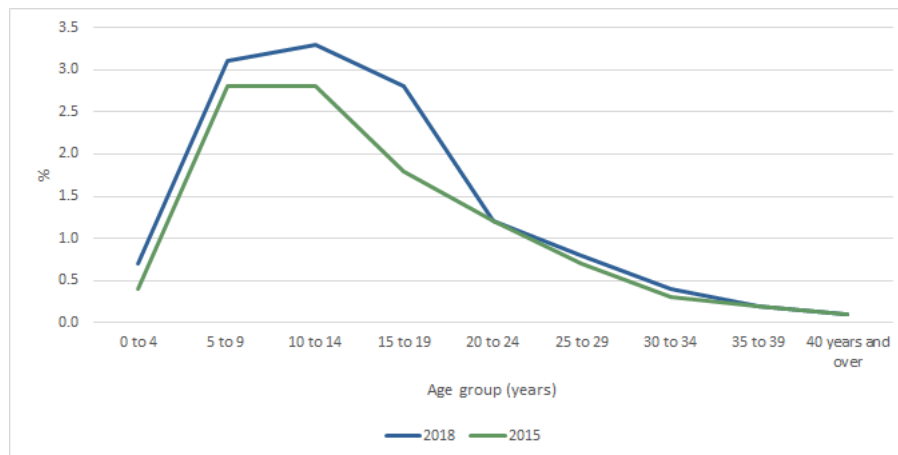
The following table shows the age breakdown from the survey over the last two decades.

<i>'000s of autistic Australians</i>							
<i>Age/year</i>	<i>1998</i>	<i>2003</i>	<i>2009</i>	<i>2012</i>	<i>2015</i>	<i>2018</i>	
0-4 years	1.0	1.2	3.5	6.0	6.2	10.8	
5-9 years	10.5	8.2	19.4	33.0	41.9	49.0	
10-14 years		10.8	19.2	26.4	39.4	50.3	
15-19 years	1.7	3.9	11.4	21.8	26.4	40.2	
20-24 years		6.2	3.7	11.5	20.0	19.8	
25-29 years			4.6	2.8	3.5	11.9	15.6
30-34 years				3.2	5.1	7.1	
35-39 years		2.7		2.5	3.5		
40 years and over		7.0		6.9	8.4		
Total		13.2	30.4	64.6	115.4	164.0	205.2

In summary:

- Autism diagnoses increased 15.5 times from 1998 to 2018 (20 years) or 3.18 times from 2009 to 2018 (9 years); diagnosis numbers for younger Australians increasing substantially over the last two decades
- Over 3% of children aged five to 14 years were diagnosed as autistic in 2018, but diagnosis rates for adults are much lower; and
- Diagnosis rates vary enormously with age and over time, so it is misleading to talk about an overall average diagnosis rate or prevalence for ASD.

