

Autism Spectrum Disorder, employment and welfare

A Submission to the Reference Group's
Review of Australia's welfare system

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Introduction

Autism Aspergers Advocacy Australia, known as A4, is the national grassroots organisation to advocate for people affected by autism spectrum disorder (ASD).

A4 recognises the need for Government to review its welfare provisions. The Review's Interim Report (links [here](#)) explains the motivation and scope for the review.



We appreciate the opportunity to comment on Australia's welfare system and on the Interim Report. Please accept this under-prepared submission. Currently, we have a massive workload addressing current Government reforms that impact on the lives of people affected by ASD. Our work is completely voluntary and unfunded: there is no financial assistance for systemic advocacy for people affected by ASD.

The submission following relates to people with ASD. Below, we explain that

- ASD is a substantial and growing component of people with disability.
- Much of the advice Government gets about people with ASD is incorrect
- people with ASD experience worse employment outcomes than people with other types of disability
- blaming people with ASD for being unemployed will not increase their labour force participation; it is destructive, it just does not help.

We address the five review items, then we comment briefly on the political context and the Committee's Interim Report.

About Autism Spectrum Disorder in Australia

ASD is a major disability type. In the 3rd Quarterly report on NDIS progress, “autism” suddenly emerged as the biggest distinct disability for participants in the NDIS (links [here \(MS Word\)](#) and [here \(PDF\)](#)).

The American Psychiatric Association, who publish the Diagnostic and Statistical Manual of Mental Disorders, says

Autism Spectrum Disorders* are a range of complex developmental disorders that can cause problems with thinking, feeling, language, and the ability to relate to others. They are neurological disorders, which means they affect the functioning of the brain. How autism disorders affect a person and the severity of symptoms are different in each person.

Autism is usually first diagnosed in childhood. About 1 in 68 children is diagnosed with autism. Autism Spectrum Disorders are three to four time more common in boys than in girls.

It is a lifelong disorder in most cases, though [in the USA where best practice early intervention is funded by the state and health insurance] there are more and more cases of children with ASD who are eventually function independently leading full lives. ...

* Changes in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th edition) includes within Autism Spectrum Disorder the previously separate categories of autistic disorder (autism), Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS).

From <http://www.psychiatry.org/autism>

In Australia, the number of children aged 0-15 years who are formally diagnosed with Autistic Disorder or Asperger's Disorder and registered with Centrelink for their family to receive Carer Allowance (child) grew from 14,495 in 2004 to 58,018 in 2013: a four-fold increase in just 9 years.

The Australian Bureau of Statistics (ABS) estimated the number of people with autism based on its periodic Survey of Disability, Ageing and Carers (SDAC, links here for [2009](#) and [2012](#) reports). The age distribution and totals are below.

	1998	2003	2009	2012
0-4 years	1000	1200	3500	6000
5-9 years	10500	8200	19400	33000
10-14 years		10800	19200	26400
15-19 years		3900	11400	21800
20-24 years			3700	11500
25-29 years			2800	3500
30-34 years	1700	6200		3200
35-39 years			4600	2700
40 years and over				7000
<i>Total with Autism</i>	13200	20900	64600	115400

The biggest rate of growth in the table above is in the adult years: people with ASD 15 years and over grew 2.2 times from 2009 to 2012. Diagnosis of ASD adults is expected to be diagnosis that could have been made in childhood but wasn't.

The ABS SDAC data showed 87% of people reported as having ASD in 2003 had severe or profound disability. In 2009 and 2012, the proportion with severe or profound disability was 74% and 73% respectively. Since most people with ASD have severe or profound disability, this is growth in people who are unlikely to be employed and likely to depend on a Disability Support Pension (DSP).

Government officials do not always provide accurate information about ASD. For example, in 2011 the Health Department told Senate Estimates “The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia” (see <http://a4.org.au/a4/node/359>).

