



*Speaking Out for Autism Spectrum Disorder
in the ACT*

Submission to
ACT Assembly
Standing Committee on Health, Ageing and Community Services
for its
Inquiry into the Employment of people with disabilities

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Introduction

Speaking Out for Autism Spectrum Disorder (SOofASD) appreciates this opportunity to provide input to government in the ACT.

SOofASD is a purely volunteer organisation in the ACT whose purpose is systemic advocacy for autistic people and people living with autism spectrum disorder. SOofASD has no funds and no paid staff/personnel.

SOofASD has a history of advocacy in the ACT, starting with *Action for Autism* in around 1997. The group merged with the unified *Autism Asperger ACT* (AAACT) but SOofASD renamed itself and separated again from AAACT as AAACT focussed on service provision and the impending NDIS arrival around 2012.

Autism Spectrum Disorder (ASD) is defined in the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition* (2013), known as the DSM-5, as neurological disorder. The previous edition, the DSM-IV, and the current World Health Organisation ICD-10 (which is aligned to the DSM-IV), describe a category of diagnoses called Pervasive Developmental Disorders that included *Autistic Disorder* and *Asperger's Disorder* (different names are used in the ICD-10). See <http://a4.org.au/ASDformal> for more detail.

Briefly, ASD can be diagnoses when both the following are observed.

- Persistent deficits in social communication and social interaction across multiple contexts
- Restricted, repetitive patterns of behaviour, interests, or activities

The cause of ASD is unknown: it is generally regarded as having strong genetic components that emerges with some environmental contexts. The genetics are complex and not yet understood. The environmental aspects are as yet unknown (though vaccines have been eliminated).

The ACT Government has a very poor understanding of ASD (see <http://sofasd.org.au/d7/node/148>). In November 2015, the Assembly passed a motion saying that “Autism Spectrum Disorder (ASD) affects around one in 160 children”. SOofASD wrote to the government (see <http://sofasd.org.au/d7/node/142>) pointing out that in June 2015, 1 in 70 children in the ACT aged 5 to 15 years were registered and receiving Carer Allowance (child) with a formal diagnosis of autism. The national rate was 1 in 49 were autistic at that time. The Minister confirmed (see http://sofasd.org.au/d7/sites/default/files/20151216083542077_0.pdf) “that the ACT Government refers to someone with Autism as being *diagnosed* with Autism, not *affected* by Autism” so the phrase used in the motion that was passed by the Assembly, “affects around one in 160 children”, is both extremely unclear about who the ACT Government actually meant and a massive underestimate of autism prevalence in the ACT.

The number of people who are diagnosed autistic is increasing in Australia (and elsewhere in the world). Recently, the *Australian Bureau of Statistics* (ABS) published its estimate that ...

there were 164,000 Australians with autism, a 42.1% increase from the 115,400 with the condition in 2012.

<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>

Other sources also show this substantial growth rate, in particular *Autism Aspergers Advocacy Australia*, known as A4, reports regularly on growth in the number of autistic Australian children receiving Carer Allowance (child) from the Commonwealth Government (see <http://a4.org.au/node/1340>) due to ASD.

Multiple sources (see <http://a4.org.au/node/1452>) indicate ASD diagnosis rates in the ACT are well below the national average (which is concerning).

The ABS also reports that

Among people with autism, 64.8% 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.

Despite increasing diagnosis of ASD supposedly milder symptoms, most people who are diagnosed with “autism” have severe or profound disability. And without pro-active efforts to improve their lives ... outcomes for autistic people are particularly poor. Also note that all ASD diagnoses mean at least “level 1 severity, requiring supports”.

Autistic people make up a substantial part of people with disability who need services and supports. Currently, around 30% of NDIS participants are autistic which is substantially more than governments expected.

The DSM-5 says

Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naïve and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression. Many adults report using compensation strategies and coping mechanisms to mask their difficulties in public but suffer from stress and effort of maintaining a socially acceptable façade.

