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Family and Community Development Committee

# **A Submission for the Inquiry into services for people with Autism Spectrum Disorder**

**By Maddie Bradford, Will Martin and Jack Lundle**

Association for Children with a Disability

for

**The Family and Community Development Committee**

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## Table of Contents

<b>Introduction .....</b>	<b>3</b>
<b>Background .....</b>	<b>4</b>
<b>Statement of Purpose .....</b>	<b>4</b>
<b>Recommendations.....</b>	<b>5</b>
<b>The prevalence of Autism Spectrum Disorder in Victoria .....</b>	<b>6</b>
<b>The availability and adequacy of services provided by the Commonwealth, State and local     governments across health, education, disability, housing, sport and employment services...9</b>	
<b>Conclusion .....</b>	<b>13</b>
<b>References.....</b>	<b>14</b>



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## Introduction

The Association for Children with a Disability (ACD) welcomes the opportunity to provide a submission to the Parliament of Victoria and The Family and Community Development Committee's inquiry into services for people with autism spectrum disorder.

This report will address the Terms of Reference (ToR) i) the prevalence of autism spectrum disorder in Victoria; and ii) the availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services.

Involvement in this inquiry offers the ACD and our members an opportunity to; further develop current policy and procedures for individuals with autism spectrum disorder and their families; and to explore new avenues surrounding the quality and delivery of services for individuals with autism spectrum disorder and their families; in an effort to improve the quality of services for individuals with autism spectrum disorder and their families and the available education for individuals with autism spectrum disorder, their families and the broader community.



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## **Background**

Established in 1980, the Association for Children with a Disability is a non-profit community based organisation representing children with a disability and their families living in Victoria. Our current membership includes over 2,000 families.

At the ACD, we strive to offer support and education for our members and influence policy development that effects human rights, discrimination, early childhood, education and disability where it relates to children with a disability and their families.

## **Statement of Purpose**

- To empower parents of children with a disability to be as self-sufficient as possible in advocating on behalf of their child and family.
- To promote and advance the rights of children with a disability and their families.
- To advocate on behalf of children with a disability and their families to ensure the best possible support and services available.
- To work collaboratively with other organisations to improve the service system for children with a disability and their families.



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## Recommendations

- To expand upon current social services to address the growing prevalence of Autism Spectrum Disorder within Victorian communities.
- To develop a needs-based support system that caters to individual's living with Autism Spectrum Disorder according to their required level of assistance.



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## The prevalence of Autism Spectrum Disorder in Victoria

Autism Spectrum Disorder (ASD), varies in its manifestation from person to person. While some people may have only mild or no intellectual disabilities, according to the Australian Bureau of Statistics at least 73% of people with an ASD are considered to have a “severe or profound disability” (ABS, 2012). As such, services for people on the ASD spectrum must meet both the needs of those people, and the prevalence of those people within the state. The prevalence of people with an ASD however, is a little harder to ascertain, especially on a state to state basis. Over the past 16 years, numerous studies and statistics have indicated not only substantial rates of ASD in children, but that those rates appear to be growing. As it stands, the most generally accepted overall figure for the rate which ASD’s occur is “1 in every 110 children” (Amaze, 2011).

This is almost a third larger than what previous figures had indicated. The first major study into the prevalence of ASD in Australia was published in 2008 by McDermott, Ridley, Williams, Glasson and Wray for the Australian Advisory Board on Autistic Spectrum Disorders. They claimed that the “prevalence of autism spectrum disorders in Australia for 6-12 year olds is 62.5 per 10,000” (McDermott, et al., 2008). This roughly equates to 1 in 160 primary school children. Overall numbers of those formally diagnosed in Australia have also risen significantly, according to ABS figures; in 2003 there were 30,400 people with ASD, this figured more than doubled to 64,600 in 2009 and in 2012 increased by 79% with 115,400 people in total diagnosed with ASD, with men “4 times more likely than females to have the condition” (ABS, 2012). While the rate of this exponential growth in the number of people with ASD has been largely calculated on a national scope, there is significant differences in ASD prevalence between the states, with Victoria housing the largest population of ASD individuals nationwide. As of 2012, 0.7% of Victoria’s population identify with ASD, amounting to a total of 41,300 people (ABS, 2012).



