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Autism Brief for the Health Department

Autism Aspergers Advocacy Australia, known as A4, asks that the federal Health Department implement policies and programs to improve the health of autistic people in Australia. Autistic people are people with autism spectrum disorder (ASD), informally referred to as just "autism". The diagnostic criteria for ASD are given in the DSM-5.

This brief contains some of the information available about the health of autistic Australians. For decades, researchers and advocates[1] have advised the federal Health Department that people with disability, including people with intellectual disability and developmental delay/disability, and autistic people in particular, have extremely poor health outcomes (see A4's response to the Disability Royal Commission and a Mental Health Brief). Following are some of the issues A4 would like the Health Department to address.

Reports and datasets from several government agencies indicate substantial increases in the number of Australians diagnosed with autism. The Australian Bureau of Statistics (ABS)[2], the Australian Institute of Health and Welfare (AIHW)[3] and the National Disability Insurance Agency (NDIA)[4] all reported increases. However, in 2011 the Health Department, answering a question on notice, advised:

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

A4 requests that the Commonwealth Department of Health and Ageing now recognise formally growing diagnosis rates of autism diagnoses in Australia and the substantial impact of autism on the health of autistic people.

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[1] Most notably Nick Lennox and Prof. JN Trollor. A simple search finds 63 research papers by N Lennox on intellectual disability and 2 on autism. Prof Trollor has 24 on autism and 39 on intellectual disability. There is some overlap.

[2] https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia

[3] https://www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism

[4] The NDIA's "deep dive" on autism no longer appears in searches of the NDIA website. It is still available here, with a commentary. The NDIA moved the report to a NDIS sub-domain: see https://data.ndis.gov.au/reports-and-analyses/participant-groups/outcomes-participants-autism-spectrum-disorder

In addition, A4 asks that the Health Department:

- recognise ASD is a distinct, increasingly diagnosed, and usually severe disability.
- create a *Roadmap for Improving the Health of Autistic People*. Autistic Australians, like autistic people overseas, often have unnecessarily and inappropriately poor health outcomes. A4 expects the Health Department to recognise deficits and improve health outcomes for autistic people in Australia. The Health Department already has a *National Roadmap for Improving the Health of People with Intellectual Disability* that does not address the needs of autistic people.
- fund fully ASD diagnosis for people of all ages. Medicare items for autism diagnosis cut-off at age 13 years and covers a small fraction of the cost. ASD is usually life-long, so people who are undiagnosed by age 13 years are still autistic … and everyone benefits from their being diagnosed. A4 believes that underfunding diagnoses for children and refusing to fund ASD diagnostic services to people aged over 13 years contravenes the CRPD.
- co-design policy and programs to improve health outcomes for autistic people with the autistic sector. Co-designed policy and programs are more likely to be effective and economic.
- address mental health and behaviour support needs of autistic Australians, especially the support that is not available through the NDIA.

The Health Department would benefit from updating and increasing its understanding of ASD. Tellingly, Health did not make a submission to the Senate Select Committee on Autism; it relied instead on a joint submission with the Departments of Social Services (DSS) and Education, Skills and Employment (DESE), with input from the Attorney-General's Department and the Department of Industry, Science, Energy and Resources (DISER) for its submission (July 2020). Their combined submission starts by claiming "autism spectrum disorder (also simply termed autism) is a pervasive developmental disorder …". This outdated view, from the DSM-IV (1994), was superseded by the DSM-5 (2013) that classified ASD as a *neurodevelopmental* disorder.

The combined submission to the Committee also says:

> In 2018, the Australian Bureau of Statistics (ABS) reported* there were 205,200 Australians with autism, a 25.1 per cent increase from the 164,000 people with the condition reported in 2015.

The ABS actually wrote[5]:

> In 2018:
>
> - there were 205,200 Australians with autism, a 25.1% increase from the 164,000 with the condition in 2015.
> - males were 3.5 times more likely than females to have the condition, with prevalence rates of 1.3% and 0.4% respectively.

The combined submission also says, “The number of people with autism in Australia has increased considerably in recent years, which has been attributed to increased awareness of the condition, changes in definitions, services and attitudes”. They do not indicate who said this, and Google does not find a reference.

