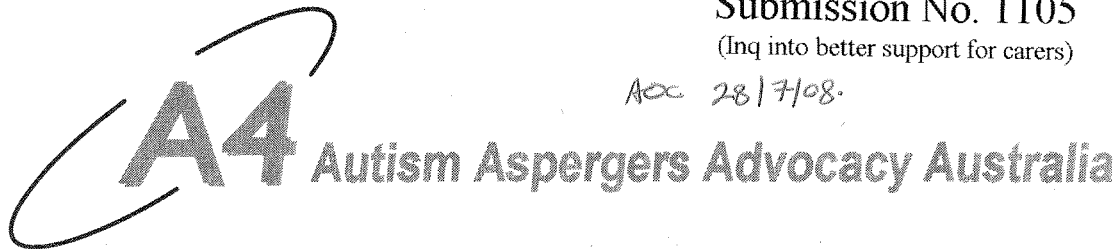


Acc 28/7/08.



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Dear sir/madam,

**Subject: Inquiry into better support for carers**

This submission relates to a particular group of carers being people caring for people with Autism Spectrum Disorders (ASD).

The diagnostic criteria for ASD specify that people with ASD experience “severe and pervasive impairment”. ASD are present in childhood and affect a person 24 hours of every day.

As stated in the Terms of reference for this Inquiry, carers of people with ASD

are often at increased risk of becoming socially isolated from their peers and disconnected from mainstream employment. Many carers also have significantly worse health outcomes than the general population (both in terms of physical health and psychological wellbeing) and endure problematic access to services and support. Carers also often face increased financial pressures, having limited opportunities to accrue savings, accumulate superannuation and save for retirement.

The available data shows most carers of people with ASD experience more than risk: mostly they are socially isolated and are not employed. Carers of people with ASD have higher rates of mental illness and poor health than other carers.

People with ASD often need ASD-specific services and support that mostly do not exist<sup>1</sup>. Accessing non-existent services and support is more accurately described as *impossible* rather than “problematic”.

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<sup>1</sup> The federal Government’s *Helping Children with Autism* (HCWA) package, which is just now getting started, promises to create some parts of the services young children with autism

Many carers report being exhausted with constant begging for services and support without success. Often they feel their requests are not even understood. Or they may face complete disbelief about their situation. Sometimes they are accused of lying because "it could not possibly be that bad".

Many students with ASD are excluded from child-care or from school. As a result many carers of people with ASD cannot remain in employment.

Most people with ASD over school age receive a Disability Support Pension. Many adults with autism need constant supervision. There are few suitable post-school places for them. Caring for a family member with ASD who is beyond school age is often a 24 hours role ... it is much more challenging than any fulltime job. As well as facing increased financial pressures, missing any opportunities to accrue savings, accumulate superannuation and save for retirement ... carers for people with ASD can face untreated challenging behaviour and routine physical violence.

Australian Bureau of Statistics (ABS) data showed around 30,000 Australians reported having ASD in 2003.

Centrelink data in 2006 showed 18,719 children aged 0-14 years received Carer Allowance for the ASD (autism or Asperger's disorder)<sup>2</sup>. CSTDA data<sup>3</sup> shows 6,252 people aged 0-14 years with autism got any help at all from the nation's major source of disability services and support. At best, 33.4% of children aged 0-14 years with autism got any Government funded disability services or support.

Australian Bureau of Statics (ABS) data from Survey of Disability, Ageing and Carers in 2003 shows there were around 10,100 people with ASD aged 15 years or older. This has risen by at least 1,100 per years since then so in 2006, there were at least 13,400 Australian adults with an ASD diagnosis in 2006. The CSTDA data shows 4,660 people aged 15 years or older (34.8% at best) accessed any Government funded disability services or support.

In bridging this abysmal gap in service and support, carers of people with ASD carry a prodigious burden. They do so at enormous personal expense.

Few people caring for a person with ASD get holidays. If their family does go on holiday the burden on carers increases instead of decreasing because they are away from their usual supports and environment and the person with ASD is outside their comfort zone.

Many carers endure harsh ideological criticism over their pragmatic responses to their situations. Many carers are criticised from government agents, the disability sector and sections of the ASD communities over the options they choose and their advocacy for their child.

Some carers are portrayed as bludgers. Parents whose role caring for a child with ASD means they cannot return to work when their child goes to school feel they are criticised by the government, the media and the community.

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need. The limited scope of HCWA shows that people with ASD and their carers need ASD-specific services and support that simply so not yet exist in Australia.

<sup>2</sup> Some families do not access carer Allowance so the actual number of people with ASD is higher than this.

<sup>3</sup> See [http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all\\_20056](http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all_20056)

Many carers report that one of the most demeaning parts of their life is the frequent need to present the person they care for and their whole situation in the most negative light.

The following points relate to the Inquiry Terms of Reference ...

- *the role and contribution of carers in society and how this should be recognised;*

1. The role and contribution of carers is enormous. There are various estimates of what carers save the Government through carrying out their role. In our society, the only meaningful recognition is financial ... and the clear evidence is that Government and the community show very poor recognition of carers.

We can attest to Bill Shorten's observation (for example on the ABC's Q and A program, 26/5/2008) that the media does a particularly poor job of recognising carers.

- *the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;*

2. Carers can participate more if they are less exhausted and do not have caring responsibilities during working hours. The regular or routine exclusion from school of children with ASD prevents (or limits) carers from participating in employment. The extent of this problem in Australia is not known ... it needs to be measured and reported.

The absence of appropriate post-school options and adult support for people with ASD is a major barrier for carers of adults with ASD who want (or need) to work.

- *the practical measures required to better support carers, including key priorities for action; and*

3. Key actions for carers of people with ASD are the creation of comprehensive services for people with ASD and their carers. A4 is happy to provide a list of essential services if the Government is interested.

The list would include meeting the nation's international obligations to ensure people with ASD have Rights to the treatment & rehabilitation they need, effective education, equitable outcomes in employment and participation, freedom from discrimination of all kinds and access to competent legal systems.

Carers need protection from discrimination, harassment and vilification. They need better access to effective ASD-specific advocacy.

- *strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.*

4. Government is being quite hypocritical about "carers making choices". Choice depends on some alternatives in services ... which government sees (wrongly) as duplication and waste. Government seeks to minimise waste by chronic under-provision of services leaving carers

to do what they can to meet the resultant massive shortfall in essential services.

Few carers feel they have a choice to transition out of caring ... many feel transition out of caring means abandoning a family member to a seriously unacceptable situation, so they have no choice and will only do so in the most dire of circumstances.

Many carers of people with ASD regard phrases like "assist carers to access the same range of opportunities and choices as the wider community" and "effectively plan for the future" evidence Governments repeatedly ignore carers and are profoundly deluded about the effects of their existing policies and practices.

A4 would be pleased to appear before the Committee. Please contact A4 via email or on 0418 677 288.

Yours sincerely,

R. Buckley

Convenor

7/7/2008