

Submission:

Inquiry into Services for People with Autism Spectrum Disorder

Submission S100

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Family and Community Development Committee

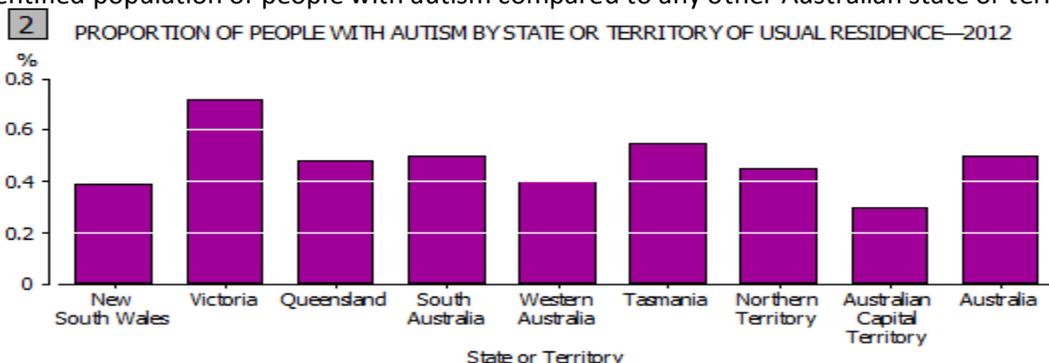
About the submission

This submission is prepared by Autism Spectrum Australia (Aspect) in consultation with Distinctive Options, The Lab Network and Smart Communities. Aspect is Australia's leading service provider for people on the autism spectrum. Our specialised, evidence informed schools program is the largest in the world. Aspect also provides a range of supports and services that include information and advice, diagnostic assessments, positive behaviour support, parent and family support, lifelong community social/recreational and vocational capacity building programs. Aspect shares evidence-informed practice and applied research both nationwide and internationally. Our services provide people on the autism spectrum with the opportunity to realise their unique potential, as well as providing much needed support to their families, carers, friends and colleagues. Our vision is to provide the best possible opportunities for people on the spectrum.

This submission would not have been possible without the input and support from a number of other people including Dr. Trevor Clark, Dr. Debra Costly, Ms. Vicky Gibbs, Ms. Julie Robertson, Ms. Caitlin Mangan, Ms. Melissa Webster, Mr. Murray Dawson-Smith, Mr. Paul Staubli and Ms. Sandra Martin, who all contributed information and advice to enhance the quality and content of the submission.

1) The prevalence of autism spectrum disorder in Victoria;

Producing precise information on the number of people with autism in the population is difficult. However, over recent decades there is an acknowledged and reported increase in the number of people diagnosed with autism. In 2002 a Latrobe University study reported the incidence of autism in Australia was 27 individuals per 10,000 (1:370). By 2008 the international rate was presented as 63 individuals per 10,000 (1:160) and by 2015 an article in The Australian newspaper cited Professor Cheryl Dissanayake of the Latrobe University Olga Tennyson Autism Research Centre as stating the rate was now closer to 200 individuals per 10,000 (1:50). Further data from the ABS, (see below table) from the 2012 Survey of Disability, Ageing and Carers indicates that Victoria has the highest identified population of people with autism compared to any other Australian state or territory.



Source: ABS Survey of Disability, Ageing and Carers, 2012



The NDIA indicates that 31% of all packages approved are for individuals with a primary diagnosis of autism. A further cohort of approximately 18% of all packages is for intellectual disability with up to 50% of this cohort having a dual diagnosis of intellectual disability and autism. Looking at this data grouped together suggests the real rate to be in the order of 40% of all NDIA packages supporting individuals with either a primary or secondary diagnosis of autism.

It is not known to what extent this increase reflects an increasing number of people with autism or other factors, including changing diagnostic criteria and increased public and professional awareness of autism. However, data does show that this is happening across all age ranges and people are being diagnosed not just as young children, but also late childhood, teens, early adulthood and even into middle age. This provides a unique blend of pressures on services as the type and quantity of services and supports can vary quite considerably over the lifespan and also between individuals.

Impacts and costs and access to appropriate service provisions

Large amounts of public money are spent every year on trying to improve the quality of life for people with autism. Based on data from the 2009 Survey of Disability, Ageing and Carers, the Australian Bureau of Statistics reported that people with autism needed assistance with a range of activities: over 40 per cent needed assistance with self-care, around 60 per cent needed assistance with mobility, and over 60 per cent needed assistance with communication, as well as with cognitive or emotional tasks. About one-third of people with autism needed assistance in these areas on a daily basis. The Australian Bureau of Statistics 2012 Survey also reported that people with autism have significantly lower rates of completing post-school qualifications and participating in the labour force than other people with a disability. Post-school life and employment outcomes for people with autism are often poor. Research into the outcomes for adults on the autism spectrum universally show poor employment, social and life outcomes (Howlin & Moss, 2012; Howlin et al, 2004; Baldwin, Costley & Warren, 2014; Cimera & Cowan, 2009; Taylor & Seltzer, 2011). The results of the most recent study in the US, the *National Autism Indicators Report: Transition into Young Adulthood* (Roux et al, 2015), highlights the poor outcomes for young adults with autism; 28% being unemployed, 26% having received no services after leaving school, only 19% were living independently of their parents. Parents involved in this study, referred to the reduction of services post-school as akin to “falling off a cliff”.

