STANDING COMMITTEE ON EDUCATION, EMPLOYMENT AND YOUTH AFFAIRS Mr Michael Pettersson MLA (Chair), Mrs Elizabeth Kikkert MLA (Deputy Chair) Ms Elizabeth Lee MLA

Submission Cover Sheet

Inquiry into Youth Mental Health in the ACT

Submission Number: 16

Date Authorised for Publication: 7 April 2020

A submission to the Standing Committee on Education, Employment and Youth Affairs

inquiry into Youth Mental Health in the ACT

6/4/2020



 $Speaking\ Out\ for\ Autism\ Spectrum\ Disorder\\ in\ the\ ACT$

$Table\ of\ Contents$

Table of Contents	1
Introduction	1
About Autism Spectrum Disorder	2
ASD in Australia ASD in the ACT	
Health care for autistic Australians	.11
ASD and mental health	. 17 . 17
Response to Terms of Reference	.20
Conclusion	.25
Annex A: CSD Autism Web Page	.26
Annex B. ACT Mental Health Services for People with Intellectual Disability Working Group	



Introduction

This document is the submission from *Speaking Out for Autism Spectrum Disorder* (SOfASD) to the inquiry that the *Standing Committee on Education, Employment and Youth Affairs* is conducting into Youth Mental Health in the ACT. *SOfASD* appreciates this opportunity that this inquiry provides us to describe mental health care for autistic youth in the ACT. It is a matter of grave concern to us that there are major flaws evident in mental health services for autistic youth in Canberra.

SOfASD's submission below focuses mainly on experiences of autistic youth in the ACT's mental health services sector. *SOfASD* do not represent or speak for people with other types of disability.

Little data or evidence is available about autistic youth in the ACT. This means we have to draw on evidence more generally about autistic adults in Australia, or even overseas.

Mental health is a major issue for autistic youth because autistic youth:

- a) have high rates of mental illness, and
- b) are often unable to access the mental health services and supports that they need.

Regrettably, what follows mostly describes bad or abysmal experiences and outcomes for autistic youth: mental health services in the ACT are mostly dysfunctional or non-existent for autistic youth.

This submission includes an extensive section about autism or Autism Spectrum Disorder because much of the information that is usually cited is incorrect or outdated, for example the prevalence of ASD is unknown; over 3% of Australian children aged 5-14 years are autistic (have an ASD diagnosis) but fewer than 0.5% of adults over 30 years of age have been diagnosed. It is incorrect to claim that 1 in 160 or 1 in 100 have autism since these rates are incorrect for most age ranges.

Please note that the following submission uses identity-first language, that is "autistic person" rather than "person with autism/ASD", which is the stated preference of many autistic people (see pages on the ASAN-AUNZ and Amaze websites).



About Autism Spectrum Disorder

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.

Basically, Autism Spectrum Disorder involves impairment of

- A. Communication and social interaction, and
- B. Restricted and/or repetitive behaviours (and interests).

ASD is often associated with sensory difficulties.

An ASD diagnosis is given *only* when a person needs disability services and supports to function effectively.

Previous editions of the diagnostic manual, DSM-IV (1994) and DSM-IV-TR (2000), separated *Pervasive Developmental Disorders* into five subtypes:

- Autistic Disorder
- Asperger's Disorder
- Pervasive Developmental Disorder not otherwise specified (PDD-NOS)
- Rett's disorder
- Childhood disintegrative disorder (CDD)

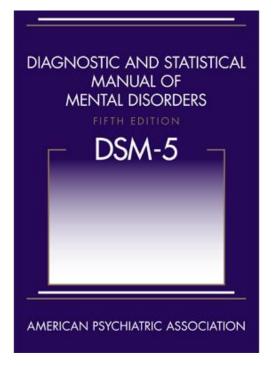
Since then:

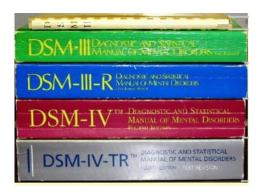
- The DSM-5 merged Autistic Disorder, Asperger's disorder, PDD-NOS and CDD into a single disorder, Autism Spectrum Disorder, which it classes as a neurological disorder;
- The genetics of Rett's disorder have been identified, which moves it to a "genetic disorders" category.

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.

ASD in Australia

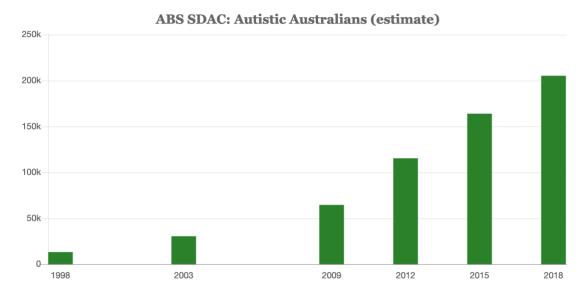
The Australian Bureau of Statistics (ABS) *Survey of Disability, Ageing and Carers* (SDAC) collects data periodically about autistic Australians.







The overall number of Australians known to be autistic has increased more than 15-fold over the past 20 years; from about 13,200 Australians in 1998 to 205,200 in 2018.



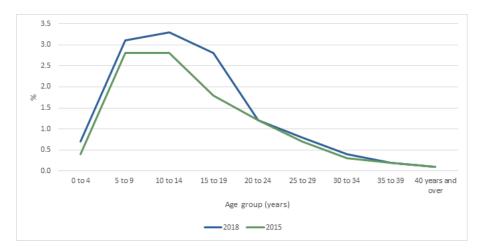
Since 2009, the ABS has reported specifically on autism in Australia. The reports are available online; the latest from 2018 data can be downloaded here.

The following table shows the age breakdown from datasets collected over the last two decades (1998-2018).