Officials will tell you, based on guesswork, that increasing ASD prevalence is due primarily to better diagnosis of milder cases. The diagnostic criteria for ASD describe “severe and pervasive impairment”, so the increase involved people with *milder cases* of “severe and pervasive impairment”. The fact is that some of the increase is due to “milder cases” but *most* of the increase in ASD diagnoses is due to people with very poor outcomes in education, labour force participation, etc. (see <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Features12012>).

Some officials and academics also claim that the increase in ASD prevalence is due to people with a disability changing their primary diagnosis to ASD, but the ABS reported repeatedly that

It is unlikely however, that people are being diagnosed with other conditions instead of autism as there is no correlating increase in other conditions in the SDAC data that would suggest alternative diagnoses (e.g. other developmental disorders, mental retardation/intellectual disability) in these late teenage years.

In fact, the AIHW found evidence of young adults changing their primary diagnosis from ASD to intellectual disability. The reason for making such a change appears to be that having ASD either does not allow or actually prevents them from accessing essential services that they can access if they have intellectual disability.

The prestigious science journal, Nature, (see <http://www.nature.com/news/the-prevalence-puzzle-autism-counts-1.9280>) says:

Shifting diagnoses and heightened awareness explain only part of the apparent rise in autism. Scientists are struggling to explain the rest.

More accurate information about the number of people with ASD might have been available had the Government kept its promise in 2009 to create a National Autism Register.



ASD and employment

Better news is that increasing diagnosis of ASD in adults from 2009 to 2012 brought increased employment rates.

In 2009, there were 22,200 adults (15+ years old) with ASD of whom just 4,500 (20.1%) were employed ... compared to 50% of people with a disability were employed. In 2012, there were 49,700 adults with ASD and 17,500 (35.2%) were employed ... compared to 47.7% of people with a disability. The unemployment rate for people with ASD fell from 14.2% in 2009 to 10.3% in 2012 and labour force participation rose from 34.3% in 2009 to 45.5% in 2012.

	2009	2012
ESTIMATES ('000)		
Employed	4.5	17.5
Unemployed	3.1	5.1
Not in the labour force	14.6	27.1
<hr/> PROPORTIONS (%)		
Employed	20.1	35.2
Unemployed	14.2	10.3
Not in the labour force	65.7	54.5

ASD and disability services

ASD is usually life long; so to achieve better outcomes a life long approach is required. We pointed out above that ASD is the most numerous type of primary disability in the NDIS at this time.

Most people with severe or profound ASD need supervision and support 24 hours per day 7 days per week. Families provide the vast majority of this support. While this is “normal” for children, it is not normal for adults. The replacement cost for the so-called “informal care” that families provide, just in terms of raw labour, exceeds \$200K per year per adult with severe or profound ASD.

There are estimated to be 16,400 adults with ASD. Feel free to estimate the value of “informal care” for adults with ASD in Australia based on these figures. Despite their enormous contribution, politicians, bureaucrats and the media characterise informal carers as bludgers and welfare cheats. Informal carers deserve much more respect than they get.

Government in Australia does not believe in, let alone fund, best practice early intervention for children with ASD (see <http://a4.org.au/a4/node/843>).

In our view, the real goal of this review should be to increase participation for Australia's more vulnerable people in employment so that they are less dependent on welfare. Ensuring that children with ASD can access best practice early intervention with optimal outcomes is

essential. The NDIS is an opportunity to provide best practice early intervention for children with ASD which will substantially improve their employment in the long run.

Our message is that real improvement in labour force participation and employment for people with ASD will not come from changing the welfare system, it will come first from ensuring employers employ people with ASD.

In addition, effective employment for people with ASD needs Government to ensure children with ASD get

- best practice early intervention for their ASD; and
- effective education at all levels.



Review Topics

The following sections address the specific review topics.

incentives to work for those who are able to work

The vast majority of people with disability already want to work. Suggestions that they need incentives are offensive: Government must recognise that such suggestions are off-putting and function as serious disincentives.