Studies have also shown that autism can have a significant emotional and financial impact on families. A 2011 report estimated that the annual economic costs of people on the autism spectrum in Australia was between \$8.1 billion and \$11.2 billion.

Increases in the prevalence of autism will inevitably have an impact on the increased need for a diverse range of specialist services, including diagnostic and early intervention therapy services, education services, health services, disability services, housing options, sporting, interest based and recreational options as well as employment and vocational opportunities.

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

Results from the 2012 Survey of Disability, Ageing and Carers (SDAC) found that there were some groups who were more at risk of having an unmet need for formal assistance. In particular:

- Around two-thirds of young males aged 0-14 years (63.6%) and 15-24 years (66.7%) who required formal assistance had an unmet need for formal assistance.
- Boys aged 0-14 years made up 19.5% of all males with an unmet need for formal assistance. In contrast, girls aged 0-14 years made up just 6.4% of all females with an unmet need for formal assistance.
- Around two-thirds of people who needed formal assistance who had autism and related disorders (66.7%), Attention deficit disorder/hyperactivity (62.2%) or other developmental disorders (69.4%) had an unmet need for formal assistance.
- Higher rates of unmet need were found amongst those with intellectual (61.4%) and psychological (59.4%) disabilities, than those with physical (51.1%) and sensory and speech (50.2%) disabilities.
- People with an unmet need for formal assistance were less likely to be participating in the labour force (35.8%) compared with those whose needs were met (42.0%), and more likely to be living in low income households (53.5% compared with 48.3%, respectively).

In a recent survey undertaken by 40 young adult Aspect participants, the most common areas identified in relation to areas where participants felt they needed more support were; preparing and supporting participants to find and obtain work, to develop meaningful relationships and friendships and to have greater independence in the community.

Despite the efforts of some highly committed staff, service providers and government bodies, there continues to be ongoing gaps in our Victorian services for people on the autism spectrum and their families.

Early diagnosis: Children can be reliably diagnosed with autism at around age 2. However a recent study utilising data from families accessing the HCWA package indicates that the average age of diagnosis in Australia is just over 4 years with the majority of children diagnosed closer to 6 years of age. In addition, based on these figures, and comparing them to the estimated prevalence of autism, it appears that approximately 25% of individuals with autism have not been identified prior to their 6th birthday. A delay in accessing diagnostic services is not only frustrating and stressful for families, but vital time is lost in commencing early intervention. Currently, there are long waitlists for state funded assessment services, sometimes in excess of 18 months. The NDIS will not be funding diagnostic assessments and the Medicare rebate covers less than 20% of the cost of most private providers. .

Families with children with autism have higher costs as a result of the child's disability coupled with diminished employment prospects. Their housing needs may not be adequately met. There is little

evidence of a flexible and co-ordinated approach to support by health, education and social services, and there is significant unmet need for short breaks.

Young people with autism at the point of transition to adult life often leave school without a clear route towards a fulfilling and productive adult life. Services are often limited for school leavers on the autism spectrum.

Carers can feel additional pressures because of the waiting times for their child/ children to access services, and they often lack the right information and enough support to meet their lifelong caring responsibilities.

Choice and Control. Many people with autism still have little choice or control in their lives due to the limited flexibility in services, their availability and funding.

Health Care. The substantial health care needs of people with autism often go unmet as Health professionals have not received appropriate training in autism.

Housing can be the key to achieving social inclusion, but the number supported to live independently in the community, for example, remains small. Many have no real choice and receive little advice about possible housing options.

Disability services frequently fail to provide sufficiently flexible and individual support.

Positive Behaviour Support (PBS) it has been recognised that Positive Behaviour Support needs to be delivered to a specific evidence based standard (Victorian Government Office of Professional Practice Behaviour Support planning toolkit 2014). The OPP have led the development and maintenance of good practice standards in the disability sector, especially in regards to Restricted Practices such as restraint (Physical restraint in disability services: Current practices, contemporary concerns & directions. McVilly, 2009). The issue of good practice behaviour support & restricted practices has gained more focus in the education sector more recently (e.g. in the ACT Schools for All Children & Young People. Report of the Expert Panel on Students with Complex Needs and Challenging Behaviour, 2015) which has led to the appointment of a Principal Practice Leader (Education) who reports to the Senior Practitioner (Disability). As the Victorian Government is withdrawing from service delivery it is essential the leadership in the state is maintained to ensure good practice PBS and continued systemic prevention and minimisation of restricted practices.