'000s of autistic Australians						
Age/year	1998	2003	2009	2012	2015	2018
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			2.8	3.5	11.9	15.6
30-34 years			4.6	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

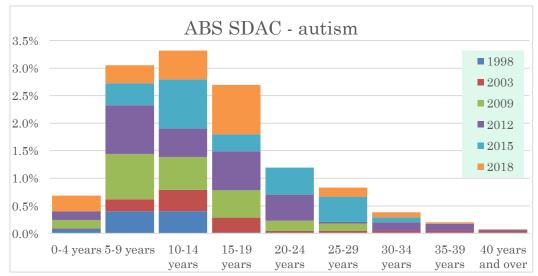


The latest ABS report compares (below) estimated diagnosis rates of autism by age for years 2018 and 2015.



The following table and chart show the number of autistic Australians over the years as a proportion of the population.

	1998	2003	2009	2012	2015	2018
0-4 years	0.078%	0.095%	0.245%	0.401%	0.399%	0.687%
5-9 years	0.399%	0.617%	1.441%	2.325%	2.727%	3.054%
10-14 years		0.788%	1.385%	1.899%	2.793%	3.318%
15-19 years	0.012%	0.287%	0.780%	1.493%	1.796%	2.697%
20-24 years		% 0.043%	0.234%	0.706%	1.193%	1.138%
25-29 years			0.178%	0.206%	0.666%	0.831%
30-34 years			0.036%	0.201%	0.291%	0.381%
35-39 years				0.173%	0.159%	0.203%
40 years and over				0.067%	0.062%	0.072%

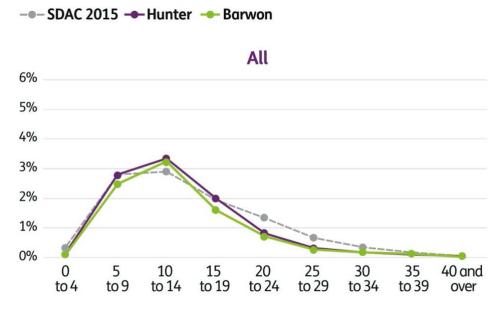




In summary, these data show:

- 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 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.



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

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 and not ID is the person's 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 autistic clients/patients. They neglect patients' major needs arising from ASD.

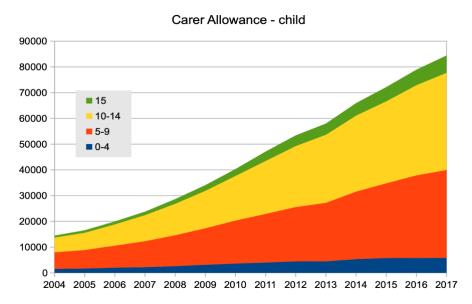


Alternatively, it may mean that a large number of people believe/expect that the NDIS will provide more funding for people who list ID as their primary disability, rather than ASD. This means that people in the disability community expect that their diagnosis matters more than their level of functioning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

The DSS database for Carer Allowance (child) is another source of data about autistic children in Australia. These data summarise autistic children in Australia from 0-15 years inclusive, though the ages 0-4 years are sometimes aggregated. Williams K, MacDermott S, et. al. (2008) in the prevalence of autism in Australia. Can it be established from existing data? (published here or here) observed that:

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

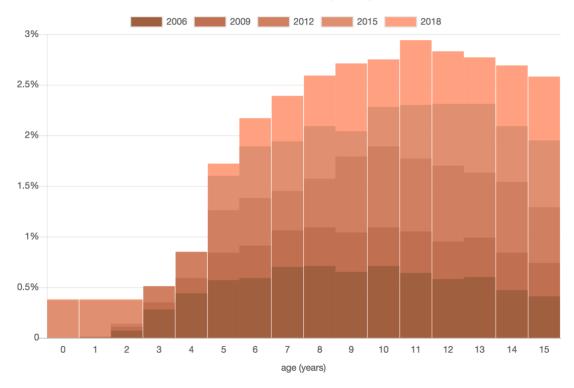
Autism Aspergers Advocacy Australia (A4) first analysed and reported on these data in A4 Update Dec 2006. A4 obtained annual data summaries since 2004 from DSS (formerly FaHCS). The datasets since 2013 include children diagnosed with Autism Spectrum Disorder (DSM-5). The continued availability of these detailed datasets is a luxury; few countries have population data available as an ongoing series and in detail that allows analyses like those following.



These data describe the population of autistic Australian children who registered for Carer Allowance (child). This means that a health or allied health professional signed a comprehensive document as evidence of the child's formal autism diagnosis.



Autistic Australian children Carer Allowance (child)



These data show similarity to the ABS data for the same age range.

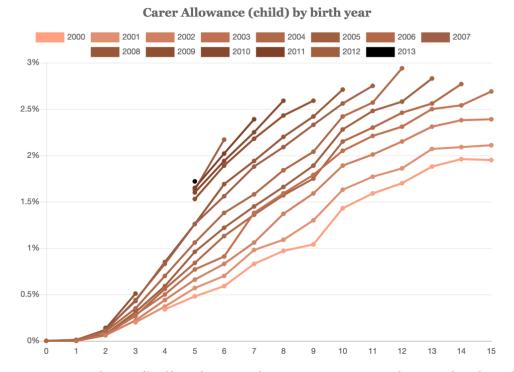
- Diagnosis rates are lower but similar for the age ranges.
- Diagnosis rate increases over the period are similar.

Different methods of data collection could explain the difference. The similarity between the datasets suggest that they describe a similar population.

These datasets are also similar in that their earlier data shows 4 males for every autistic female but the ratio is progressing over time towards 3 males to each female. Please contact A4 for more detail on this issue if you are interested.



