

AMAZE SUBMISSION

**Productivity Commission's inquiry
into the role of improving mental
health to support economic
participation and enhancing
productivity and economic growth**

April 2019



Executive Summary

Australia has the opportunity to improve the social and economic outcomes of autistic people, which will have positive impacts for society, including economic benefits. This is demonstrated by:

- 85% of Australians having personal contact with an autistic person; and
- the annual economic cost of autism in Australia being estimated between \$8.1 billion (low prevalence) and \$11.2 billion (high prevalence), with reduced employment being the most significant cost (between \$1.9 billion and \$3.2 billion annually).

Current data outlines the life outcomes for autistic people in Australia at present are:

- between 50% to 70% experience a co-occurring mental health condition, with indications the prevalence could be higher;
- mortality rates are over two times higher than the general population, with the largest increase in risk of death being associated with co-occurring mental health conditions;
- in 2015, the unemployment rate for autistic people was 31.6%, which is three times the rate for all people with disability and almost six times the rate of people without a disability;
- 35% of autistic students achieve Year 10 or below, compared with 17% of all students – only 6.5% have a Bachelor's degree or above, half the rate of all people with a disability; and
- autistic people and their families experience significant social isolation with 51.6% agreeing that they feel socially isolated and 39.3% agreeing that they sometimes feel unable to leave the house due to concerns about discriminatory or negative behaviours in the community.

This evidence suggests that addressing the mental health needs of autistic people is an important factor in improving their life outcomes, including their economic and social participation. However, addressing mental health is only one part of the whole of life approach required to improve life outcomes for autistic people across the board. That is why the Australian Autism Alliance is calling for a National Autism Strategy to improve life outcomes for autistic people, with improving mental health a priority within the strategy.

It is particularly important that whole of life outcomes of autistic people are improved to ensure that the needs of the younger generation of future working autistic Australians are met, noting that 2.8% of children aged 5-14 years are autistic (approximately 81,000 children).

Specifically in relation to mental health, autistic people currently face significant barriers when seeking to access a diagnosis of, and support for, mental health conditions. These barriers can include a lack of autism recognition and understanding by mental health practitioners, communication difficulties (particularly when a person is non-verbal), and sensory sensitivities. There is also a lack of coordination and collaboration between mental health, mainstream health, disability services and other sectors, including education, employment, justice and housing.

Amaze welcomes this inquiry and supports its aim to contribute to improving mental health for people of all ages and cultural backgrounds.

1. Introduction

Amaze is the peak body in Victoria for autistic people and their supporters. Amaze is a not-for-profit organisation established in 1967 that represents around 55,000 autistic Victorians.

Amaze seeks to achieve three key outcomes:

- Community understanding of autism in Victoria increases over time.
- Attitudes and behaviours towards autistic people by the Victorian community (government, private and social sectors) improves over time.
- Opportunities for meaningful participation and valued contribution increase for autistic people.

Amaze is a partner of the Australian Autism Alliance, which brings together key autism organisations representing people on the autism spectrum, their parents and carers, service providers and researchers who aim to realise the potential of autistic Australians. Together, the Alliance organisations reach over 170,000 people through various communication channels. The Alliance made supporting the mental health of autistic people a priority in the *Australian Autism Alliance 2019 Federal Election Manifesto*¹.

Amaze welcomes the Productivity Commission's inquiry into the effect of mental health on people's ability to participate in and prosper in the community and workplace, and the effects it has more generally on the economy and productivity.

The aim of Amaze's submission is to:

- highlight the link between autism and mental health; and
- make recommendations that if implemented, are likely to improve mental health outcomes for autistic people as well as productivity and economic outcomes.

2. What is autism?

Autism is a neurodevelopmental condition that affects the brain's growth and development. It is a lifelong condition, with symptoms that appear in early childhood.

