



The Commissioners  
Inquiry into Disability Care and Support  
Productivity Commission  
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Dear Commissioner

Subject: **Eligibility for disability care and support of people with autism spectrum disorders**

I am disappointed and concerned that Carers Australia told you ...

... there's confusion around "profound/severe" [disability]. The people we have spoken to whose child might have autism or they may have two children with autism, for example, they think that this system will be for them. These children may not be in the profound or severe classification but there is an expectation that they will be assisted through a scheme such as this.

Page 394 of the Hearing Transcripts (see [http://pc.gov.au/data/assets/pdf\\_file/0010/99946/20100713-canberra.pdf](http://pc.gov.au/data/assets/pdf_file/0010/99946/20100713-canberra.pdf))

Later on, the representative of Carers Australia referred to "autism or severe disabilities" which shows that they regard "autism" as distinct from "severe disabilities".

Carers Australia feels that people with autism spectrum disorders "may not be in the profound or severe classification". Apparently, Carers Australia would prefer the Productivity Commission to recommend that beneficiaries under a new national disability scheme should not include people with autism spectrum disorders .

Most people who are diagnosed with these autism spectrum disorders (ASD or "autism") experience *severe or profound* disability. We hope that all people who experience severe or profound disability (and who are not fully supported by compensation for their disability) will be eligible to benefit from any new national disability care and support scheme.

We offer the following evidence that most people with autism spectrum disorders experience severe or profound disability.

- The *Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> edition* (1994) [and the *text revision* version (2000) DSM-IV-TR] defines Pervasive Developmental Disorders, the category of disorders that includes autism spectrum disorders. as "characterized by severe and pervasive impairment ...". In other words, a minimum requirement for diagnosis on an autism spectrum disorder is that the person has at least severe impairment.

- The section on the Course of Autistic Disorder in the *Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> edition* says  

Available follow-up studies suggest that only a small percentage of individuals with the disorder go on as adults to live and work independently. In about one-third of cases, some degree of partial independence is possible.
- The Australian Institute of Health and Welfare reported (see <http://www.aihw.gov.au/publications/aus/bulletin42/bulletin42.pdf>) that the Australian Bureau of Statistics collected data in Australia showing ...  

Autism and intellectual impairment were associated with high proportions of severe or profound core activity limitation—87% and 75% of children with these respective conditions also had a severe or profound core activity limitation.
- The Australian Institute of Health and Welfare reported (see AIHW (Oct 2007) *Disability support services 2005–06: National data on services provided under the Commonwealth State/Territory Disability Agreement*, Canberra, AIHW cat. no. DIS 51, page 54 <http://www.aihw.gov.au/publications/index.cfm/title/10488>)  

Service users with autism reported high support needs over most life areas. ...

Service users with autism generally reported a much higher level of support needs than service users overall. ... The proportion of service users with autism needing some form of help (always or sometimes) within these three areas was between 80 and 90%, compared with around 60–70% for all users.
- In Victoria, discussion by the Department of Human Services of care and support services for people with high and complex needs from 2002-5 (see <http://www.dhs.vic.gov.au/operations/regional-operations-performance/multiple-and-complex-needs-unit/history/activities> and [http://www.dhs.vic.gov.au/data/assets/pdf\\_file/0003/173091/litreaturereview2002.pdf](http://www.dhs.vic.gov.au/data/assets/pdf_file/0003/173091/litreaturereview2002.pdf)) include  

The importance of Asperger's Syndrome in any discussion of high and complex needs is highlighted by several authors. In particular, a number of writers note challenges in providing appropriate responses to children and adolescents with Asperger's Syndrome. Accurate assessment is seen to be critical because it has direct implications for the types, and effectiveness of intervention. The Victorian Dual Disability Service notes that the key challenge for specialist dual diagnosis services is ascertaining the best way to proceed in unusual cases which are not within the 'normal' range of a mental health caseload. 'Patients with autistic features, such as Asperger's

syndrome, appear to pose particular problems as they are difficult to diagnose and can appear to have a psychotic illness and are often brought to the attention of mental health services who remain unsure whether this is a disorder that they can, or should, manage.'

and (from

[http://www.dhs.vic.gov.au/data/assets/pdf\\_file/0010/173089/complex-phase-july2003.pdf](http://www.dhs.vic.gov.au/data/assets/pdf_file/0010/173089/complex-phase-july2003.pdf))

Average annualised costs of the 21 case studies show that currently each client costs the Department of Human Services and other government agencies (for example, police, courts) around \$248,000 per annum.