The following figure shows diagnosis rate by age and years of birth. It shows that the median age of diagnosis if around 9 years of age.



Bureaucrats and NDIS officials consider age 9 years too late to fund early intervention for a child's ASD.

These are national figures; figures for the ACT are expected to be worse than national averages because the ACT has low diagnosis rates and delayed ASD diagnoses.

Consistent evidence of increasing autism diagnoses from multiple sources contradicts advice that the federal Health Department gave to Senate Estimates in 2011 saying:

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

SOfASD is not aware that the federal Health Department has revised its view since 2011, 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.

The significant drop off in number of autistic Australians after age 25 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.

The cause of ASD is unknown. Whether there is an actual increase in ASD prevalence is also unknown; possibly the increase is entirely due to



improving diagnosis rates. A4 doubts that increasing prevalence accounts for most of the growth in diagnoses.

Most of the public services for diagnosing ASD currently have a waiting list of 10 months or more. The result is that few autistic children are diagnosed autistic by age 5 years, in time to access essential early intervention for their ASD. NDIS policy cuts off support for early intervention prematurely, when the child enters school or at age 7 years.

In much of Australia, the public health system has primary responsibility for diagnosing ASD but <u>reports show</u> services are discriminatory, inaccurate and far too slow in responding to the health needs of autistic patients.

In the ACT, public sector diagnostic services under-diagnose autism and many families have to get expensive second opinions in the private sector ... usually after a delay.

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.

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.

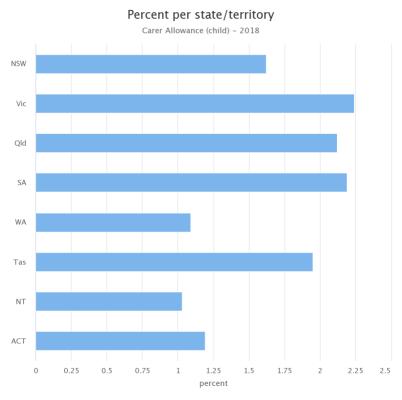
Diagnosis rates for autistic children now exceed significantly the number of children with Intellectual Disability which by definition is 1.8-2.2% of the population.

With the COVID-19 pandemic, Governments in Australia need to recognise and respond significantly better to the needs of Australians with disability, including the needs of autistic Australians. The disability sector sent an open letter to governments.



ASD in the ACT

The following graph shows the percentage of children aged 0 to 15 years receiving Carer Allowance (child) in each state. Note that the average age of diagnosis is around 9 years of age, so many autistic children have not been diagnosed so they are not counted in these data.



The autism diagnosis rate in the ACT is 3rd lowest of all states and territories. Numerous families report that the ACT CSD diagnostic service says their child is not autistic but subsequently their child is diagnosed with ASD. It is likely that other families do not pursue a second opinion.

The <u>latest NDIS Quarterly Report</u> shows that 1,950 of 7,260 NDIS participants (27%) in the ACT are autistic. Nationally, 104,618 of 338,982 NDIS participants or 31% are autistic, so the ACT has a lower rate than the national average.

There is long-standing difference between *SOfASD* and ACT Government officials over ASD prevalence figures for the ACT.

- https://sofasd.org.au/d7/sites/default/files/20121221%20ACT%20AS D%20diagnoses.pdf
- https://sofasd.org.au/d7/node/32
- https://sofasd.org.au/d7/node/132
- https://sofasd.org.au/d7/node/142
- https://sofasd.org.au/d7/node/148

However, SOfASD and A4 have strong track records of accurate reporting on diagnosis rates for ASD in Australia. Their concerns over underestimates for NDIS planning proved accurate. The NDIS stopped its



intake in the ACT after the predicted number of participants was exceeded.

The ACT Government's persistent underestimating of ASD numbers and service needs contribute to especially poor mental health outcomes for autistic youth in the Territory.

The introduction of the NDIS in the ACT caused the closure of Autism Asperger ACT. The ACT is the only Australian state or territory without an autism association.

Health care for autistic Australians

Reports from individuals suggest that:

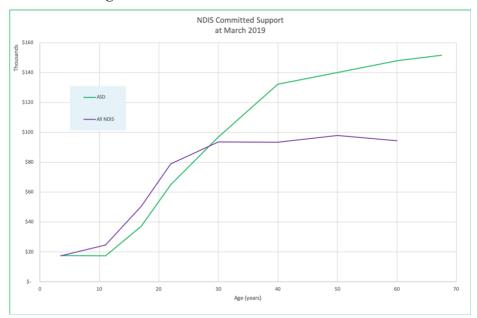
- some autistic individuals get the treatment and support they need in the private health sector, but
- health and mental health care for many autistic Canberrans is very unsatisfactory.

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. 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 for autistic patients to get essential supports because governments, clinicians and health administrator do not recognise the needs of autistic patients – so they do not develop ASD-related support services.



SOfASD feels that neglect of services and supports for autistic youth contributes significantly to higher costs for the autistic adults as shown in NDIS data following.



Professor Julian Trollor (head of the Department of Developmental Disability Neuropsychiatry within the School of Psychiatry at the University of NSW) gave the Disability Royal Commission evidence 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 indicates supports and outcomes for autistic Australians are unsatisfactory. Professor Trollor's work focuses on people with Intellectual Disability (ID) and autistic people. SOfASD's interest is specific to autistic people; however, many of autistic people also have ID, so those interests often overlap.

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

SOfASD, like A4, does not agree with all that Professor Trollor told the Disability Royal Commission.

For example, his statement that around one in 100 Australians are autistic (line 30, page 23 of the transcript) is not helpful since more than one in 30 Australian children aged five to 14 years are diagnosed autistic



but fewer than one in 500 Australian 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 we say initially that the "affected" bits of the Australian flag are the coloured (non-white) bits. Then we revise our criteria so that just bits that are red or blue are the "affected" parts; we adopt more restricted criterion. The criteria changed but the "affected" part of the flag remains the same.