In a remarkable leap of logic, Treasurer Hockey and the Government say a marginal tax rate of approaching 49% is a disincentive for high income earners but he does not recognise that the massive impost on income for people with a disability might be a disincentive in some cases. Most people with a disability want to work even though the current regime puts them effectively on the highest marginal tax rate.

People with ASD do not need much more incentive to work. People with ASD, even those severely or profoundly affected by ASD, find the routine of a workplace attractive; much more attractive than community access programs that are often relatively unpredictable for participants.

Frankly, the Government asked the wrong question. The Government needs to work out how to get Australian employers to employ people with a disability.

The Government could start by showing leadership. The Disability Discrimination Commissioner documented that the Government reduced its employment of people with a disability from 5.8% to 3.8% in recent times. This does not show leadership.

A4 has a steady stream of complaints that Disability Employment Service providers simply do not understand people with ASD and how to help them into employment. Reports from “the field” indicate that many DES providers cannot even conduct an effective interview of a potential client with ASD. DES providers who cannot interview a client have very little chance

of helping clients with ASD into employment or of ensuring employment is ongoing. Few DES providers understand people with ASD. Consequently, they have employment outcomes for people with ASD are particularly poor.

Both Government that is meant to offer appropriate services and supports, and the wider community that is supposed to *Include* people with ASD, fail to recognise ASD as a distinct disability.

There is evidence that supporting appropriate employment programs for people with ASD can succeed (see <http://aut.sagepub.com/content/3/3/229.short>) but such programs are usually short term.

Another option would be to ensure *Specialisterne* (see <http://specialisterne.com/>) and similar organisations that specialise in developing employment for people with ASD are functioning effectively in Australia (see <http://www.forbes.com/sites/techonomy/2013/10/28/creating-great-employees-who-happen-to-be-autistic/>).

If Australia is still discriminating against 49% of working women who bear children (see [here](#)), then there really is little chance that people with a disability will get a fair go.

adequately support those who are genuinely not able to work

Data from the ABS, shown in the Introduction above, show that up to 2012, three quarters of people with ASD have severe or profound disability ... and fewer than half the adults with ASD are not participating in the labour force. In 2012, the employment rate for people with ASD was 35.2%. The rest (64.8%) need income support and access to services and support for their disability.

The third Quarterly report on the NDIS showed people with ASD are the biggest distinct disability group in the NDIS trial sites at the end on March 2014. It is yet to be seen whether the number of people with Intellectual Disability as their primary disability overtakes ASD as the NDIS includes more people with a disability.

Unfortunately, few people with ASD in Australia get the services and support that they need, specifically:

- best practice early intervention recommended by the Health Department and DSS (see <http://a4.org.au/a4/node/843>)
- effective education
- specialist behavioural support for students and adults with ASD.

According to the NDIS progress report from the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme, both the NDIA and the Committee are “clearly satisfied that the evidence means that the current [NDIS] guidelines are insufficient”. At this

stage, “The current NDIS design is particularly bad in relation to autism” (see <http://a4.org.au/a4/node/869>).

One area of particular concern is support for people with ASD in mental health services. Since the Burdekin report, one of the first acts of the Disability Discrimination Commissioner, identified an issue with the lack of suitable services for people with both Intellectual Disability and mental illness, a number of appropriate services have been funded across the country.

Many people with ASD also experience mental illness. They are routinely excluded from mental health services. Unfortunately, just when people with ASD need a Disability Discrimination Commissioner to report on their exclusion from mental health services, the Government got rid of the distinct Disability Discrimination Commissioner.



Government needs to recognise properly that ASD is a distinct disability. The current growth in ASD is unsustainable. The Government needs to do much more to understand and address the issues, especially in relation to adults with ASD.

As we said above, many families provide the “informal care” that adults with ASD need when employment, supported accommodation and even basic behavioural services are not available. Support for people with ASD and for “informal carers” to support adults with ASD is inadequate. We are happy to elaborate for the Committee if it is really interested.

support social and economic participation through measures that build individual and family capability

Government had proven repeatedly that it is not serious about building “individual and family capability”.