While there is anecdotal evidence of “increased awareness of the condition”, the “changes in definitions”[6] narrowed the diagnostic criteria, it did not broaden them. This would result in fewer people meeting the diagnostic criteria, not more. “Services and attitudes” (meaning diagnostic practice awareness?) in Australia and in some other countries have improved. Anecdotally, new psychologists are better trained in autism diagnosis.

When bureaucrats attribute increasing autism diagnosis rates to “increased awareness” they mean/imply recent diagnoses are for less severe disability. The ABS reports that 87% of autistic Australians had severe or profound disability in 2003 but this dropped to 68.9% in 2018. The most recent report shows more than 2/3rds of autistic people have severe or profound disability. More people are being diagnosed autistic without being diagnosed with intellectual disability. The ABS’s latest reporting on autism in 2018 says:

> **Severity of disability**
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> In 2018, among all people with autism, 68.9% (141,400) reported having a profound or severe core activity limitation, that is, they need help or supervision with at least one of the following three activities: communication, self-care and mobility.
>
> Almost half (44.1%) of all people with autism had a profound or severe communication restriction. This indicates they needed assistance at least some of the time to understand or be understood by others, for example they may communicate more effectively using sign language or other forms of non-verbal communication.
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> Similarly, one in two (50.9%) of all people with autism had a profound or severe mobility restriction, indicating that they needed help or supervision to move around.

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[5] https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia

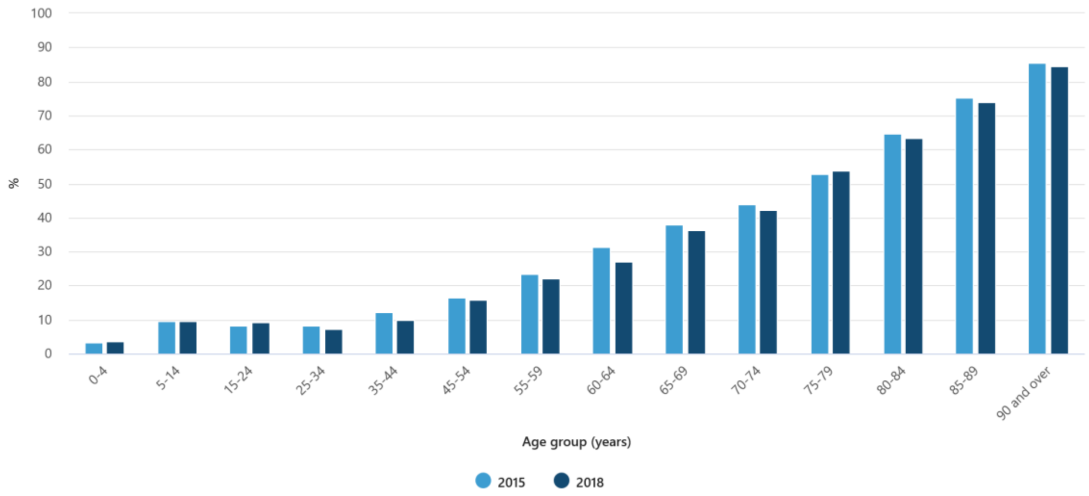
[6] Comparing criteria for DSM-IV *Pervasive Developmental Disorders* with DSM-5 *Autism Spectrum Disorder*. “Changes in definition” differ substantially from changes in diagnostic practice with its improving recognition of ASD without ID.

> Just over one third (36.0%) of all people with autism had a profound or severe self-care limitation, indicating they need support or supervision with dressing, bathing, eating or toileting.

Note that autism data from the USA is usually for 7- or 8-year-olds. The diagnosis rates and their growth in Australia are like the USA for the same age group. Also, the variation between states is seen in both countries.

The following figure from the ABS shows the age distribution of disability in the Australian population.