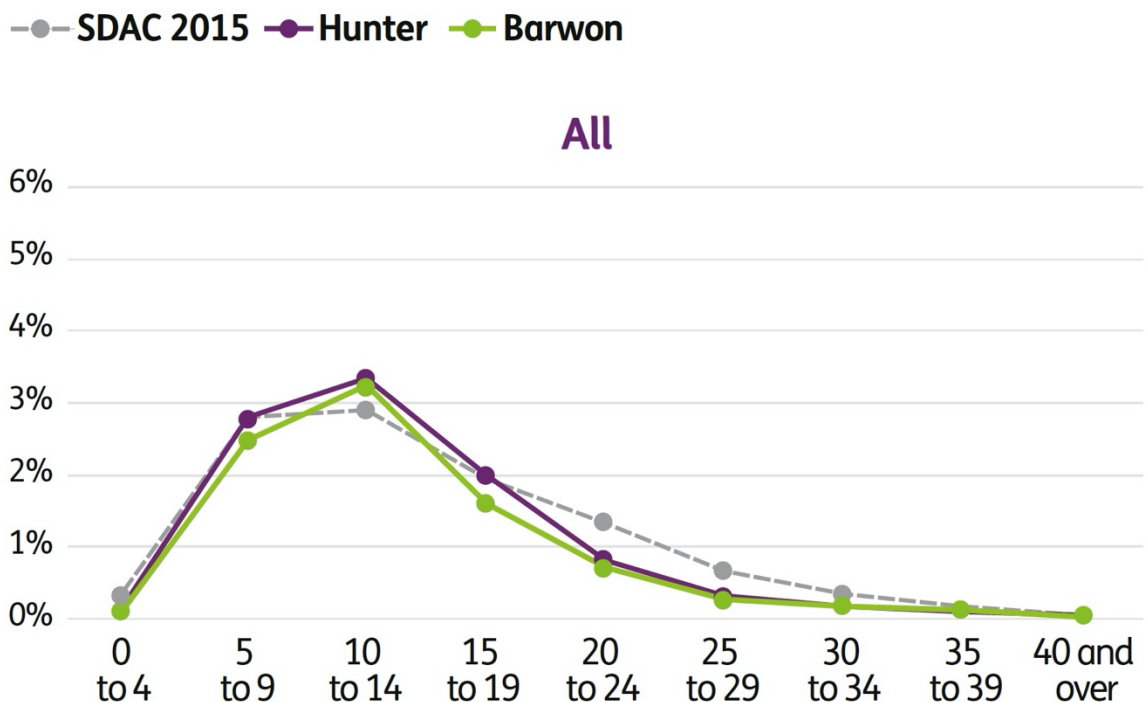
The latest ABS report compares (below) estimated diagnosis of autism by age for years 2018 and 2015.



Diagnosis rates for autistic children now exceed significantly the number of children with Intellectual Disability which by definition is 1.8-2.2% of the population.

5 Similar growth is seen in the number of autistic Australian children aged 0 to 15 years who receive Carer Allowance (child). In these data, each child has a formally documented diagnosis of autism.

10 The NDIS recently compared its “mature sites” in 2019 with the ABS data for 2015 and released the following chart. The NDIS should compare its figures with data collected closer to 2019. Note that the SDAC level rose 20% from 2015 to 2018; the diagnosis rate is expected to be even higher in 2019. The chart shows the NDIS has a similar pattern of ASD diagnoses across age ranges to that seen in ABS data.



15 This chart suggests a significant percentage of autistic Australians aged 15-35 years do *not* meet the NDIS requirement/expectation for eligibility.

20 The NDIS also reports that it has 10,000 participants with Intellectual Disability (ID) as their primary disability and ASD as a secondary diagnosis. The DSM-IV and DSM-5 indicate that when a person is diagnosed with both ASD and ID, ASD is the primary disability except in very rare circumstances. The high number of NDIS reported with ID as primary and autism as secondary suggests that the disability and health sectors are operating on outdated disability assessments. It indicates that many clinicians, disability and health service providers are unaware of ASD and its impact on their clients/patients hence client/patient needs are neglected.

25 Alternatively, it may mean that a large number of people believe/expect that the NDIS will provide more funding for people who list ID as their primary disability, rather than ASD. This means that people in the disability community expect that their diagnosis matters more than their level of functioning in NDIS planning ... at least in relation to autism.

The significant drop off in number of autistic Australians after age 15 years is very concerning. A4 does *not* believe that this is due primarily to either:

- increasing ASD prevalence in children, or
- higher death rate for autistic adults.

5 The cause of ASD is unknown so whether there is an actual increase in ASD prevalence is unknown. If prevalence is increasing, A4 doubts that it accounts for most of the growth in numbers.

10 In much of Australia, the public health system has primary responsibility for diagnosing ASD but [reports show](#) services are discriminatory, inaccurate and far too slow. Public sector diagnostic services under-diagnose autism and many families have to get expensive second opinions in the private sector ... usually after a delay. Most of the public services for diagnosing ASD currently have a waiting list of 10 months or more. The result is that a small fraction of autistic children are diagnosed in time to access essential early intervention that the
15 NDIS cut off when the child enters school.

Autistic people have a higher fatality rate than the general population, as discussed below. However, we doubt this accounts for the massive drop off in ASD diagnoses for Australians aged 25 years and over.