ASD criteria are more restricted with successive editions of DSM: the defining characteristics for ASD were narrowed over time but only a small proportion (if any) are affected by the more restricted/precise criteria. The intention was always to describe the same group of autistic people.

The change over time has been greater awareness of ASD; that clinicians are more likely to recognise that people are autistic.

People working in the health sector have a strong culture of elitism and ableism. The DRC 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. The lives if autistic Canberrans are like those described before the DRC.

Australia's health sector needs extensive re-education to address its inappropriate attitudes to people with disability and disrespect for their human rights. Caleb's story of being denied essential treatment because he is autistic shows just how bad it is in the ACT.

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 A&E experiences to SOfASD: some report that when they arrive they tell staff that their autistic youth is hypo-sensitive or has "unusual", different or absent response to pain. Then A&E staff keep the youth waiting for hours without giving them any attention. When the parent(s) 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 staff took no notice of the information they were given about the autistic youth. The hospital's approach is cruel; it is neglect and abuse.



ASD and mental health

Relatively little is known about the mental health of autistic youth in the ACT or autistic Australians generally. The available research shows particularly poor outcomes.

The Australian Longitudinal Study of Adults with Autism (ALSAA) reported:

It has been reported that between 25% and 84% of autistic adults have a diagnosed mental health condition, with depression and anxiety the most commonly reported conditions. Autistic adults have higher rates of suicide, increased mortality and reduced life expectancy.

A paper from the Study of Australian School Leavers with Autism (SASLA) reported:

BACKGROUND:

People with Autism Spectrum Disorder (ASD) are at significantly increased risk of suicidal thoughts and behavior. ...

METHOD:

The sample comprised 185 people (92 females) with ASD aged 14 to 80 years who were participating in a national survey.

RESULTS:

Forty-nine percent of participants returned scores in the clinical range for depression and 36% reported recent suicidal ideation. Females, comprising almost 50% of the sample, returned higher depression scores than males, however no differences were identified between males and females in terms of suicidal ideation.

. . .

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 youth and their parents report being turned away from mental health services, such as CAMHS, because "we don't treat people with autism". Routinely, autistic youth who present with anxiety, trauma or depression are denied mental health services for those conditions because of their autism.

This denial of service seems to be due to the clinician's preference rather than any explicit policy. In the past, some clinicians were willing to treat autistic clients but current staff 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.

SOfASD 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* instead of treating their mental illness. Clinicians should be treating the patient's comorbid mental illness, not their ASD. This problem is the result of chronic undertraining of mental health clinicians in relation to ASD.

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.

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

Police are not trained to attend crises involving autistic people. Some police respond very inappropriately; yelling commands loudly and rapidly which makes their commands incomprehensible to an autistic youth. Then police escalate their dysfunctional conduct and outrage when their instructions are not followed. They resort to violent restraint and abuse of the autistic youth. Sometimes police resort to lethal force (see https://a4.org.au/node/941 & https://a4.org.au/node/1647).

After ACT police restrained an autistic youth and *SOfASD* contacted the ACT Police Minister, the Minister 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".

A Freedom of Information response shows ACT police do not receive training in "the treatment of patients with autism spectrum disorder", so the Minister's claim is false. 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.

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

In events described to *SOfASD*, ACT police officers brutally restrained an autistic youth then demanded that ambulance officers attend, chemically restrain the youth and assist in transporting him to hospital. The police refused all advice from ambulance officers and from the youth's family. AFP and ambulance officers took the youth to 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 the youth, but only to declare that as he is autistic there is nothing they can do for him. There was no discernible justification for the polices' actions.

The event traumatised both the youth and his mother. Now, if he encounters police when he's out in public, the youth responds with extremely distressed behaviour. Further encounters with ACT police quickly turned violent, exacerbating the trauma of the youth and his family. They cannot get treatment for the autistic youth's trauma.

The ACT 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.

Mental health services for people with cognitive disability have been inadequate historically. The *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:

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). Since then, the number of autistic youths has grown to exceed those of youth with intellectual disability. Autistic youth have high rates of mental illness and suicidal ideation. Governments in Australia have not recognised of any shortage of appropriate mental health services for autistic Australians.

Responding to Burdekin, Governments at the time created some mental services for people with a dual diagnosis of mental illness and ID. Some remnants of these services exist today.

The services that arose form Burdekin's report usually cater strictly for patients with ID and mental illness; typically, they exclude people with ASD as well as ID and mental illness. Rarely are there mental health services for people with other cognitive disability and mental illness. The



Disability Royal Commission may have something to say about these matters after its focus on people with cognitive disability.

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

ACT service and supports for autistic citizens

Frequently, autistic people in the ACT are denied access to health and mental health services. There are very few services for autistic Canberrans and those that do exist are often hard to access.

Annex A shows the ACT Government's Autism web page. It shows that services basically cut off at age 12 years. Even those services are hard to access. Families usually have to wait 12 or more months to access the service. The need to wait is not indicated on the website. The CSD Annual Report 2018-19 says

A key challenge in 2018–19 was facilitating seamless service pathways for families in the context of a reconfigured early childhood early intervention service system as a result of transition to the NDIS. Continuing to deliver Autism Spectrum Disorder assessments in a market where recruitment of suitably qualified professionals is difficult was challenging.

. . .

To address the recruitment issues to support autism assessments, the CDS undertook a procurement process to engage private psychologists to work both with, and on behalf of, the CDS to deliver the assessments. This ensured the CDS continued to offer an Autism diagnostic service throughout 2018–19 to ACT children up to 12 years old.