Employment is a major aspiration for people with autism but people with autism often remain heavily dependent on social security benefits. Many individuals have highly employable skills but are unable to navigate and secure employment through the current pre-employment recruitment, interview and screening processes and continue to experience rejection and social isolation from the workforce. Greater awareness and training is required for the recruitment and employment sector to provide adequate pathways into the workforce for individuals with autism.

3) The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS);

In the Victoria context a number of facts are known. We know that:

1. Approximately 42% of all NDIA packages are going to support individuals with autism in response to a primary or secondary diagnosis of autism.
2. Approximately 105,000 will be eligible for some level of support
3. Given 42% of all packages will need specialist autism support if they are to achieve their potential this suggests up to approximately 44,000 individuals will need some level of support and/or advice from staff knowledgeable in autism.
4. A significant number of individuals with autism (high functioning) will not meet the eligibility criteria for NDIA individual packages but will nevertheless need some level of engagement with the support system.
5. The mental health, out of home care and justice (prisons) system have all requested professional development support to effectively manage high numbers of undiagnosed people on the autism spectrum.
6. A significant cohort of individuals with autism will need episodic support at various times throughout their lives (examples of episodic support could include simple work place advocacy through to periods of respite or one to one support to manage "one-off" events)
7. The risk of family breakdown among families with and without children on the autism spectrum are similar until children reach adolescence from this point it is considerably higher for families with one or more family members with autism to be at risk of breakdown thus the need for extended family support to this cohort will need to be developed and provided.
8. For work options and outcomes for individuals on the spectrum to be optimised then additional resourcing will need to be committed to practical skill development while workplaces will require training and support to ensure individuals who are employed achieve long term employment success.

4) Evidence of the social and economic cost of failing to provide adequate services;

The social and economic costs of failing to provide adequate services will be difficult to quantify and this submission will not attempt to put a price on the costs. It is recognised that previous evaluation and review into long term cost and impact particularly in the Early Childhood Intervention environment has had more focus including the KPMG review into the effectiveness of early intervention. This review highlighted evidence and supported the value of investment in early intervention and lead to the Commonwealth government expanding early intervention program beyond autism to include general disability (Better Start program).

Aspect recommends that efforts be directed into furthering the evidence base regarding the social and economic costs by considering the following:

Early Diagnosis: Consideration be given to the social and economic costs of the:

- a. Long term impact of late diagnosis and the benefits of early intervention.
- b. Distress caused to families who are not able to understand or respond to a child's behaviours.
- c. Incorrect diagnosis leading to inappropriate treatment regimes.
- d. Social isolation of children and families with a person on the autism spectrum.

Education: Consideration is given to the social and economic costs of:

- a. Poor academic outcomes for students with different learning styles not acknowledged and accommodated for within the school setting.
- b. Inability of schools to support people on the autism spectrum students leading families to home school and thus limit the ability of parents to enter the workforce and the potential economic impact on the family and social development of the student.
- c. Students experiencing bullying and social isolation leading to early exit and exclusion from the school system.
- d. Impact on teachers and other students' academic outcomes due to behaviour management issues and lack of training for teachers in strategies to better manage this cohort.
- e. Health impacts for students who are not engaging in active sports or performance arts etc.
- f. Students engaging in inappropriate relationships due to poor awareness of social rules (inappropriate use of texting etc.)
- g. Loss of self-esteem by students due to academic underachievement.

Family Dynamics: Consideration is given to the social and economic costs of:

- a. Family breakdown, which is similar across all groups until adolescence when family breakdown for families with a child with autism is significantly higher.
- b. Inability of both parents entering the paid workforce due to care needs of child.
- c. Ongoing costs of support for majority of people on the autism spectrum individuals as they are unsuccessful in gaining employment.
- d. Social isolation of families due to behaviours of the child at all ages
- e. Additional support costs for home modifications, home maintenance, medications and other in home support costs.
- f. Children attending support services requiring additional monies for extra support costs.

Employment: Consideration to be given to the social and economic costs of:

- a. We are sufficiently utilising highly skilled and competent people that could contribute to the workforce.
- b. Costs to the public purse through loss of income tax income and other indirect and direct taxes on expenditure (GST, Stamp Duty etc.)

- c. Loss of self-esteem, increase in self-harming behaviours and possible contact with the justice system.
- d. Cost of social support payments (unemployment or disability supports).
- e. Increase in mental health demands on the service system.
- f. Lack of independence and capacity to make life choices.