20 The drop off in ASD diagnosis rates after 25 years of age is more likely due to poor ASD awareness, or even diagnostic denial, among health professionals generally. In some cases, adults reject an ASD diagnosis because discrimination, real or perceived, against autistic people in the health system denies them services they need. Some health services and clinicians simply refuse to treat autistic patients.

25 ***Health care for autistic Australians***

Numerous reports from individuals suggest that:

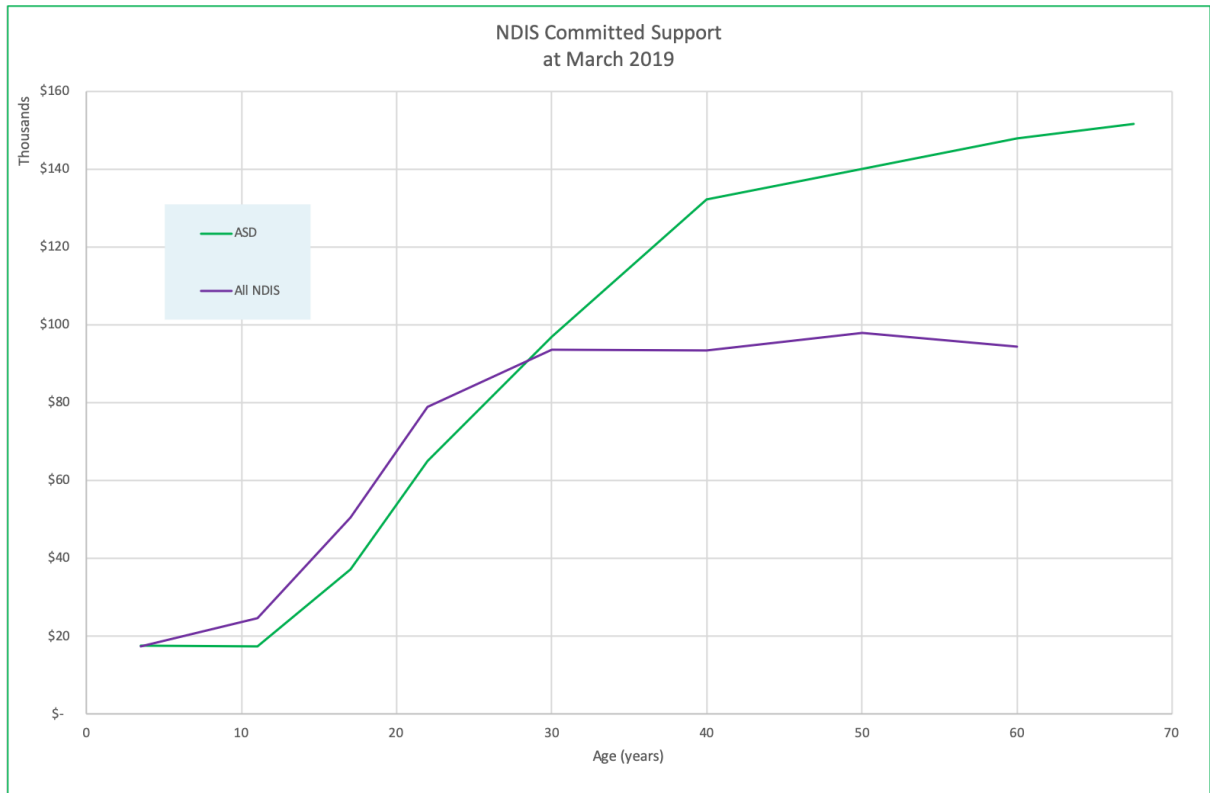
- some autistic individuals get the treatment and support they need in the health sector, but
- health care for many autistic Australians is very unsatisfactory.

30 Some health care professionals and clinicians make substantial adjustments to ensure autistic patients receive the treatment they need. However, they do this on an individual basis; accommodations for autistic patients are not a normal feature of Australia's health systems. This means that families mostly find such services via their local support network if such a service exists in their area.