The Annual Report did not document the actual waiting time, the number of children diagnosed (or not diagnosed) or how many took themselves off the waiting list because they had to find expensive alternative services in the private sector.

The main source of supports for autistic Canberrans is the NDIS.

The ASD community feels that the NDIS does not recognise and properly understand ASD and autistic Australians. It does not train its staff well. It disrespects ASD stakeholders and operates a farcical Autism Advisory Group. Its policies and practices disadvantage autistic applicants and participants.

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 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 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.

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".

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

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.

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.

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 mental health services for autistic youth in the ACT

There is very little prospect that mental health services in the ACT will improve for autistic youth while health officials in the ACT ignore the needs of, and sometimes act against, our autistic citizens.

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. Annex B below describes the outcome; that Health officials focused on ID and ignored the autism-related aspect of the task their Minister gave them. They misinformed themselves about autism and limited their report to supports for people with ID, possibly including some support that might benefit a few autistic clients/patients. They excluded ASD-specific needs from consideration and excluded the autistic community from their review process.

The ACT Government prides itself in its human rights intentions yet when it comes to the rights of its autistic citizens it has a strong record of failure.

- The ACT Government minimises its support for autistic Canberrans the ACT is the only Australian ACT state/territory jurisdiction without a state/territory-level autism association.
- Diagnostic services in the ACT are seriously deficient: they are characterised by under-diagnosis and excessive delays.
- ACT health and mental health services that exclude autistic patients.
- Access to effective education for autistic students is unreliable; it is simply absent for many autistic students.

The ACT Health and Mental Health Ministers declined to meet ASD community representatives ahead of due dates for this submission and A4's submission on health supports for people with cognitive disability (which includes autism) to the Disability Royal Commission.

Clearly, the ACT Government's mental health staff cannot address the needs of autistic youth in Canberra. Any future development will depend on actual stakeholder engagement and on using expertise from outside the ACT.

Improved mental health outcomes may arise from this inquiry, the Disability Royal Commission and the Senate Inquiry into Autism if they recognise that ASD is a distinct disability with distinct needs that are not being recognised and addressed. The challenge for the future is to avoid lumping ASD in with other disabilities that are static (not growing) as a proportion of the population and whose treatment is properly recognised as the responsibility of health and mental health services. Experience shows that when ASD is merged into a broader category, the needs of autistic people are ignored.



The ACT Government must recognise and address the distinct and unmet needs of autistic Canberrans include youth in the ACT.

There may be youth in the ACT with other disabilities whose mental health needs are un- or under-recognised and who also need their supports substantially improved. Hopefully, this inquiry will result in improved mental health services and supports for these people.

Response to Terms of Reference

Following is *SOfASD*'s response to the detail of the inquiry's terms of reference.

The Committee resolves to inquire into and report on the state of youth (under 25 years of age) mental health and operation of youth mental health services across the ACT, with particular reference to:

i. hearing the voices of the ACT community, including young people and their families, young people from culturally and linguistically diverse (CALD) backgrounds and Aboriginal and Torres Strait Islander (ATSI) communities, young people living with disability, young people with lived experience of mental health and addiction challenges, young people affected by suicide and people involved in preventing and responding to mental health and addiction challenges;

As described above, ACT government officials excluded any voice of autistic Canberrans from their recent Working Group that was created in response to the Mental Health Minister's interest in Intellectual Disability and Autism Spectrum Disorder (see Annex B below).

Very little is known about autistic people or autistic young people in the CALD and ATSI communities. *SOfASD* expects that autistic youth from these communities experience challenges from mental illness and addictions at much higher rates than the general youth population.

ii. ACT's current approach to prevention and early intervention strategies and services for youth mental health and addiction, and what needs to change;

There is no "current approach to prevention" of mental illness and addiction for autistic youth in the ACT. Having an approach would be a significant change and is likely to improve outcomes for autistic Territorians.

Similarly, introduction of "early intervention strategies" to address mental illness and addiction for autistic youth in the ACT has significant prospect for better results than the current absence any strategy.



iii. reviewing the work being undertaken in ACT schools to identify students at risk and early intervention strategies available to address such concerns;

SOfASD is not aware of any specific "work ... in ACT schools to identify students at risk" such as autistic students who are at substantially higher risk than of mental illness and/or suicide than youth generally.

iv. the availability of professional mental health services for students and their families at school and out of hours, including weekends and school holidays;

Similarly, SOfASD is not aware of suitable services for autistic youth in the ACT. SOfASD is concerned that these services simply do not exist and that autistic students are usually excluded from services for non-autistic youth in the ACT.

In the past, CAMHS had a strong interest in autism but now the service excludes many, possibly all known, patients known to be autistic. Many autistic youth with mental illness have nowhere else to go to get the mental health services they need. It seems this is a staff decision rather than an actual policy.

v. reviewing data published by Mission Australia, the Black Dog Institute and other organisations on youth mental health statistics in the ACT, as well as relevant experiences and learnings from other jurisdictions;

SOfASD is not aware of publications or reporting that separates experiences, service provisions or outcomes for autistic youth.

The Mission Australia's Youth Survey Report 2019 says 6.5% of survey respondents were participants with disability. The biggest subgroup were autistic respondents but at 6.5% of survey respondents, youth with disability are underrepresented in this survey ... and it's also likely the autistic respondents to the survey would not represent the population of autistic youth.

Other than these basic numbers, the report says nothing at all about autistic youth.

The Black Dog Institute's *Youth mental health report; Youth Survey 2012- 16* doesn't mention autism or even disability.

Similarly, the Australian Institute of Health and Welfare omits autism/ASD from its chart of Prevalence of mental disorders in the past 12 months among those aged 4-17. ASD is a mental disorder affecting over 3% of this population; it should appear in their chart.