The Government made a small step in the right direction when it introduced the *Helping Children with Autism* package. At the launch of the package, the Prime Minister said it was “just a beginning” ... but there has been no progress since then, and the NDIS wound back that first small step. At this stage, the HCWA package that funded about 5% of the early intervention deemed necessary for children with ASD and was as good as it gets in Australia.

Repeatedly, Government in Australia has funded reviews of the evidence and science on how to improve social and economic participation of people with ASD. Governments and its agents in Australia have copious advice on how to improve equality of outcomes for people with ASD; but they reject the advice of experts in ASD (see <http://a4.org.au/a4/node/843>).

Despite the clear requirement to fund affordable best practice early intervention, the NDIA told the Parliamentary Joint Standing Committee on the National Disability Insurance Scheme that it put off funding necessary early intervention for children with ASD; instead ...

The Agency has engaged an internationally recognised epidemiologist and academic, Dr Katrina Williams, to convene a group of experts to update the research evidence for the management of autism. It told the committee that this work will lead to the development of more specific guidelines for needs assessment and reasonable and necessary interventions for children with autism.

Education is the foundation of social and economic participation. People with ASD have abysmal outcomes in education (see [link](#)). Australian law encourages schools to exclude students with ASD or any disability that may involve different or challenging behaviour (for example, see [here](#), [here](#) and [here](#)). Australian law is contrary to the international treaties on the Rights of the Child. Australia students with sever or profound behavioural difficulties do not have access to properly accredited behavioural specialists. While New Zealand has two universities that train graduates for the internationally recognised accreditation, Australia has none (see <http://www.bach.com/>).

Compare the actions of Governments in Australia to the actions of the US Government who fund early intervention to improve life long social and economic participation through Medicaid (see [link](#)) and legislate to fund research into improving services and supports for adults with ASD (see [link](#)).

If Government wants people with ASD to have better outcomes in social and economic participation, then it needs to recognise and address the needs of people with ASD. It must

1. recognise that ASD is a distinct disability with specific needs in early intervention, education, health and disability services and supports;
2. ensure that people with ASD can access services and support for their ASD including in relation to employment;
3. ensure that people with ASD get effective access to mainstream services and supports including those that underpin employment; and
4. recognise and protect the rights of people with ASD.

be affordable and sustainable both now and in the future and across economic cycles

Basically, Government wants to minimise welfare spending. They prefer by far to minimise apparent short-term costs rather than try to minimise long-term costs.

The community prefers that Government takes a long-term view of welfare; preferring long-term savings over short-term cost minimisation that results in greater overall cost.

To improve affordability and sustainability of welfare service and supports for people with ASD, Government needs to ensure people with ASD access effective early intervention and education.

Government can also minimise long-term support costs by ensuring people with ASD access proactive behavioural services.

Sadly, Government prefers short-term savings that typically result in greater costs in the long-run. Government refuses to be accountable for its decisions. Officials are never held responsible for decisions that are costly in the long-term. Again, Government really is not credible on this issue because it persists with its costly short-sighted approach to “affordable and sustainable”.



be easy to access and understand, and able to be delivered efficiently and effectively.

Welfare must be reasonably accessible for those who need it. It does not need to be “easy” to access. Politicians, bureaucrats and the media keep telling us it is already far too easy to access.

There is no point in us commenting on the efficiency and effectiveness of bureaucracy. Suffice it to point out that Government touts competition as essential for efficiency in the private sector, yet bureaucrats abhor/detest competitive (duplicated) services in the public sector.

Political and Economic Context

Government and the media must stop portraying people affected by disability as rorters, bludgers, slackers, etc. It demoralises people with disability and people who support them.

The evidence is that people with disability make very good employees ... when they are given a chance.

Government claims that growth in Disability Support Pension is “unsustainable”. The data above shows that the number of people with severe or profound disability due to ASD has grown far more than the growth in DSP over the same period. The growth in ASD is unsustainable.