35 People who are not connected to such local networks often miss out.

Many autistic adults do not have a diagnosis; nor is it likely they will get one. Without an ASD diagnosis, there is very little prospect that autistic adults will get the ASD-specific services and supports that they need. Even with a diagnosis it is difficult to get essential supports because governments do not recognise the
40 need for it – so they do not develop ASD-related support services.

A4 feels that neglect of services and supports for autistic adults contributes significantly to the above average cost for the autistic adults who do have an ASD diagnosis.



A4 reinforces evidence given by Professor Julian Trollor (head of the Department of Developmental Disability Neuropsychiatry within the School of Psychiatry at the University of NSW) regarding health services and supports for autistic Australians – both in his appearance before the Commission ([Day 3 – Health Care, Sydney](#)), and previously in his group’s published report. Professor Trollor’s work focuses on people with Intellectual Disability (ID) and autistic people. A4’s interest is specific to autistic people; however, many of them also have ID, so those interests often overlap.

10 Professor Trollor raised concerns over the lack of data on health outcomes for autistic Australians, group homes and the legal system. He is also concerned that autistic people:

- are not being treated inside the health and mental health system and also not being addressed outside the health sector – autistic people just miss out everywhere on many of the services and supports they need.
- have a right to health services under Article 25 of the CRPD but that goal is not being met (lines 34-9, page 26 of the transcript)
- have high mortality rates including suicide
- have high rates of undiagnosed, untreated and/or poorly managed illness

A4 does not agree with all that Professor Trollor said.

His statement that around one in 100 Australians are autistic (line 30, page 23 of the transcript) is not helpful since over three in 100 Australian children aged five to 14 years are diagnosed autistic but fewer than one in 500 adults are diagnosed autistic. Also, the increase in autism numbers from 2009 to 2018 is 3.18 times or 218% which is substantially more than the 79% that Professor Trollor mentioned (lines 32-3 on the same page).

We also disagree that more recent diagnostic criteria for ASD lead to more ASD diagnoses. If anything, the ASD diagnostic criteria have narrowed with successive editions of the DSM. Increasing diagnoses are due to greatly improved awareness; the increase is *not* due to broader diagnostic criteria for ASD because more recent criteria are not broader.

Imagine looking at an Australian flag and we say the “affected” bits of the flag are coloured (non-white) bits. Then we revise the criteria for “affected” parts of the flag that is just the parts that are red or blue, adopting more restricted criteria. More restricted criteria mean the same amount or less of the flag meets the criteria. ASD criteria with successive editions of the DSMs are more restricted: the defining characteristics for ASD have been reduced/narrowed. But only a small number (if any) are affected by the more restricted/precise criteria (much like there’s not a lot of green or gold on the Australian flag).

People working in the health sector have a strong culture of elitism. The Commission has already heard numerous reports of staff in the health sector devaluing people with disability and their lives. These reports indicate the sector’s deep disregard for human rights principles.

Australia’s health sector needs extensive revision to tackle its perspective on human rights in relation to people with disability. [Caleb’s story of being denied essential treatment](#) because he is autistic shows just how bad it gets.

Sometimes, autistic people are treated especially badly because people working in the health sector simply do not understand how autistic people experience their world. Frequently, Accident & Emergency Departments in hospitals are set up to torture autistic patients: they are noisy, busy and overly stimulating. They are inappropriate environments for autistic people seeking treatment.

Multiple parents have reported their experience to A4: they tell A&E staff that their child is hypo-sensitive or doesn’t show “unusual” outward signs of pain but behaves differently in response to pain. Then their child is kept waiting for hours without getting any attention. When the parents ask what is going on, hospital staff say “your child isn’t showing signs of pain so we’re not giving him/her any attention”. The hospital’s approach is cruel; it is neglect and abuse.

ASD and mental health

The area of mental health is especially problematic for autistic patients. The problem is exacerbated because autistic people have higher rates of mental illness than the general population so they are more likely to need mental health services. The Australian Government’s [Raising Children website](#) states “nearly three-quarters of children with autism spectrum disorder (ASD) also have another medical or psychiatric condition”.

[Foley & Trollor \(2015\)](#) wrote regarding the management of mental ill health:

... substantial gaps remain for adults with ASD. Diagnostic overshadowing, limitations of communication skills and the heterogeneous nature of this patient population can make practice in this area more challenging, and can contribute to poorer outcomes, including overprescribing of psychotropic medications.