Previously, we've described "relevant experiences and learnings from other jurisdictions" in relation to autistic youth and adults.



vi. reviewing data relating to family-based prevention and early intervention, including the impacts of screen time on children's mental health, family separation/divorce and family lifestyle;

SOfASD is not aware of research into mental health prevention or early intervention for mental health for autistic patients. Generally, experts on autism/ASD advise that autistic children do better when they get evidence-based early intervention for their ASD. But senior NDIS officials regard expert advice about ASD as "contentious" or "contested". Their policies result in few families accessing evidence-based early intervention for autistic children.

The result is that autistic adults have higher care needs than people with disability more generally.

vii. reporting on how the ACT Government is preventing mental health and addiction challenges and responding to the needs of young people with those challenges; and

SOfASD doubts the ACT Government is doing anything to prevent mental illness or addiction among autistic youth in Canberra.

Annex B below shows ACT health and mental health officials ignored the Minister's request when they were asked about services for autistic adults.

viii. family based prevention and early intervention strategies, community confidence in the youth mental health system and better outcomes for ATSI, CALD youth, youth living with disability as well as other groups of youth that have disproportionally poorer outcomes.

See https://a4.org.au/node/2174 for a discussion of supports for autistic members of the ATSI community.

Very little is known about ASD in Australia's CALD community.

Areas the inquiry will focus on include:

i. mental health challenges and needs of young people in the ACT across the full spectrum from mental distress to enduring psychiatric illness;

Professor Trollor told the Disability Royal Commission that autistic people and people with intellectual disability have higher rates of mental illness than the population generally. Since most autistic people are under 25 years of age, clearly mental illness is a "challenge" (PC term for problem) for autistic youth.

Autistic youth need supports that simply are not available in the ACT. They are excluded from existing public mental health services and often



cannot afford or access private mental health services. Their childhood needs are poorly recognised and rarely addressed which means they are at risk from mental illness that intensifies the longer they are denied treatment.

ii. ready access to mental health support and services by young people;

Few autistic Canberrans can access mental health support and services. They are denied access to public mental health services and can only access mental health services in the private mental health sector if they or their family can afford private health insurance. Even then, there are limited services available for them in the ACT.

iii. identifying roles and responsibilities of the family unit in supporting youth facing mental health and addiction challenges, and supporting families in carrying out these roles and responsibilities;

Most families understand their roles and responsibilities.

The much bigger problem is that ACT Mental Health does not understand its responsibilities and human rights obligations to autistic Canberrans. ACT Mental Health avoids its responsibility to provide mental health service for autistic Territorians.

iv. prevention and early intervention of mental health and addiction strategies;

ACT Health officials need to first recognise their responsibility to support autistic Canberrans. Prevention and early intervention are not even considered without first accepting responsibility for supporting autistic Canberrans.

v. identifying and responding to young people with mental health and addiction challenges:

The first step needed is to respond to autistic young people who clearly self-identify as having mental health and addiction challenges.

vi. youth suicide prevention and support for those close to someone who has taken their own life;

Similarly, ACT Mental Health needs first to treat autistic patients who present with suicidal behaviour and ideation, rather than turning them away.



vii. range of services available in ACT schools including counsellors, pastoral care workers, psychologists and other mental health professionals both in schools and within the Directorate;

ASD is defined by behavioural symptoms. Behaviour support is essential for many autistic students at school and through their life. Without professional behaviour support, many autistic students are stressed and even traumatised as they become youth.

Australia trains very few behavioural clinicians. Neither the federal government nor the ACT registers behavioural clinicians.

The lack of a recognised registration scheme means that ACT schools simply cannot provide the professional behaviour support that many autistic students need. Clinicians in schools are not trained properly in ASD. Their efforts to support autistic students while they lack training and knowledge often does more harm than good.

Too often, police are used as the last resort which increases stress and trauma. The outcomes resulting from this approach are usually very bad.

School staff are not professionals because their employer dictates their code of conduct, they do not manage their own professional standards.

viii. the extent and availability of mental health first aid training for teachers and learning assistants; and

SOfASD in not aware of any "mental health first aid training" for anyone to address the needs of autistic children, students or youth.

ix. any other relevant matter.

Police in the ACT need training in how best to approach autistic people.

The ACT has a Mental Health Crisis Team that does not attend mental health crises generally, and certainly not when an autistic person is involved.



Conclusion

Mental health services for autistic Canberran youth are inadequate because the culture of the ACT's health care sector does not respect autistic people and their human rights. Governments in the ACT and Australia need to protect the rights of autistic citizens, especially when autistic citizens need mental health services, a sector where the rights of autistic people are largely ignored or denied.

The mental health sector needs clinicians and administrators with far better training, knowledge and understanding about autistic people.

Politicians in the ACT need to hold health and mental health administrators and bureaucrats responsible for ensuring the mental health sector delivers at least adequate outcome for all autistic patients. Good or best outcomes are preferred.

The health sector in the ACT needs to improve its measurement and reporting of mental health outcomes for autistic Canberrans.



Annex A: CSD Autism Web Page

Home >> Child Development >> What We Offer >> Autism

Autism

What is Autism?



The Child Development Service is a Canberra based service that provides residents in the ACT with free Autism assessments for children aged 0-12. A referral from a Paediatrician or Psychiatrist is required.

Autism Spectrum Disorder is characterised by persistent deficits in social communication and interaction across multiple areas. Difficulties with restricted, repetitive patterns of behaviour also impact everyday functioning (Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-5)).