Disability prevalence rates by age - 2015, 2018

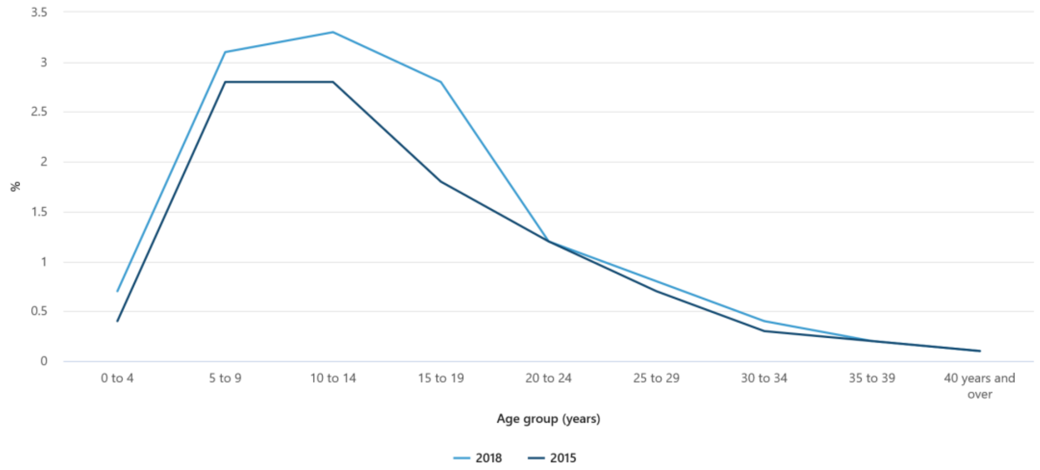


Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2018

Overall, the percentage of Australians with disability is decreasing. This is quite different from the autistic sub-population where diagnoses are increasing at a substantial rate.

Autism is a distinct disability: it is not just a part of some other disability type. Autistic Australians show a very different age profile. The ABS reports that the age distribution for autism diagnoses (which is often interpreted as being indicative of "prevalence") in 2018 was:

Prevalence of autism, by age - 2015 and 2018



Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2018

The diagnosis rate for people aged over 35 years is 1/10th that for teenagers. The chart shows that growth in autism numbers from 2015 to 2018 was largely from the ageing of teenagers 15-19 years old and a lesser increase in diagnoses up to 15 years of age.

Notice that the ABS estimates there were 50,300 autistic children aged 10-14 years. It takes 10,060+ new diagnoses each year to maintain this diagnosis rate in the population. The data for Medicare Item 135 in Annex A of the joint submission shows 13,138 new diagnoses by paediatricians and 309 by psychiatrists (Item 289) of children under 13 years of age in 2019 which suggests that diagnosis rates continue to rise. The Medicare data shows 20-30% increase over the 3 years to 2018 or 2019, consistent with growth in numbers reported by the ABS. Presumably, the Health Department can find the numbers for 2020 and 2021 and see whether this growth in autism diagnoses is ongoing.

The shape of the autism diagnosed by age curve is challenging (chart above). The reason for the massive difference between child and adult diagnosis rates is not known.

- It is unlikely that actual autism prevalence has increased to this extent.
- Nor is most of the drop off in diagnosis rates for adults likely to be due to chronic mortality issues even though autistic people are likely to die younger.
- The cost and difficulty of getting an ASD diagnosis as an adult (or over 13 years of age) is a likely contributor to the low adult diagnosis rate. Also, the lack of expertise in the health sector for diagnosing autistic adults is a likely contributor.
- There are some signs that some less severe cases are being diagnosed resulting in higher diagnosis rates for younger Australians, though this brings little improvement in education and employment outcomes (which would be expected for noticeably milder cases being diagnosed)

The "prevalence" chart above suggests massive under-diagnosis of autistic adults. The health and generally outcomes for autistic adults, especially undiagnosed autistic adults, are extremely poor. The Australian Psychology Society observed[7]:

> International research shows that outcomes for adults with autism are mixed, with lower rates of social inclusion and employment and often poor daily-living skills, and poor mental and physical health. The best outcomes appear to be for those with higher IQ and better language skills, but around half of adults with autism remain living at home, less than half engage in some form of employment or education, few marry and only about 25 per cent have friends (Howlin & Moss, 2012).

The ABS reports abysmal outcomes for autistic Australians in education and employment.