Autistic people and their parents report being turned away from mental health services because “we don’t treat people with autism”. Routinely, autistic people

who present with anxiety, trauma or depression are denied mental health services for those conditions because of their autism.

5 This denial of service seems to be due to the clinician's preference rather than any explicit policy. So, some clinicians are willing to treat autistic clients and some are not.

Sometimes, specialists in private practice become known to the autistic community as being especially sympathetic or well regarded. But many autistic patients cannot afford private practice.

10 A4 is concerned that many mental health patients who are termed "treatment resistant" or "unresponsive to treatment" have undiagnosed ASD, and that clinicians try to treat their undiagnosed ASD with drugs which is known to *not work*. Clinicians should be treating the patient's comorbid mental illness instead of ASD. This problem is the result of chronic undertraining of mental health clinicians in relation to ASD.

15 The mental health sector needs to improve substantially both its undergraduate and ongoing professional training in relation to autistic patients.

The neglect of mental health services and support for autistic people can have fatal consequences. Around the country, mental health crisis teams refuse to attend crises for autistic people. Instead, police are required to attend.

20 Sometimes, police handle highly stressed autistic people in public situations appropriately. We rarely hear of these instances.

25 Police are not trained to attend crises involving autistic people. Some police respond very inappropriately: they loudly yell instructions that are incomprehensible for the autistic person. Then they escalate their dysfunctional conduct and outrage when their instructions are not followed. They resort to violent restraint and abuse of the autistic person. In some instances, police use lethal force (see <https://a4.org.au/node/941> & <https://a4.org.au/node/1784> and <https://a4.org.au/node/1647>).

30 After police in the ACT restrained a young autistic man, the Police Minister in the ACT insisted that "police officers, ambulance paramedics, and healthcare workers undertake ongoing training in mental health conditions, including the treatment of patients with autism spectrum disorder".

35 The police complaints process is just abusive of anyone who tries to use it. Complaints about police are always rejected and everyone who complains is deemed a liar.

[A Freedom of Information response](#) shows the Minister's claim is not true. There has been no training for ACT police in more than a decade. One training session for ambulance officers was conducted. During that training, ambulance staff expressed concern that ACT police are not appropriately trained.

40 Clearly, the ACT Police Minister is badly misinformed and passed the misinformation on to the ASD community.

45 In events described to A4, ACT police officers brutally restrained a young autistic man then insisted that ambulance officers attend and chemically restrain him. The police refuse all advice from ambulance officers and from the young man's family. AFP and ambulance officers took the man to Canberra Hospital where AFP officers insisted he remain for hours in traumatic circumstances until he and his mother were completely exhausted. Only then did mental health staff

attend to him, but only to declare that there was nothing they could do due to his autism so he was discharged.

Both the young man and his mother were traumatised. Now, if he encounters police when he's out in public, he responds with extreme distressed behaviour.
5 Subsequent encounters with ACT police have turned violent and exacerbated their trauma. It is very difficult to get treatment for their trauma.

Mental health services for people with cognitive disability have been inadequate historically. *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness* (1993), known as [The Burdekin Report](#), states:
10

Psychiatric difficulties confronting many intellectually disabled people are compounded by a scandalous shortage of appropriate psychiatric services.

Page 660.

The Burdekin Report highlighted “a scandalous shortage of appropriate psychiatric services” for people with intellectual disability (ID). Governments at
15 the time responded by creating some mental services for people with a dual diagnosis of mental illness and ID. Some remnants of these services exist today.

But these services usually cater strictly for patients with ID and mental illness; typically, they exclude people with ASD as well as ID and mental illness. Rarely
20 are there mental health services for people with other cognitive disability and mental illness.

Currently, psychiatric difficulties confronting many autistic people are compounded by a scandalous shortage of appropriate psychiatric services, to paraphrase the Burdekin Report.

25 ***Personal accounts***

Account #1 - Jan 2020.