Some common signs of Autism may include:

- Not responding to their name by 12 months of age
- Not pointing to objects of interest by 14 months of age
- Not playing pretend games (e.g. feeding a doll) by 18 months of age
- Avoiding eye contact and wanting to be alone
- Having trouble understanding the thoughts and feelings of others (and perhaps personal space)
- Difficulties with social interactions
- Uses few or no gestures (e.g. waving goodbye)
- Repeating the same words or actions over and over
- Becoming upset by minor changes
- Have obsessive interests
- Hand flapping, rocking body or spinning in circles
- Unusual reactions to the way that things sound, smell, taste, look or feel

Source - Centres for Disease Control and Prevention

Autism consists of a diverse range of behaviours and can be very different between individuals, therefore people with Autism may have some or all of these difficulties.



How is Autism Assessed?

The Child Development Service follows best practice evidence based standards in conducting its assessments. Our multi-disciplinary team comprises of Psychologists, Speech Pathologists and Occupational Therapists with additional training and experience in the field of Autism.

We use a selection of the following tools and methods during the assessment process which may include the following:

- Detailed developmental and family history
- Autism Diagnostic Interview Revised (ADI-R)
- Autism Diagnostic Observation Schedule 2nd Edition (ADOS-2)
- School/Childcare/Playgroup/Home Observations
- Review of paediatric/medical/academic records

Additional speech/cognitive/functional testing as required

Who is Eligible for Assessment?

Children up to 12 years of age who live in the Australian Capital Territory (ACT) and have a referral from their paediatrician or psychiatrist.

There is no fee for this assessment.

Autism Assessment Referral Process

Step 1

Discuss any concerns you may have about your child's development with your child's paediatrician or psychiatrist. If indicated your child's paediatrician or psychiatrist may choose to refer to the Child Development Service for an Autism Assessment.

Referrals for Autism Assessment by these medical professionals can be directed to the Child Development Intake Service on phone 6207 8884, facsimile 6205 1266 or email Child.Development@act.gov.au.

Your paediatrician or psychiatrist can also provide you with information about private autism assessment if you wish to pursue this option.

Please note – If your child does not have a paediatrician they will need to be referred to one by a GP. Paediatricians are available through the private sector OR ACT Health Community Paediatricians. You can contact ACT Health Community Paediatricians through the Community Health Intake number on 6207 9977.

Step 2

The Child Development Service will write to you to confirm that we have received the referral, and to let you know about you about any additional information that may be required before an assessment can be arranged. This information forms a necessary part of the assessment process.

Additional information includes:



A Medical Assessment by your child's referring paediatrician or psychiatrist

We will require a report that addresses your child's current developmental concerns. This will be provided to the Child Development Service following their initial assessment.

• A hearing assessment for children under 7 years of age.

Hearing assessments can be arrange through ACT Health Audiometrists via contacting Community Health Intake on ph:6207 9977.

Alternatively you can access a private audiologist or contact Australian Hearing.

 A recent developmental assessment (less than 12 months old) or cognitive assessment (less than 2 years old)

How to access this assessment:

- Your school counsellor or psychologist may conduct this assessment if your child is in an educational setting e.g. preschool or school
- If your child is under 5 and is not in an education setting please notify the Child Development Service regarding the developmental/cognitive assessment to discuss options.

Step 3

Once all of the required information is received, we will write to you to confirm that your child has been added to the Autism Assessment waiting list.

Step 4

We will call you by phone when an appointment becomes available to arrange the assessment appointments.

Please be aware that waiting periods will apply before your child is able to be offered an assessment with our team.

Autism Assessment Process

Step 1

Parents or carers will be invited to attend a structured interview to obtain detailed developmental and family history with the assessing psychologist.

Step 2

Observations of your child will be arranged with members of our multidisciplinary team. This may include a structured play based assessment at our service AND/OR an observations of your child in a natural environment such as their child care centre or school.



Step 3

We may gain your permission to speak with other people in your child's life that know them well e.g. school teacher or paediatrician.

Step 4

The multidisciplinary team will consider all information gathered and reach a decision.

Step 5

The assessing psychologist will discuss the outcome of the assessment with you and your family. You will receive a comprehensive report which will include recommendations and appropriate referral if required.

Step 6

Families will be offered referral to the Child Development Service social workers and/or offered a Post Diagnosis Autism workshop as needed.

Useful Links

Concerned about possible Autism symptoms?

ASDetect is a free app that assists parents and caregivers to assess the social attention and communication behaviours of their children younger than $2\frac{1}{2}$ years (between 11 and 30 months).

This video-led self-assessment app is based on comprehensive, rigorous, world-class research conducted at the <u>Olga Tennison Autism Research Centre</u>.

Marymead

The Marymead Autism Centre is based in Canberra and provides a wide variety of services in additional to information including Early Days workshops, support and social groups as well as NDIS preplanning and coordination support. Please note that you or your child do not need to already have an Autism Spectrum Disorder (ASD) diagnosis to access our services, we can help you with the process of getting an ASD diagnosis.

Positive Partnerships

An <u>online resource</u> developed to provide support for school-aged students with Autism. There is information for parents and carers as well as for teachers and schools with the goal to improve outcomes for school-aged students on the autism spectrum both at home and in school.

Autism CRC

A <u>single online gateway</u> to Autism resources, tools and publications. The website contains up-to-date information from the early years through to adulthood and includes research papers and a wide range of resources for the Autism community, service providers, educators and clinicians.



More information about Autism Spectrum Disorder

Raising Children Network ** is an Australian website with evidence based information on a range of ASD related topics.



Annex B. ACT Mental Health Services for People with Intellectual Disability Working Group

The following is from the webpage: https://sofasd.org.au/d7/node/232

ACT Health - neglecting supports for autistic Canberrans

SOfASD used the ACT Freedom of Information process to request all information about ACT Health reviewing its support and services for autistic Canberrans (see FoI request: ACT Health supports for autistic people). The ACT Government's response is in 6 files (links below).