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This exponential growth in diagnosis is not unique to Victoria, nor Australia, but appears to be occurring worldwide. In the U.S. for instance, the National Health Interview Survey identified “a nearly fourfold increase in parent-reported ASD between the 1997–1999 and 2006–2008 surveillance periods” (Blumberg, 2013). While the apparently growing rates of ASD prevalence can be attributed to a number of factors, the apparent increase has been claimed to be the “the result of diagnoses of children with previously unrecognized ASD” (*ibid*, 2013). This position is consistent with findings by Australian Academic, Amanda Baxter from the Centre for Mental Health Research at the University of Queensland who claims that while there is increased diagnoses in children, the large majority of people with an ASD “have actually transitioned into adulthood” (Baxter, 2015). As such, these individuals have avoided diagnosis or are only being diagnosed in the past 15 years under more accurate diagnostic parameters. This is also consistent with Australian Bureau of Statistics findings, which show that of the 115,400 ASD individuals in Australia, 75.6% are between the ages of 1-19 years old, totaling 87,200 people (ABS, 2012). According to Baxter these findings indicate that ASD is “a biological disorder with a very strong genetic basis” that has “been around for a very long time and will continue to be around” (Baxter, 2015).

These findings indicate that while numbers of ASD individuals appears to be increasing, the more likely situation is that these instances of ASD were already there, but just left unrecognised and untreated previously. The reason for this has been largely attributed to changes to the primary tool for diagnoses of ASD, the Diagnostics and Statistics Manual of Mental Disorders (DSM). The DSM provides the diagnostic criteria clinicians can use to determine different types of mental and behavioral disorders. While criteria explicitly for Autism was only added as recently as 1980, (ASD children were previously defined as having ‘childhood Schizophrenia’) this diagnostic criteria has since been changed four times between the DSM III(1980), DSM III Revised(1987), DSM IV(1994), and DSM V(2013), as understandings of ASD developed and the criteria for a diagnosis became more broad and inclusive.

These changes are a key part of why there has been an exponential rise in the confirmed



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prevalence of ASD. Take for instance the differences between the DSM III and its revised version, which increased the amounts of specific information required for a diagnosis making positive identification more rigidly categorised. The DSM IV however, “reduced these amounts of information significantly” (ABS, 2012), which has since seen the previously mentioned exponential rise in diagnoses. Under the DSM IV, people with an ASD could be diagnosed with one of four separate disorders, Autistic Disorder, Childhood Disintegrative Disorder, Aspergers Disorder, and the largely umbrella term Pervasive Developmental Disorder Not Otherwise Specified. Under the DSM V however, all four are merged into the diagnosis of Autism Spectrum Disorder (American Psychiatric Association, 2013) which reflects that ultimately Autism works on a spectrum of severity, rather than in categorical diagnoses as previously thought. It also provides for clinicians to add “specifiers in regards to cognitive skills (with or without intellectual disability) and co-morbidities (e.g., ADHD, anxiety disorder, specific language disorder) to allow for a more comprehensive description of an individual” (Autism Advisory Board on Autism Spectrum Disorders, 2013).

As such, ACD conclude that the apparent growth in prevalence of ASD is not representative of the more people being born with the disorder, but rather a result of more comprehensive diagnoses, which is including children that otherwise would have slipped through the cracks. We would recommend the Victorian Government respond to these changes and growth in diagnosed ASD children with a corresponding expansion of funding and programs to address ASD issues effectively.



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**The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services.**

Although ACD are actively involved in empowering ASD individuals and carers in all areas of their lives, we have chosen to narrow our focus in this section to the availability and adequacy of services provided by the Commonwealth, State, and local governments across the education sector.

Australia has a commitment to uphold a number of human rights, particularly in regards to the education of children with a disability. Indeed, as per Articles 28 and 29 of the Convention on the Rights of the Child 1989 (CRC), all children have a right to free, compulsory primary school education, accessible and available forms of secondary education, and should be encouraged to develop to their fullest potential, inclusive of personality, talents, and mental and physical creativity (Amaze, 2014:3). Furthermore, state governments in Australia must ensure individuals with a disability have equal opportunity to an education free from discrimination, which likewise promotes the development of an individual to their fullest potential, as outlined in Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006, which Australia is a signatory of (ibid.). Such guidelines highlight the obligations Australia has to “the right of all students with disability to receive a quality and inclusive education free from stigma and discrimination” (ibid.). Overall, ACD proposes that whilst there has been a significant increase in services in the educational sector for ASD individuals, there are still gaps in the adequacy of these services, particularly in relation to those with particularly complex autism, and high functioning autism.

Current funding for national disability services in Australia are characterised by a blending of the “fair go” principal, which arose in the 1940s, and a focus on a sustainable welfare system, which stemmed from broad socio-historical factors in the 1970s, such as rising unemployment and political instability (Mayes, 2015:260-261) (Yeend, 2000). As mentioned above, rates of ASD across the country have risen significantly in the past decade). To



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address this, a number of legislative measures have been adopted by both national and state governments over this period. In 2008, the Helping Children with Autism (HCWA) Package, was introduced by the Federal Government, which committed \$190 million in funding over four years (Roth, 2013:2). Elements of this assistance included financial support for children under 6 to undertake early intervention programs, Medicare rebates for diagnosis and allied health professionals, and professional development of teachers and staff (ibid.). On a state level, new legislative framework introduced in 2009 by the Victorian Parliament committed to developing the Autism State Plan, with the aim of building more comprehensive services for those with ASD (Amaze, 2011). In 2010, the federal government devised the National Disability Strategy, a ten-year plan which was launched in 2013, covered six key policy areas, and included the National Disability Insurance Scheme (NDIS), which was aimed at creating a long-term care and support solutions (Council of Australian Governments, 2011).