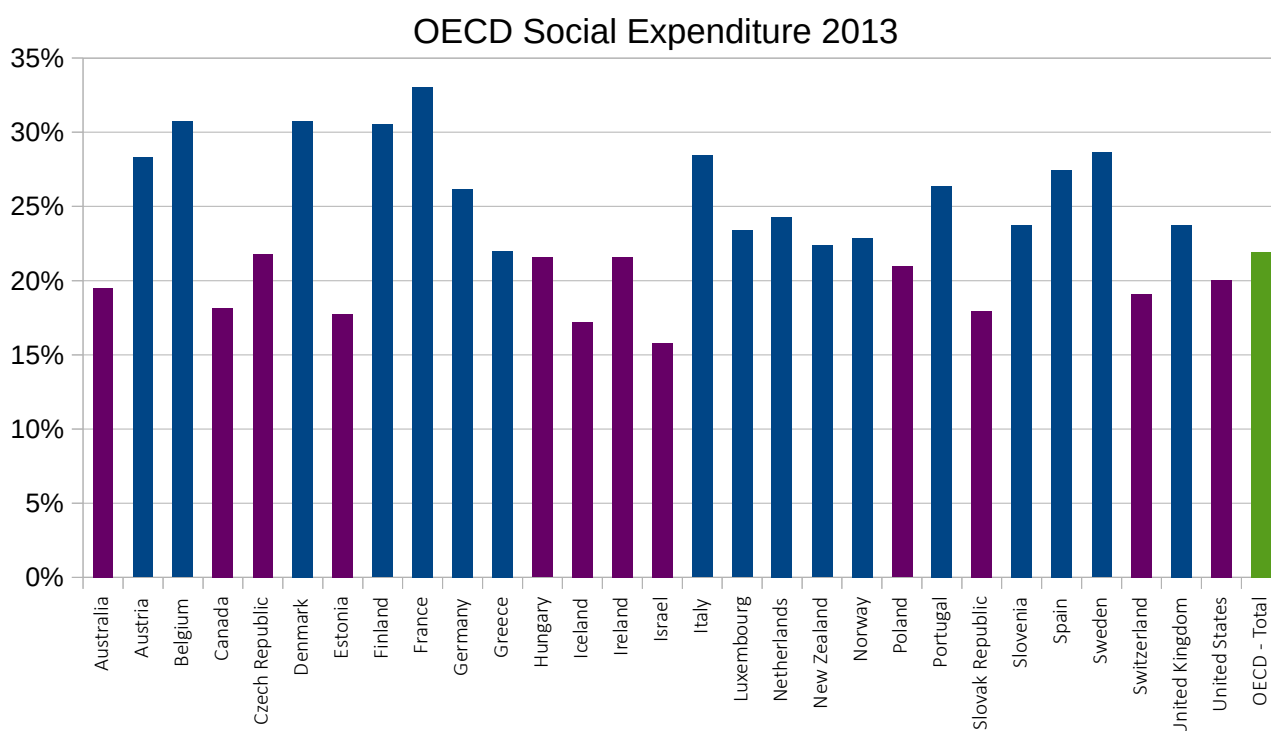
If Government were serious about addressing the issue of unsustainable growth in welfare and support for people with ASD then it would direct much more attention to recognising and understanding why the number of people, especially adults, diagnosed with severe or profound ASD has increased to such a significant extent.