- g. Current limitations on active paid workforce participation.

Housing: Consideration be given to the social and economic costs of

- a. Demand on the public purse for the provision of public housing.
- b. Loss of revenue to the State through potential stamp duty and other costs in home ownership.
- c. Social costs due to lack of community inclusion and engagement through home ownership/occupancy.

- d. Inability to engage in community including relationship building through friendship networks.

Disability Services: Consideration be given to the social and economic costs of:

- a. Services failing to meet the developmental needs of individuals through lack of staff skills and knowledge.
- b. Inadequate support models leading to increasing behaviours and potential for self-harm or harm to other service users and/or staff.
- c. Increasing costs to service providers through work cover claims, loss of staff and ongoing staff recruitment and training.
- d. Demand on the State for the provision of disability specific housing to meet the needs of individuals no longer able to live at home or in mainstream public housing.

5) The projected demand for services in Victoria.

The Australian Bureau of Statistics 2012 prevalence survey identified Victoria to have the highest prevalence rate of autism of all the states and territories. Additionally in terms of the longer term prevalence, since the commencement of the Helping Children with Autism (HCWA) Program in Victoria in 2008 more than 16,000 children have had funding approved following a primary diagnosis of autism. The annualised referral and approved funding data for the HCWA program show an average 6-8% annual increase on the number of children being diagnosed with autism since the funding commenced.

It is estimated that through the roll out of NDIS approximately 44,000 individuals will need some level of support and/or advice from staff knowledgeable in autism.

The NDIA reported in December 2015 that the highest number of plans approved to date were for individuals with a primary diagnosis of autism.

The types of supports that are most commonly requested for children are social emotional and cognitive and communication support. In adults the most common requests for service through current NDIS plan payments are as follows:

- 1) Assistance with daily life at home, in the community, education and work (including supported independent living)
- 2) Improved daily living
- 3) Assistive Technology (including communications)
- 4) Transport to access activities
- 5) Improved life choices
- 6) Finding and keeping a job
- 7) Increased social and community participation

In terms of adequate provision to support demand, in reviewing the current NDIS approved provider list for Victoria, whilst we acknowledge that there is a growing need for specific allied health and clinical therapeutic providers across the lifespan, many therapists to date have only focused their work around early intervention and children. There is limited expertise in clinical and therapeutic services for adults. Furthermore there is less than 12 multi support cluster approved providers currently listed on the Victorian NDIS approved provider list that identify or indicate any specialist or specific knowledge or experience in working with individuals with autism.

Given the current limitations in knowledge, experience and expertise in supporting individuals with autism as outlined above, it is likely to be increasingly difficult to achieve successful quality outcomes for individuals with autism, there is also likely to be limitations in relation to choice for individuals and families selecting their support.

Recommendations

The increasing numbers of people with autism in Victoria will demand a need for additional investment, support and services. Aspect would like to make the following recommendations:

- **Recommendation 1:** The government must invest financial resources into services including clinical and diagnostic services to provide adequate and responsive support to individuals with autism their families and their carers with a continued focus on early intervention and a focussed investment through key life stages and transitions including schooling, Post schooling, vocational and housing community living.
- **Recommendation 2:** The sector supporting individuals with autism must ensure that supports are of a high quality leading to attainment of the individuals' goals, whilst delivering a range of flexible and affordable support options.

- **Recommendation 3:** That all disability services undertake a review of their current practices and consider the development of specific services and strategies designed to accommodate and integrate the needs of individuals with autism across the spectrum and life stages.
- **Recommendation 4:** The government and disability agencies and advocates must support and promote greater public awareness and community understanding of people with autism this should include the employment sector.
- **Recommendation 3:** Both Tertiary and vocational institutes delivering courses in health, education and disability, develop and incorporate a unit that is specific to understanding, working with and meeting the needs of people with autism.
- **Recommendation 4:** The government and disability sector invest in providing existing disability support workforce with specific training and professional development to better understand and support the needs of individuals with autism.
- **Recommendation 5:** That the government invest further funds to be directed into furthering the evidence base regarding the social and economic costs of autism.
- **Recommendation 6:** A quality framework and evidence base of best practice be used to monitor the quality of support provision and outcomes achieved for individuals with autism.
- **Recommendation 7:** Recommend the maintenance of a state wide Positive Behaviour Support leadership body (such as the OPP but coordinated by NGOs) to ensure maintenance, monitoring and development of good practice PBS that operate across disability & education sectors, including restricted practices. Further recommend work towards a National Framework for Reducing & Eliminating the Use of Restrictive Practices in Disability Service Sector (2014) agreeing definitions, monitoring processes and data collection. Also recommend developing clear specifications around PBS and restricted practices that are Autism specific, include provision of accredited evidence based autism specific PBS training across the disability and education sectors.