Carers Australia is not unique in having an incorrect perception of the severity of disability due to autism. In its submission to a Senator Committee, FaHCSIA also misrepresented the severity of autism/ASD (see [http://www.aph.gov.au/senate/committee/clac\\_ctte/disability\\_trusts/submissions/sub13.pdf](http://www.aph.gov.au/senate/committee/clac_ctte/disability_trusts/submissions/sub13.pdf)) saying

Many people with disability, such as those with mental illness or impairment (for example autism, ...) may not require care on a daily basis ...

FaHCSIA's view that people with autism are unlikely to "require care on a daily basis" is inconsistent with both the diagnostic criteria and the evidence documented above.

People with ASD, their families and associates have very limited capacity to challenge misinformation and misrepresentation like this. They do not get any government support for an autism peak body and they do not have a supporting charity. Families and friends are so overwhelmed with scaffolding over abysmal services that they cannot tackle adequately community awareness or systemic advocacy.

The peak bodies for disability in Australian that are recognised by Government do not include representatives of the autism/ASD community. The Commonwealth recognises and funds (contribute to) a number of disability peak bodies (see <http://www.fahcsia.gov.au/sa/disability/progserv/providers/AustralianDisabilityEnterprises/Pages/DisabilityPeakBodies.aspx>) but does not fund any peak body for autism spectrum disorders.

Our experience is that those who are not directly involved in care, support and services for people with autism spectrum disorders lack a sufficient understanding of autism to advocate for or represent those that it affects. They do not appreciate the nature and severity of autism spectrum disorders, and complexity of the needs of the people it affects. At this time, peak bodies and generic disability advocates cannot represent adequately the interests of people with autism/ASD, their families and associates.

Poor understanding is demonstrated in the confusion often seen in classifying autism spectrum disorders into larger groups for reporting purposes. For example, Price Waterhouse Coopers (October 2009)

*National Disability Insurance Scheme – Final Report* (see [http://www.fahcsia.gov.au/sa/disability/pubs/policy/National\\_Disability\\_Insurance\\_Scheme/Pages/default.aspx](http://www.fahcsia.gov.au/sa/disability/pubs/policy/National_Disability_Insurance_Scheme/Pages/default.aspx)) shows autism spectrum disorders included in different groups at different times.

- In Figure 7, page 43, “autism” is distinct from other categories.
- In Table 8, page 55 has “Autism & Aspergers’ syndrome” within the “Mental Health” category.
- In Table 43, page 98, “autism” is under the “Intellectual/learning” group.

Typically, autism/ASD is lumped into some group for the purposes of reporting, but this does not mean there is any eligibility or provision of disability services as a result.

The number of people diagnosed with autism spectrum disorders more than doubles every five years.

The ASD community is disappointed that funding for people with autism spectrum disorders does not keep pace with growth in the number of people diagnosed with ASD or even with the CPI.

The ASD community is disappointed that data show fewer than half the people with ASD, despite their substantial need for disability services, get any service at all from CSTDA funding ... which is the primary vehicle for the delivery of disability services in Australia.

Substantial growth in the number of children diagnosed with autism spectrum disorders involves increasing demands on the very limited resources available for people with a disability. We understand that other disability groups may not be aware of this rapid growth in the number of people with autism spectrum disorders ... and that some of them resent the consequent decrease in the share of the services that are available for each individual with a disability.

Please be aware that autism spectrum disorders typically involve “severe and pervasive impairment”. I hope the evidence above convinces you that people with autism spectrum disorders, their families and associates need substantially improved services and should be eligible for benefits under any new national disability care and support scheme.

Yours sincerely,

Bob Buckley  
Convenor

14/8/2010