Autism Spectrum facts:

- In 2015, the ABS reported there were 164,000 Australians with an autism diagnosis and a prevalence rate of 2.8% for those aged between 5-14 years (81,000 children). However, the true prevalence of autism in Australia is likely to be much higher given the large numbers of autistic adults who remain undiagnosed.²
- Eighty-five per cent of Australians have personal contact with a person with autism.³
- Autism is the largest NDIS diagnostic group with 29% of total plans.⁴

¹ Australian Autism Alliance, Australian Autism Alliance 2019 Federal Election Manifesto, *Change 4 Autism*, available from http://www.australianautismalliance.org.au/wp-content/uploads/2019/02/Australian-Autism-Alliance-Federal-Election-Manifesto_web.pdf.

² ABS, 2017, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015. <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>.

³ Amaze, Strategic Directions to 2040 and Strategic Plan 2018-2021, 2018.

⁴ NDIS National Dashboard as at 30 June 2018. <https://www.ndis.gov.au/medias/documents/national-dashboard-aug18/National-Dashboard.pdf>

Every autistic individual is different and will experience autism in different ways, however the below features are always present in some form.

Challenges in communicating and interacting with other people

- Sharing interests and emotions - this can range from a lack of interaction to wanting to interact, but not knowing how to do it in an appropriate way.
- Using and understanding non-verbal communication, such as body language, eye contact or facial expressions.
- Making friends, maintaining friendships and adjusting behaviour to different social situations.

Sensory processing difficulties

- Being either over- or under-sensitive to sensory stimuli, including to sounds, smells, tastes, textures or visual stimuli. Often the same person will be over-sensitive to some things and under sensitive to others.

Repetitive routines in behaviour interests or activities

- Repetitive speech, movements or use of objects.
- Routines, rituals or resistance to change.
- Interests that are very intense or narrow in focus.

3. Autism and mental health

Autism is a lifelong, neurodevelopmental condition that affects the ability of all diagnosed individuals to participate in interactions with other members of society at work, at play and in all aspects of daily living.

Australian and international studies have consistently found that autistic people are at higher risk of one or more co-occurring mental health conditions than the general population, most commonly depression, anxiety and obsessive compulsive disorder.⁵ The estimated prevalence of mental health conditions among autistic people varies due to methodological variations between studies, but is in the range of approximately 50–70%,⁶ noting that there are indications the prevalence could be higher.⁷ It is important to note that many autistic people experiencing mental health conditions may not actually know or feel confident knowing whether they are experiencing a mental health condition.⁸ As such, the prevalence may be higher.

Autistic women and girls in particular are often misdiagnosed, or solely diagnosed with conditions such as learning disabilities, anxiety and/or eating disorders (with some

⁵ Foley K and Troller J 2015. Management of mental ill health in people with autism spectrum disorder. Australian Family Practitioner, 2015:44:11:p. 784 – 790.

⁶ Lever AG and Geurts HM (2016) Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. Journal of Autism and Developmental Disorders 46(6): 1916–1930; Foley K and Troller J 2015. Management of mental ill health in people with autism spectrum disorder. Australian Family Practitioner, 2015:44:11:p. 784 – 790.

⁷ Au-Yeung, S.K et al. 2015, Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults.

⁸ Crane L et al 2017. Know your normal – Mental health in young autistic adults. Ambitious about Autism and Centre for Research in Autism and Education, UCL Institute of Education, UK, June 2017. Available at <https://www.ambitiousaboutautism.org.uk/the-research>.

undergoing unnecessary interventions and/or taking unnecessary medications).⁹ There is evidence suggesting that the prevalence of mental health conditions, such as anxiety and depressive disorders, may be higher among autistic females than autistic males.¹⁰

A 2019 Australian study found that the mortality rates for autistic people was 2.06 times that of the general population, and that the largest increase in risk of death for autistic people was associated with comorbid mental health conditions.¹¹ This study also found that the leading cause of death for autistic people was deaths caused by ‘injury and poisoning’, which includes causes such as accidents, suicide, and self-harm. Past studies have also reported elevated risk of death from suicide for those on the autism spectrum compared to the general population.¹² These findings alert the need for health promotion and management of concurrent mental health conditions for those on the autism spectrum.