S's visit to the Canberra Hospital's emergency department was woeful. In a nutshell, arrived by ambulance, vomiting etc. after a significant overdose of a variety of long term acting (cytotoxic) drugs 18 hours prior. The hospital waited 3
30 hours to take blood and the psych. registrar arrived about 4 hours later. He asked leading questions so she could be discharged.

There was no follow up, although they said there would be.

S disclosed her ASD and other mental health issues to the doctor in the ED. Her mother “sensed” that because S is autistic, and (thankfully) had no physical
35 injury, hospital staff convinced themselves that she was “OK”.

She was not OK. Her overdose was very intentional and she did not let anyone know until she woke up the next day extremely ill. Her suicide attempt was *very* concerning for her mother. Her mother feels she may lose her daughter, S, because no-one in the health sector is paying attention.

40 S is fortunate because her mother can afford insurance and S gets private mental health support through Dr Lim, otherwise I might be telling a different story.

Account #2 – Mar 2020

After a discussion about ‘who bought the wrong cereal’ B threw a kitchen knife at her mother causing a cut 2cm deep in her mother’s neck. Her mother went to hospital: thankfully, there was “no structural damage to important bits”.

5 Her mother discharged herself, against medical advice, in order to attend a meeting that she had scheduled with Jon Orb of ACT Health. He did not attend.

10 Instead, she talked with two of his staff who informed her that [the recent ACT Health Working Group on Intellectual Disability](#) may have dropped the ball on autism, but that whatever they come up with most likely will *not* cater for the extreme cases like B, her daughter. The ACT Working Group was for “more mainstream issues” (this is not what the Minister’s initial request asked for). B’s mother wondered if the Working Group even read [the letter](#) that started the process.

15 In relation to the fact that B’s parents cannot live safely with their 10-year-old daughter – that there is no appropriate support in such cases in the ACT – the officials suggested B’s parents, whose interrupted work affects their careers and means they are not paying off their mortgage, should simply move out and rent. B’s parents are considering separate supported accommodation for B that is very close to home and meets other strict conditions. Currently, B cannot access a respite service.

20 Clearly, even having a parent/carer show up with a recent knife wound does not prompt some health officials to properly consider the service and support needs of autistic patients.

Prospects for improving ASD support

25 There is very little prospect that health supports will improve while health officials ignore the needs of, and sometimes act against, autistic Australians.

30 Recently in the ACT, the Minister for Mental Health asked his Directorate to review the services and supports for people with intellectual disability and autism. [The outcome](#) was that Health officials focused on ID and ignored the autism aspect of their role. They misinformed themselves about autism and limited their report to supports for people with ID, possibly including some that might benefit autistic clients. They excluded ASD-specific needs from consideration and excluded the autistic community from their review process.

35 The ACT Health and Mental Health Ministers declined to meet ASD community representatives ahead of due dates for this submission and submission to the [Inquiry into Youth Mental Health in the ACT](#).

The Victorian Government created a [Victorian Autism Plan](#), however, it remains largely ineffectual and unimplemented.

The other state and territory governments show little or no interest in autistic people.

40 Our conclusion is that prospects for the future of autistic Australians are very poor.

45 The best prospects for improved health and mental health outcomes are for the Disability Royal Commission and the Senate Inquiry into Autism to recognise that ASD is a distinct disability with distinct needs that are not being met. The challenge for the future is to avoid lumping ASD in with other disabilities that are static (not growing) in numbers proportion of the population and whose

treatment is properly recognised as the responsibility of health and mental health services. When ASD is merged into such a category, the needs of autistic people are ignored.

The distinct and unmet needs of autistic people must be recognised.

- 5 There may be other un- or under-recognised disabilities that also need their supports substantially improved. Hopefully, the Disability Royal Commission will bring the need to improve services and supports for people with these disabilities to the Government's attention.

Answers to Questions from the Issues Paper

10 Question 1:

What do you think about the quality of health care for people with cognitive disability?

Autistic Australians cannot rely on health care.

Some clinicians accommodate the needs of autistic patients but many do not.

- 15 Health systems and their culture support and facilitate the exclusion of autistic patients.

Question 2:

- 20 A. If you are a person with cognitive disability, can you tell us about any problems you have had in getting health care?