As part of their 2015 Program for Students with Disabilities, the Department of Education in Victoria have committed to improving educational services for ASD individuals through programs like the Autism Friendly Learning Strategy (Department of Education and Training, 2015). In trying to localise support and strengthen the ways in which ASD individuals are managed in school environments, Autism Inclusion Schools was implemented, which has now been rolled out across 15 different schools and has implemented strategies such as student support groups (ibid.). By creating individual learning plans for each child with ASD, such groups provide an environment “implemented in the context of the needs of their school community” (Department of Education and Training, 2015). This is done in conjunction with the online and face-to-face staff training (ibid.). As mentioned above, ACD highlight this commitment to the increased provision of educational services for ASD individuals is incredibly important. Indeed, although evidence on the topic is still relatively limited, reports assessing the effectiveness of early intervention for ASD individuals highlight the significance of early intervention programs for children, particularly behavioural, educational and/or developmental approaches (Roth, 2013:2).



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However, there is mounting evidence to suggest that there are significant gaps in the current provision of educational support and services for ASD individuals. In terms of the Program for Student with Disabilities for example, issues include the limited number of Student Support Officers (SSOs), and as a result of this, the restrictions placed on the quality and quantity of support they can provide ASD individuals (Amaze, 2014:8). Furthermore, the diagnostic basis for access to the program has been criticised, while a needs-based assessment has been promoted instead (Amaze, 2014:8). Currently, ASD individuals can only be funded in one of seven of the eligibility categories, despite the fact that many ASD individuals have multiple disabilities (ibid.). For example, 50% of ASD students also suffer from an intellectual disability (ibid.). Such issues with the Program for Students with Disabilities have serious ramifications for ASD individuals, and means that those who suffer from high-functioning or particularly complex autism, are likely to have their educational needs overlooked.

Other issues surrounding the provision of educational services for ASD individuals includes a lack of personalised ASD programs, long waiting lists for services, and an emphasis on case management (Roth, 2013:2-3). While the implementation of the NDIS was aimed at addressing these problems, and providing support for individuals with a disability and their carers, research has flagged significant gaps in the program (National Disability Insurance Scheme, 2013) (Hogan, 2015). As per the 2015 annual report, the NDIS was noted to have had “an inadequate workforce and pricing for services, a lack of consultation between government and disability service providers and poor provider access to market information” (Hogan, 2015). Concerns have also been voiced regarding the sustainability of the NDIS, with states such as South Australia having double the number of children enrolled in the scheme than anticipated (Mann, 2016). If this trajectory continues, funding and services will need to be expanded accordingly, lest ASD individuals are not provided with the services they require (Mann, 2016) (Morton, 2016).



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Recent media reports highlight the insufficiencies for ASD individuals in the education sector. Media revelations include the autistic Hunter student who was allegedly locked in a school cupboard, the Autistic Family Collective Survey which highlighted the prevalence of death threats and physical abuse aimed at autistic schoolchildren, and the internationally-recognised case which revealed an autistic Canberra schoolboy was locked in a cage in his classroom to manage his behaviour (Wakatama, 2016) (Brown, 2016) (ABC News, 2015). Although these are extreme examples, they nevertheless highlight the need for educational services to meet the needs of those with high-functioning or complex autism. As Buckley (2015) notes, “limited access to professional behaviour support for autistic people remains a major service deficit... People cannot access services that do not yet exist” (Buckley, 2015).

As such, ACD stress that while educational services for ASD individuals have improved significantly over the past decade, there are still gaps in the adequacy of these services which need to be addressed, particularly in relation to those with particularly complex autism, and high functioning autism.



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## Conclusion

In conclusion, the prevalence of ASD is growing in conjunction with greater awareness and more comprehensive diagnosis. As such, larger numbers of educational services need to be provided for ASD individuals. ACD propose that whilst there have been improvements in the availability and accessibility of educational services for ASD individuals, the growth in numbers and gaps in current services need to be addressed by the Victorian Government, particularly in relation to those with high-functioning or complex ASD.



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Suite 2, 98 Morang Rd, Hawthorn VIC 3122

**P:** 03 9818 2000 or 1800 654 013 (rural callers) **F:** 03 9818 2300 **E:** [mail@acd.org.au](mailto:mail@acd.org.au)

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