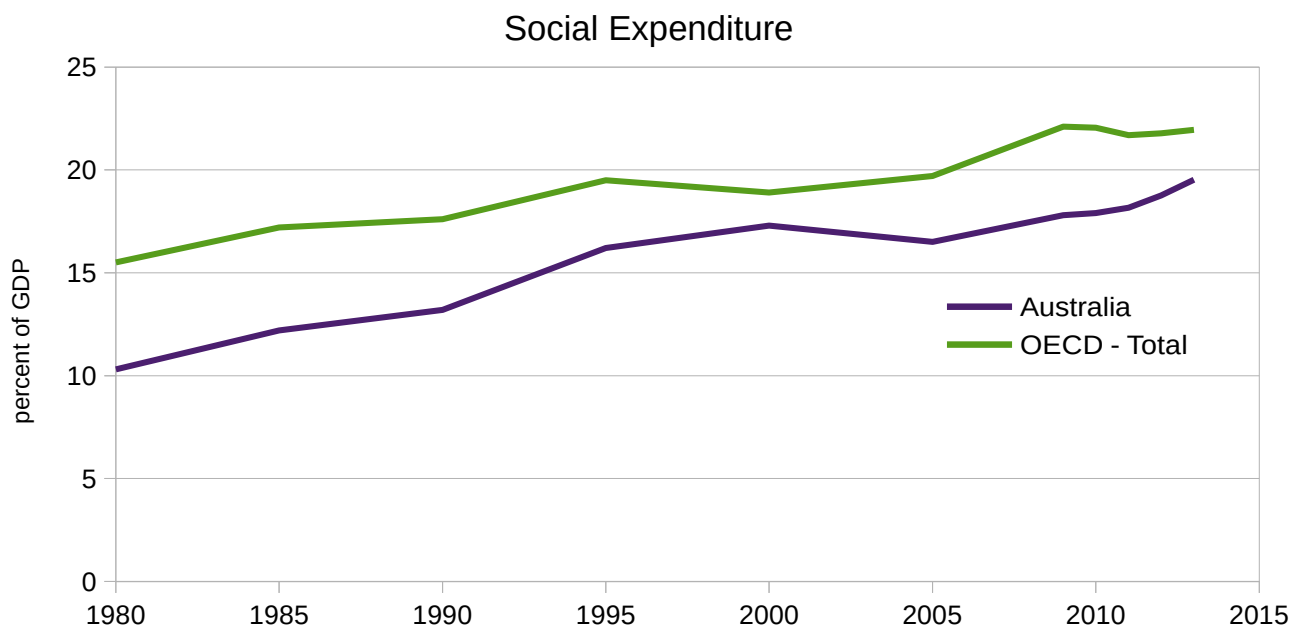
Apart from the growing number of adults with ASD who get a DSP, the number of people getting DSP is decreasing.

But Government agencies like the Health Department deny there is any growth in the number of people with ASD (as shown above). The Government has done very little to understand or address the issue of substantial growth in people with severe or profound ASD ... unlike the USA which has legislated for health insurance to cover treatment and rehabilitation and also to fund significant research.

The Treasurer says that a marginal tax rate of over 45 cents in the dollar is a major disincentive to high income earners. Yet the Government is happy to impose an effective effective marginal tax rate of at least 50 cents in the dollar on people getting a DSP when they start to earn. Its advisors have suggested that imposing an effective marginal tax rate of 75 cents in the dollar would be appropriate.

The Government claims Australia's welfare system is unsustainable. It cites growth in DSP as evidence. OECD data shows Australia has below average Social Expenditure.





The result of all this is that Australia has unacceptable levels of poverty among people with a disability (including people with ASD); Australia is doing worst in the OECD.

Comments on the Interim Report

Sustainability must be much more than the penultimate (second to last) point in “Case to Reform” summary.

For too long, Australia and its Government have worshiped at the altar of Productivity; but those prayers have been futile and our nation's economy has suffered as a consequence. Perceptions of employers in Australia are that employing people with a disability is unproductive.

Sustainability needs to replace *productivity* in the national ideology ... and not just in relation to welfare.

The section on People with disability (page 33-34 in the Interim Report) shows a poor appreciation of the challenges relating to disability and employment. A report such as this should have been informed by [*SHUT OUT: The Experience of People with Disabilities and their Families in Australia*](#), especially Sections 2.3 and 2.4, and other similar reports.

As with employment and career issues for women, employers need to fix the system for people with a disability ... and stop trying to fix the people.

Australia needs a culture of creating jobs for everyone, including people with a disability. Government and the media have to stop blaming people with a disability for not being in jobs when the issue is that few Australian employers, including Government, employ people with a disability, especially people with ASD.