A4 is a systemic advocacy organisation.

B. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

- 25 A4 can tell you about the experience of many autistic Australians having problems accessing health care.

- 30 Autistic people have communication difficulties. This means they are slower or simply unable to explain their symptoms to clinicians. Few clinicians take the time to understand. For this, and other reasons (such as clinicians being uncomfortable when they are with autistic people), many autistic people have undiagnosed health issues.

Many autistic people have atypical responses to symptoms. They may be hyper- or hypo-sensitive. Clinicians do not have or take the time needed to understand symptoms in autistic people.

- 35 Autistic people may be distressed in a diagnostic or treatment context. This results in distressed behaviour (often referred to as challenging or unwanted behaviour) which the health system used as grounds for refusing the autistic person's right to health services.

- 40 Health systems usually expect/demand "normal" responses and calm behaviour in stressful environments. This is a major barrier to health services for many autistic people.

Question 3:

A. If you are a person with cognitive disability, can you tell us about any problems you have had with the NDIS and getting health care?

A4 is not a person.

- 5 B. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

Many clinicians and health administrators regard people with autism as lesser people. Autistic people are given low priority and may be denied health services as a result. This is clearly demonstrated in [Caleb's story](#).

- 10 Autistic patients are often seen as difficult or challenging so health systems cut short their treatment and rehabilitation.

Systemic neglect of diagnostic services for autistic adults result in massive impediments to undiagnosed autistic Australians needing to access ASD-specific services and supports in either the NDIS or the health systems.

- 15 Neglect of clinical behaviour support denies [autistic people the behavioural support they need](#). As yet, Australia has very limited training and does not have a registration process for behavioural clinicians.

- 20 Senior bureaucrats in the NDIS regard expert advice on evidence-based early intervention for autistic children as “contested”. The NDIS often refuses to fund evidence-based early intervention. Early intervention for autistic children is often neglected because relatively few families are prepared to challenge the NDIA, a government agency, in the Administrative Appeals Tribunal.

The NDIS often neglects support needs of school age children claiming that the clinical needs of autistic children of school age are a school responsibility.

25

Question 4:

A. What do you think should be done to fix the problems people with cognitive disability have in getting health care?

- 30 The problems are rooted deep in Australia's health systems. Fixing them requires major cultural change in the sector.

First, teaching staff for the sector need to understand, recognise and respect the human rights of autistic people. They need to understand that autistic people have the same right to enjoy their lives as all others. They need to understand autistic people are not lesser citizens.

- 35 Then health sector educators need to teach their students to respect autistic patients and colleagues. And they need to teach students about ASD.

- 40 The culture of the health sector needs to change. Rather than creating specialist service providers for things like dual diagnosis of ID and mental illness, the health sector should adopt a culture of inclusion so all health services are inclusive of people with disability. Specialist services for select combinations of disability types and health issues, as followed the Burdekin Report, will always miss out supports for some people. The only real solution is inclusive health and mental health systems.

Health administrators need to ensure that they grow services and supports for increasing numbers of autistic patients so that autistic patients can access the health- and mental health related service and supports that they need.

5 **B. How could the NDIS and health systems work better for people with cognitive disability?**

Both the NDIS and the health sector show disrespect and inadequate understanding of autistic participants. Many people working in these sectors tend to regard ASD as a fad; despite clear evidence to the contrary, they regard an ASD diagnosis as a fashion accessory.

10 Data about the outcomes for autistic people and the cost of support show that they need to take ASD far more seriously.

Question 5:

15 **Why do people with cognitive disability experience violence, abuse, neglect or exploitation in health care? What are the causes?**

Autistic people experience violence, abuse, neglect or exploitation in health care because people who work in health care do not respect autistic people. Autistic people are regarded as lesser people or sub-human; they are seen as being in the way of others who deserve better treatment.

20 The cause is the entrenched culture of the sector.

Question 6:

25 **A. Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in doctor's or GP's surgeries, medical centres, hospitals, specialists or consultants?**

Yes. Autistic people are more likely to choose GPs who show them more respect and understanding. They have more choice of their GP and they may have more contact. They are likely to be better understood and treated by allied health professionals who get to know them better.