Before you download all this information (links below, they are quite big files), be warned that very little of it is about services for autistic people. Most of the material is specifically about people with Intellectual Disability (ID). Also, the FoI document is poorly prepared: the page numbers in the document list near the front are incorrect and some document titles are listed incorrectly.

It seems that the people who compiled the FoI response, and the people who were involved in responding to the ACT Mental Health Minister, know very little about autism spectrum disorder (ASD). They seem to assume (quite wrongly) that autism/ASD is *just* part of Intellectual Disability. They decided that they should *exclude* autistic people and their representatives from all discussion.

ASD or autism is distinct from Intellectual Disability ... though the disorders may be comorbid for some people (usually said to be 30-50%). The DSM-IV and DSM-5 are quite clear that ASD is usually the primary disability.

- In the DSM-IV, Autistic and Aspergers Disorders were grouped in Pervasive Developmental Disorders on Axis I. They were quite distinct from "Mental Retardation", better called Intellectual Disability, that was listed on Axis II, a quite separate part of the manual.
- The DSM-5 requires that clinicians specify "with or without" Intellectual Disability in an ASD diagnosis.

ACT Health created its *Mental Health Services for People with Intellectual Disability Working Group*. From the outset, autism/ASD was omitted from the Working Group's title. This is classic *Yes Minister* strategy; getting rid of any difficult bits from the title.

Apparently, this was an ACT Government *secret* Working Group as we have not found any public statements or information about it.

The Working Group's draft *Terms of Reference* (ToR) (see FoI pages 85-87) claims it was "committed to developing an action plan for improving the provision of mental health services for people with intellectual disability and Autism Spectrum Disorder in the ACT". The opening notes refer the Working Group to "the National Roundtable on the Mental Health of People with Intellectual Disability (2018)" — see link below — which is a document that omits/neglects autistic people.



The ToR says the group's role/purpose is to "discuss and develop a strategy for mental health services for people with Intellectual Disability, inclusive of Autism Spectrum Disorders where appropriate, in the ACT". The Working Group was set up to neglect autistic people except when services developed for people with Intellectual Disability are also "appropriate" for autistic people. The Working Group's "Reporting Mechanism" clearly and deliberately omits/neglects any specific needs of autistic people.

The Working Group's membership has no one representing autistic people. There is no record of the Working Group communicating with the ASD community in the ACT. The Working Group disregards the principle of "nothing about us without us", of community consultation or stakeholder engagement.

The Minutes of the first meeting 15/11/2018 (FoI pages 81-84) show that members of the Working Group believe "The majority of people identified with autism spectrum disorder also have an intellectual disability (about 70%), group advised it would be appropriate to address these groups within this strategy". The ASD community feels that ID is comorbid with ASD in 30-50% of autistic people ... and that autistic needs must also be specifically and distinctly addressed, ASD is not just a part of someone's ID. The Working Group's ignorance of this is disappointing ... but expected.

Not surprisingly, given its ToR and membership, the Working Group does not make any recommendations in relation to services for the substantial number of autistic citizens who need health and mental health supports. There is no discernible policy or action plan. Note the action plan mentioned/proposed at FoI pages 159-60, even if it is just meant for people with ID, is blank.

There is an ACT Health document, *Mental Health Services for People with Developmental Disability*, (see FoI pages 124-155 - not available on the internet) that essentially avoids ASD-related issues, especially issues relating to distressed behaviour (usually called challenging, problem or unwanted behaviour, behaviours of concern, etc.). Basically, it shows that:

- there are very few services for autistic people in the ACT, and
- no discernible plan to improve the situation.

Other documents provided by or referred to in the FoI are available online. For example:

- Sullivan, Heng, et.al. (2018) Approaches to primary care of adults with intellectual and developmental disabilities: Importance of frameworks for guidelines is available here. It does not mention "autism" or "autistic" at all.
- the WISH report is here.
- Reed, G. M., First, M. B., Kogan, C. S., Hyman, S. E., Gureje, O., Gaebel, W., ... Saxena, S. (2019). Innovations and changes in the ICD-11 classification of mental, behavioural and neurodevelopmental disorders. World psychiatry: official journal of the World Psychiatric Association (WPA), 18(1), 3–19. doi:10.1002/wps.20611 FoI pages 93-109.



• Zhou, Du (2019) Adverse drug event-related hospitalisation in persons with neurodevelopmental disorders: a state-wide retrospective cohort study. 63(5):429-440. doi: 10.1111/jir.12586. - FoI pages 110-21.

In June 2019, Ms O'Dea wrote (FoI, pages 165-6) to various ACT politicians about health issues for autistic Canberrans. The brief prepared for the ACT Mental Health Minister 8/8/2019 (FoI pages 162-4) neglects to mention (remind the Minister of) the Working Group.

It appears that the Canberra Hospital's Emergency Department developed an Action Plan - see link below (also FoI page 171). This "plan" claims that the "stakeholders" were identified before 20/9/2019 ... yet the ASD community in the ACT is unaware of this activity. Apparently, this plan sprung up spontaneously, with no documented motivation or development process.

This planning may have stalled: items due for completion by 18/10/2019 and 15/1/2020 are not marked as completed.

The conclusion is simple: ACT Health ignores ASD advocacy and stakeholders.

see also:

- https://sofasd.org.au/d7/node/236
- AABASD The Interface Between Autism Spectrum Disorders and Mental Health: The Ways Forward (2012).

files:

- FOI20-01 CHS Response_Part1.pdf
- FOI20-01 CHS Response_Part2.pdf
- FOI20-01 CHS Response_Part3.pdf
- FOI20-01 CHS Response_Part4.pdf
- FOI20-01 CHS Response_Part5.pdf
- FOI20-01 CHS Response_Part6.pdf
- Communique_Full.pdf
- Autism-ActionPlan-ED.pdf