Governments in Australia have done very little to recognise the needs of autistic adults or to develop the services and supports that autistic adults need distinctly for their ASD. The lack of services is reflected in the substantial levels of unmet need that the ABS reports periodically. This lack of appropriate services for autistic adults may also contribute to the high rates of NDIS underspending.

Employment outcomes for autistic people

Very little is known about employment outcomes for autistic adults in the ACT. Anecdotally, there are few discernible supports and few autistic people have successful employment records.

The exception is the [Dandelion Project](#) which aims to find an elite group of autistic adults for specialist employment roles. Unfortunately, this approach make only a minor difference to the overall numbers.

If the ACT Government wants a better understanding of employment outcomes for adults with disability in the ACT, it could:

- Obtain data from Centrelink, especially data about Newstart and the Disability Support Pension;
- Ask the ABS to collect more detailed information about people with disability in the national census; and
- Talk to autistic people about employment.

The latest figures from the ABS on employment outcomes for autistic Australians says ...

The labour force participation rate was 40.8% among the 75,200 people of working age (15-64 years), living with autism spectrum disorders. This is compared with 53.4% of working age people with disability and 83.2% of people without disability.

The unemployment rate for people with autism spectrum disorders was 31.6%, more than three times the rate for people with disability (10.0%) and almost six times the rate of people without disability (5.3%).

Employment policy and programs that aims to help people with disability rarely improves outcome for autistic people because such efforts fail to recognise and respect the distinct nature of ASD. Generic disability policy and practice usually leaves autistic people behind.

The terms of reference mention “attraction and retention” of people with disability. These are not the issue.

The foundation problem in employment of autistic people is that employers do not want to employ them. This arises from the federal government promoting extremely negative images of people with disability: politicians and bureaucrats routinely denigrate people with disability, describing them as bludgers and rorters. So, it should be no surprise that employers do not want to employ people they’ve been told (quite incorrectly) are lazy and unreliable.

SOofASD has observed that the high effective marginal tax rate on people with disability is not necessarily a disincentive to employment: autistic people want to work even if they don’t get paid much for their efforts. For a person getting DSP, each \$1 earned substantially reduces their payment. The result is one of the highest marginal tax rate in the country on some of the poorest and most vulnerable citizens.

More recently, the federal government has created its cruel and malicious robo-debt scam. People on DSP, if they now get a job, invite the government to fabricate substantial debts against them. Many people have difficulty contacting the relevant government agencies about the debt. The effort needed to address a debt that was fabricated by the government is usually substantial. Autistic people have poor communication skills and are often poorly organised; they are likely to be unable to challenge fabricated debt effectively.

The federal government's debt fabrication scam is likely to be a substantial disincentive to autistic people seeking employment.

Education is the foundation for employment

Employment of autistic people depends to a significant extent on the outcomes for autistic people from their education.

SofASD is not aware of the ACT Government monitoring and reporting on education outcomes for autistic students ... nor for students with disability generally in the ACT.

The ABS reports that nationally education outcomes for autistic people are abysmal.

In 2015, almost all children on the autism spectrum had some form of educational restriction (96.7%), including a small number who were unable to attend school because of their disability. Almost half (48.0%) the children attended a special class in a mainstream school or a special school.

Of the young people (aged 5 to 20 years) with autism who were attending school or another educational institution, 83.7% reported experiencing difficulty at their place of learning. Of those experiencing difficulties, the main problems encountered were fitting in socially (63.0%), learning difficulties (60.2%) and communication difficulties (51.1%).

Young people (aged 5 to 20 years) with autism may need a high level of support to participate in their education. In 2015, over half (55.8%) of young people with autism needed special tuition and 41.8% needed help from a counsellor or disability support person, while 20.7% didn't receive any additional assistance (excluding attending a special school or special classes in a mainstream school).

More than two out of five (44.1%) children indicated they needed more support or assistance at school than they were receiving.

People with autism are less likely than others to complete an educational qualification beyond school and have needs for support that differ from people with other disabilities. People with other disability were 2.3 times more likely to have a bachelor degree or higher than people with autism, while people with no disability were 4.4 times more likely to have one. All people with disability and those with no disability were 1.6 times more

likely to have an Advanced Diploma, Diploma or Certificate III or IV than people with autism.

