

**Submission to
Standing Committee on Employment, Education and
Workplace Relations**

**on
*the Education of Boys***

From Robert Buckley,

on behalf of

Action for Autism (ACT) and Autism Association if the ACT Inc.

The point we wish to make in our submission is that children with disabilities, particularly those disabilities that are poorly understood by educational authorities, face exclusion from the educational system and consequent disadvantage through their entire lives. These disabilities affect boys overwhelmingly. This is particularly evident for intellectual, cognitive, and complex neuro-developmental disorders, of which Autism Spectrum Disorder is a clear example.

The failure of education systems throughout Australia to address the needs of boys and girls with non-physical and multiple disabilities leads to those children not developing functional capacities for life in the society and to the minimisation of their dependence on others. This in turn condemns them to a life of increased dependence on others, and throws a considerably greater cost onto their families and the taxpayer.

Autism Spectrum Disorder (ASD)¹ is a life-long neuro-developmental disorder affecting social skills, communication and play. Recent international research shows around 1% of boys and 0.25% of girls could be diagnosed with an ASD before they reach school age. In Australia, the diagnosis rate for ASD is lower but is rising rapidly, and the gender-ratio of children diagnosed is four boys to every girl

People with ASD experience a wide range of disability. Some people with ASD benefit from relatively minor adaptations to their environment and respect for their differences. People with classic autism, around 25–30% of those with ASD, are among the most disabled and vulnerable in our community. For example, most children with autism have no functional language or social skills and are unlikely to develop them without specific early intervention. Language and social skills are essential prerequisites for learning.

Experience in the United States and Europe established the most effective treatment for ASD is early intervention using intensive behavioural intervention. Children who do not received successful pre-school intervention, need specialised, small class setting with curricula adapted to the specific needs of the individual child when they reach school. This approach is rarely available to children with ASD in Australia.

Prior to school age, those children with ASD who receive any treatment are generally treated for generic behaviour disorders. Such treatment is rarely effective. More

¹ Autism Spectrum Disorder or ASD, includes classic autism, some times still called Kanner's syndrome, Asperger's syndrome, PDD-NOS usually now called atypical autism.

commonly, child development services attribute the child's biologically based behaviours to bad parenting practice. Instead of treating the child, parents are patronised (or insulted) and sent inappropriately on parenting courses taught by people who have little or no understanding of ASD. In relation to a child with ASD, such courses are generally irrelevant and ineffective. Meantime, the child's behaviour deteriorates no matter how hard parents try. Parents soon become disillusioned or blame each other and the family may break down.

As a result of a lack of effective early intervention services and appropriate educational programs at infants and primary schools, the child's deterioration continues when they start school. Students with ASD typically have minimal language, poor social skills, little cultural understanding and present with chronic learning disorders.

Australian school systems typically regard ASD as a subgroup of intellectual disability² or mental retardation. This categorisation is incorrect. It leads to expensive and ineffective service provision.

The effects of intellectual disability and ASD on learning are quite distinct. Students with an intellectual disability generally learn, albeit slowly and sometimes with limits, in group settings. Their impairments tend to be even across skill domains.

Students with autism, in contrast, show an uneven development in their skills, with some skills markedly depressed (for example, language or social skills) and some markedly developed, for example numeracy.

Students with Autism do not learn in large group settings. Students with ASD need special, sharply focused and often individual measures to learn appropriately. Evidence suggests that they typically do learn quickly in a suitable program.

Without adequate preparation, students with ASD are often confused and anxious in social situations and group settings. Children with ASD often develop challenging behaviours from inappropriate settings.

Behaviour management strategies commonly used in schools can be counter-productive for students with ASD. A student with ASD who struggles with social skills may regard any form of notoriety as rewarding. A student who is anxious in group or social situations will regard time-out as a reward: he/she will practice behaviours that result in periods of time-out or the relative calm outside the Principal's office.

As a result of their untreated behaviour problems many children with ASD are often regarded as "deliberately non-compliant" or "aggressive" or "undisciplined" rather than a child who has a disability. The result is that their disability is ignored and instead the child is considered a "Behaviour problem". They are considered too difficult for the educational system to handle with the result that they are often, denied access to an education as they are excluded from school for much of each school year.

Imagine you are a student with autism hence you have very little functional language. Mostly, you do not understand people and the language they use around you. Because you do not have social skills you do not understand why people act as they do and what their behaviour signals. You do not know what behaviour is appropriate and what is not. One day, out of frustration you hit someone or throw some furniture. From your perspective, there is a little more chaos than usual for a short time but

² actually, a poorly understood group of disabilities that also affect significantly more boys than girls.

soon after your parent appears and takes you home: to your familiar environment away from the stress and anxiety. What did you learn in that lesson? What would you do next time you are frustrated, confused or simply not feeling good? And what happens to your education?

Little is known about long-term outcomes for people with ASD, particularly in Australia. Some research suggests many will develop mental illness. They appear to be highly represented in mental institutions, supported accommodation and among the homeless. Some are sent to prison. A lucky few find their way into some type of employment.

Children with ASD are ignored by the education, public health, mental health, community care and disability services systems in Australia. Government departments use the lack of research and out-dated prevalence figures to justify their inactivity. The Commonwealth/State Disability Agreement (CSDA) prohibits the provision of clinical services. The Commonwealth Department of Family and Community Services does not even consider Asperger's disorder a disability.

Figures in recent AIHW reports show young people with developmental disorders and autism are the second largest group of consumers of (predominantly inappropriate) services provided under the CSDA.

Recently, several specialist groups from the USA have opened offices or clinics in Australia and a few Australians have gone overseas for autism-specific training. Children with autism with particularly persistent parents may be able to access a basic service.

Neither Medicare nor private health insurance covers the cost of diagnosis or treatment. In the ACT, the Government agency whose duty it is to provide a diagnosis, Child and Adolescent Mental Health, does not have the resources to provide diagnosis and now refuses to do so.

The public health, community care and education systems discourage families from treating ASD using behavioural intervention.

Occasionally, the education sector seeks appropriate strategies as it is responsible for students no matter their ability or disability for up to 30 hours per week, simply because they go to school.

We are aware of two schools supporting demonstrably successful behavioural intervention for children with autism: North Ainslie Primary School in the ACT and Bulleen Heights in Victoria. Both schools only came about through the continued advocacy of parents — and they remain in operation through the continued advocacy of parents in the face of persistent attempts by the respective departments of education to diminish or close entirely the programs.

ASD is a rapidly growing health issue, not a manifestation of socio-economic problems as many would have you believe. ASD needs to be recognised as a distinct issue and treated accordingly, particularly in early childhood, health and education. Governments, both state and federal, needs to recognise the scale of the challenge ASD poses and to plan to meet the needs of people who are severely disabled by their ASD.

The existing practice of Ministers and their departments of denying responsibility for ensuring effective treatment is available for people with ASD imposes enormous financial and human costs on the community.

Although this submission has focused on students with autism, we would urge committee members to examine the failure of education systems at all levels to

provide adequately and effectively for the needs of students with disabilities. This is despite the fact that, according to the Australian Bureau of Statistics 20% of Australians have a disability and 14% have a profound handicap.

Please contact us if you want any more information.

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