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[7] https://psychology.org.au/inpsych/2017/april/richdale

Some officials believe, and even claim, that rising diagnosis rates are due to over-diagnosis or some form of diagnostic transfer. But the Government's quest for evidence of over-diagnosis was not very fruitful - see https://a4.org.au/node/1213.

The following table, from A4's recent submission on NDIS sustainability, shows NDIS participation rates for autistic children state/territory. It shows the percentage of each state's children who are currently autistic NDIS participants (not including those with autism as a secondary disability).

	NDIS - autism			NDIS rates	
Age (years)	*0 to 6*	*7 to 14*	*15 to 18*	*0 to 6*	*7 to 14*
ACT	248	1,325	398	0.63%	2.97%
NSW	7,124	23,869	6,100	1.03%	2.90%
NT	148	568	102	0.61%	2.03%
QLD	4,257	17,125	4,267	0.96%	3.05%
SA	1,795	8,622	2,406	1.29%	5.01%
TAS	431	1,513	469	1.04%	2.87%
VIC	5,197	21,159	4,707	0.93%	6.23%
WA	1,587	6,782	2,301	0.66%	2.41%
Australia	*20,788*	*80,972*	*20,752*	*0.95%*	*3.09%*

On average 3% of school-age children are NDIS participants with autism as their primary diagnosis. The variation between states is more than a factor or 2. The highest rates are in Victoria (6.23%) and South Australia (5%).

Health officials often (and incorrectly) regard autism as a subtype of Intellectual Disability. The ACT Health Directorate told its Review of Intellectual Disability that 70% of autistic people have an Intellectual Disability; then they dropped any consideration of the needs of autistic Canberrans. The maximum rate of intellectual disability is 2.2% (2 standard deviations below the mean) though most estimates suggest 1-1.8% of people have intellectual disability. With 3.3% of school-age children being autistic (and NDIS participants), if all children with intellectual disability (max. 2.2%) were also autistic then at most 67% of autistic children could have intellectual disability. The CDC in the USA, using data from 2008, estimated around 30-40% of autistic children also had intellectual disability, though many are also had borderline ID. With increased ASD diagnosis rates since then, the rate of autism with comorbid ID is likely to have dropped further since then.

Apparently, the health sector expects that Australia's health system can address the needs of autistic Australians by addressing the needs of people with Intellectual Disability. Basically, the health officials expect that needs not related to intellectual disability do not need to be addressed, and the "roadmap" for Intellectual Disability has autism covered. This gross misconception ignores the distinct needs of autistic people such as social isolation, communication disorder, dysfunctional behaviour, sensory issues, and many more that are not associated with intellectual disability. It ignores the part of every ASD diagnosis where the diagnosing clinician identifies that the person being diagnosed *needs* disability support for their autism.

There may be some overlap between intellectual disability and autism in relation to mental health. Occasionally, for example the Burdekin Report of the early 1990s, identified the discriminatory lack of mental health support for people with intellectual disability. A similar issue now exists for autistic people with mental illness: their needs are unrecognised and unmet. This is another example of disability discrimination.

Autistic diagnoses have been a challenge for women. Traditionally, the male:female ratio for autism was reported as 4:1 or higher. Based on ABS 2018 data, government's joint submission on autism said:

> Boys are diagnosed with autism at 3.5 times the rate of girls, with prevalence rates of 1.3 per cent and 0.4 per cent respectively.

The latest NDIS Quarterly Report has a M:F ratio of 2.8:1 for autistic NDIS participants.

The government's joint submission to the Senate Select Committee on Autism fails to mention autism is the biggest disability in the NDIS. At the time, 31% of NDIS participants listed autism as their primary disability. This is substantially more autistic NDIS participants than the NDIA expected.

The number of autistic NDIS participants continues to increase. Minister Reynolds suggested that there may be sustainability issues associated with the number and cost of autistic participants.

For decades, Australian researchers[8] have been telling the Health Department about especially poor outcomes for people with intellectual disability and developmental delay. The Government has largely ignored the information, though the Health Department recently released its National Roadmap for Improving the Health of People with Intellectual Disability … now that autism has overtaken ID in NDIS participant numbers. The Health Department says it has an emphasis on mental health, though it seems to have little or no idea how to address the mental health needs of autistic Australians.