Behaviour is a significant challenge to the education many autistic students.

Behaviour issues for autistic students were highlighted over the internationally infamous boy-in-a-blue-cage episode in the ACT (see [Autism cage details emerge as United Nations investigates abuse of children](#)). Despite this, the ACT Government has not improved its approach to behaviour support for autistic students (see [starting 2017 school year again without discernible progress on services for problem behaviour](#) and [recognise behavioural clinicians in the ACT](#)). The ACT Government keeps doing the same thing and expecting a different outcome in the education of autistic students. The ACT Government must be judged according to its inaction in the matter.

Learning from other states, Commonwealth and International

As discussed above, national employment outcomes for people with disability in Australia are particularly poor. And employment outcomes for autistic people are substantially worse.

SofASD is not aware of any national, state or territory effort that shows any better employment outcomes for autistic adults.

Government failure/refuse to recognise the distinct nature of ASD, that ASD is different from other disability, means the different strategies, policies and programs are needed to achieve more equitable outcomes for autistic people.

Governments should recognise that inclusion for autistic people is different from inclusion generally.

The NDIS's hope to fund just 75% of access to employment for autistic adult NDIS participants is a huge disappointment – see <https://ndis.gov.au/appeal.html>.

Rather than recognise the growing number of Australians diagnosed with ASD in Australia, the Government believes ASD is substantially over-diagnosed. So far, efforts to find this over-diagnosis have failed – see [Government not intending its autism over-diagnosis claim](#).

Australian outcomes for autistic people are especially poor compared to outcomes in other countries. SofASD believes evidence from overseas demonstrates that better employment outcomes for autistic adults result from:

1. National legislation that ensures clear human rights
2. Promoting employment of people with disability to employers (rather than denigrating people with disability as budgers and rorters)
3. More equitable education outcomes for autistic people
4. Effective early diagnosis and intervention for autistic children.

Autism and the ACT Public Service

SofASD is unaware of effort to employ autistic people in the ACT Public Service. SofASD has not seen reporting of employment rates for autistic public servants.

Gender related matters

In Australia, there are nearly 4 males diagnosed with ASD for every female. Some people believe that there is serious under-diagnosis of ASD for women. Similar rates are observed overseas.

Other matters

Above, we've shown that employment outcomes for autistic people are especially poor. There is also research showing that living with ASD affects the economics of the whole household: having an autistic person in a household reduces total income – see [study finds Autism sets back families \\$35,000 per year](#). There are numerous factors that affect family income.

SofASD is concerned that the NDIS has collected all the available government funding. There is very little funding left to improve education, employment, accommodation, etc.

The demise of Autism Asperger ACT is an example of the “unintended consequences” of the NDIS. In the post NDIS era, it is significantly harder to start or resume an organisation like Autism Asperger ACT.

There are indications that many autistic adults are neither labour force participants nor DSP recipients. In recent correspondence, the Commonwealth Department of Social Security told Autism Aspergers Advocacy Australia that there are nationally 9,500 DSP recipients with *Autistic Disorder* and 6,800 DSP recipients with *Asperger's Disorder* ... that is 16,300 autistic DSP recipients.

In 2015, about 44,500 autistic Australian with severe or profound disability aged 15 to 64 years old were not in the labour force. These people are the most likely autistic Australian to receive Disability Support Pension ... but only 16,300 of them receive DSP, leaving around 28,200 who may not get essential support.

Conclusions

Little is known about employment outcomes for autistic people in the ACT. It is likely that employment outcomes for autistic people are as dismal in the ACT as they are nationally.

Disability policy and programs will not deliver equitable outcomes for autistic people until programs recognise ASD is a distinct disability.

Delayed diagnosis, inadequate early intervention, ineffective education all contribute to abysmal employment outcomes for autistic people. Outcomes will remain abysmal while governments keep doing the same things and hoping for different outcomes.