30 **B. Is the violence, abuse, neglect or exploitation that people with cognitive disability experience, different in public, private or not-for-profit health care?**

A4 does not have data to answer this question.

35 Anecdotally, arrogance correlates with price levels. And arrogance and high prices often come with violence, abuse, neglect and/or exploitation of autistic people.

Question 7:

A. Are experiences of violence, abuse, neglect or exploitation in health care different for particular groups of people with cognitive disability?

40 A4 is about autistic people; A4 cannot speak for people with cognitive disability more generally.

In Australia, health services frequently treat people with cognitive disability poorly. As a result of the Burdekin Report, health systems made some provisions

of specialist mental health services for people with a “dual diagnosis” of mental illness and ID. There is a very clear distinction between ASD and ID. Services designed for people with ID and mental illness often/usually exclude autistic patients.

- 5 There is nowhere for autistic patients to go to get health and mental health services when they are excluded from mainstream health and mental health services.

B. Are experiences of violence, abuse, neglect or exploitation in health care different for First Nations and culturally and linguistically diverse people with cognitive disability?

10

There is little or no data. Anecdotally, minorities and culturally separate groups have worse access to mental health services.

C. How does a person’s gender, age, or cultural or sexual identity impact on people with cognitive disability getting health care?

15

All we can say is that diagnosis of autistic women is increasing. In recent years the gender ratio rose from below 1:4 female to male to more than 1:3.5 in more recent data. This increase suggests that women’s access to diagnosis and any ASD-related services that exist may be improving.

The available data suggests that autistic adults are severely underdiagnosed.

20

A4 does not have any data on the impact of culture or cultural background on the recognition or supports for autistic Australians. We can observe that ASD diagnosis rates are low in WA and NT where the first nations population is higher.

25

Question 8:

A. What could prevent people with disability experiencing violence, abuse, neglect or exploitation in health care?

30

1. Basic protection of human rights.
2. A more inclusive health sector.
3. Disability training for health professionals, clinicians and administrators.

B. What would make a person with cognitive disability feel safe when getting health care?

Recognition, respect and empathy from health staff.

C. Can you give us any examples?

35

Most people with disability value their lives. Like everyone, they do the best they can and rejoice in their successes.

Many health sector staff have elitist views of people. They regard the lives of people with disability as being less important, as unsuccessful because they don’t do the same things as they do.

40

Health staff need to understand that different people have different goals and expectations. For them, life is successful when they achieve their goals even if those goals are not the same as someone working in the health sector.

People with disability may not compete on the sporting field or achieve above average intellectual outcomes – but most health staff are not at the elite level in these areas either.

5 Question 9:

A. What would stop a person with cognitive disability reporting violence, abuse, neglect or exploitation in health care?

Problem reporting processes in the health sector are notorious. They protect health staff. They provide no protection for autistic people.

10 At best, reporting problems results in the frustration of just being ignored. Often, the reporter is treated as a liar. The reporting process turns into a bureaucratic nightmare before being dismissed without balanced consideration.

B. What would make it easier for a person with cognitive disability to complain about violence, abuse, neglect or exploitation in health care?

15 There is no point in making it easier to complain until the complaints processes start to deliver improvements to health systems.

It would be better to actually implement an effective “continuous improvement process”. People prefer to suggest improvements rather than complain or report issues.

20

Question 10:

Have we missed anything? What else should we know?

The lack of training and professional registration for behaviour clinicians is a major gap in services and support for autistic Australians who need it.

25 ***Conclusion***

Health and mental health services for autistic Australians are inadequate because the culture of the health care sector does not respect autistic Australians and their human rights. Australia need to protect the rights of autistic Australians, especially in hospitals and health services where the rights of autistic people are largely ignored.

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The health and mental health sector need far better training about autism spectrum disorder for clinicians and administrators.

35 Politicians need to hold health administrators and bureaucrats responsible for ensuring the health sector delivers at least adequate outcome for all autistic patients. Good outcome are preferred.

The health sector needs to improve its measurement and reporting of health and mental health outcomes for autistic Australians.