Research tells us …

> Rates of death are higher for autistic individuals compared to the general population. There is higher risk of death for autistic individuals who have additional mental and physical health conditions. The leading causes of death for autistic individuals with and without ID are "nervous system and sense disorders", which includes epilepsy and "injury and poisoning", respectively. To minimize risk of death, it is important to manage the mental and physical health individuals on the autism spectrum and to better understand the circumstances surrounding preventable deaths for this population.

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[8] Especially Nick Lennox and Prof. Trollor.

> Hwang YIJ, Srasuebkul P, Foley KR, Arnold S, Trollor JN. Mortality and cause of death of Australians on the autism spectrum. Autism Res. 2019 May;12(5):806-815. doi: 10.1002/aur.2086. Epub 2019 Feb 25. PMID: 30802364.
>
> https://pubmed.ncbi.nlm.nih.gov/30802364/

and

> Autism spectrum disorder is associated with high rates of co-occurring health conditions. While elevated prescription rates of psychotropic medications have been reported in the United Kingdom and the United States, there is a paucity of research investigating clinical and prescribing practices in Australia. This study describes the problems managed and medications prescribed by general practitioners in Australia during encounters where an autism spectrum disorder was recorded. Information was collected from 2000 to 2014 as part of the Bettering the Evaluation and Care of Health programme. Encounters where patients were aged less than 25 years and autism spectrum disorder was recorded as one of the reasons for encounter and/or problems managed (n = 579) were compared to all other Bettering the Evaluation and Care of Health programme encounters with patients aged less than 25 years (n = 281,473). At 'autism spectrum disorder' encounters, there was a significantly higher management rate of psychological problems, and significantly lower management rates of skin, respiratory and general/unspecified problems, than at 'non-autism spectrum disorder' encounters. The rate of psychological medication prescription was significantly higher at 'autism spectrum disorder' encounters than at 'non-autism spectrum disorder' encounters. The most common medications prescribed at 'autism spectrum disorder' encounters were antipsychotics and antidepressants. Primary healthcare providers need adequate support and training to identify and manage physical and mental health concerns among individuals with autism spectrum disorder.
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> Birch RC, Foley KR, Pollack A, Britt H, Lennox N, Trollor JN. *Problems managed and medications prescribed during encounters with people with autism spectrum disorder in Australian general practice.* Autism. 2018 Nov;22(8):995-1004. doi: 10.1177/1362361317714588. Epub 2017 Sep 15. PMID: 28914073.

It is important to note that these abysmal health outcomes for autistic adults arise when the autism diagnosis rate for Australian adults is most likely a small fraction of the actual prevalence. Too often, discrimination and other barriers to health care are fatal for autistic people.

Evidence given to the DRC[9] describe a health system failing autistic people.

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[9] https://disability.royalcommission.gov.au/system/files/2020-10/Report%20-%20Public%20hearing%204%20-%20Healthcare%20for%20people%20with%20cognitive%20disability.pdf

> 84. Dr AAJ also expressed the view, based on both professional and personal experience, that there are virtually no services to support acutely unwell people with severe autism in Australian hospitals.
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> …
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> 93. Ms Abi said that online groups of people with autism and their parents have taught her more than any health professional with respect to care and treatment for her sons. She also expressed the view that there are insufficient good health practitioners who are both affordable and available to meet the health needs of her children.
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> …
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> 134. Professor Trollor recommended mandatory training for the health workforce on the needs of people with intellectual disability and people with autism, including enhanced training for specific medical speciality groups and career pathways in sub-specialties. In addition, Professor Trollor highlighted the importance of professionals working in the disability system acquiring basic competencies in disability health care.

The ACT government's recent Health disability strategy ignores the needs of its autistic citizens.

Overseas research shows many specific poor outcomes for autistic people that are likely to present similarly in Australia.

The opportunity exists for the Department of Health and Ageing to initiate programs to substantially improve health and mental health outcomes for autistic Australians.

Acknowledgement

This brief was written primarily by Bob Buckley of A4 with substantial input from Dr Jessica Paynter of ASfAR.

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