4. Economic costs associated with autism

In 2011, Synergies Economic Consulting prepared a report for the AEIOU Foundation on the economic costs of autism in Australia.¹³ The review estimated that the annual economic costs of autism in Australia were between \$8.1 billion (low prevalence) and \$11.2 billion (high prevalence). The study examined three categories of costs:

- Direct costs: health care, social services, education.
- Other tangible costs: reduction in income from lost employment; and the cost of informal care for adults with autism.
- Intangible costs (impacts on quality of life - “the burden of disease”).

The total direct and other tangible annual costs were between \$4.2 billion and \$7.3 billion, with the most significant costs arising from reduced employment (between \$1.9 billion and \$3.2 billion annually) and the cost of informal care for autistic adults (between \$1.5 billion and \$2.7 billion annually). The costs of underemployment were not included due to a lack of data.

5. Key outcomes for autistic people

Synergies Economic Consulting also conducted a literature review that revealed that the key outcomes for autistic people include poor mental health, low educational attainment, low employment, reduced living independence and reduced social functioning. Synergies Economic Consulting noted that these outcomes will each impact on mental health and/or general well-being.¹⁴

⁹ Coombs E et al 2011, An investigation into the relationship between eating disorder psychopathology and autistic symptomatology in a non-clinical sample. *British Journal of Clinical Psychology*, 50(3), 326-338; Victorian Parliament 2017. Inquiry into Services for People with Autism Spectrum Disorder - Final Report. Family and Community Development Committee. June 2017. Available at <https://www.parliament.vic.gov.au/fcdc/article/2588>.

¹⁰ Autism Spectrum Australia (Aspect). We Belong: The experiences, aspirations and needs of adults with Asperger’s disorder and high functioning autism, April 2013.

¹¹ Hwang YI et al 2019. Mortality and cause of death of Australians on the Autism Spectrum. *International Society for Autism Research*, 2019, p1-10.

¹² Hirvikoski T et al 2015. Premature mortality in autism spectrum disorder. *The British Journal of psychiatry*, 207(5).

¹³ Synergies Economic Consulting 2011. Economic Costs of Autism Spectrum Disorder in Australia. April 2011. Available at http://a4.org.au/sites/default/files/Synergies_costsfofautism_FINAL_170511.pdf.

¹⁴ Ibid.

Education

Evidence indicates that at school, autistic students are significantly more likely than their typically developing peers to be suspended or excluded¹⁵, targets of bullying¹⁶, to suffer depression and anxiety¹⁷ and to under-perform academically relative to their level of intelligence.¹⁸ Exclusion and bullying in school also has long term adverse impacts on mental health and community participation.¹⁹ These experiences and outcomes not only prevent autistic students from achieving a level of educational attainment to which they are capable of achieving, but also restrict their subsequent workforce and broader community participation with significant economic impact.

This is demonstrated by ABS data, which reports that 34.7% of autistic students only achieve Year 10 or lower, compared with 17.8% of students without a disability. Further, 6.5% of autistic students have a bachelor's or higher degree, compared with 28.7% of students without a disability.²⁰

Employment

In 2015, the unemployment rate for autistic people was 31.6%, more than three times the rate for people with disability (10.0%) and almost six times the rate of people without disability (5.3%).²¹ Work is essential to an individual's economic security and is important to achieving social inclusion. As a leading social determinant of health, work can be a large contributor to physical and mental health, personal wellbeing and a sense of identity. Unemployment and underemployment can result in lifelong consequences and economic costs, including loss of confidence, lowered self-esteem, increased mental illness and dependence on government and family support.²²

A recent study of autistic adults participating in a supported employment program charted the change in a number of variables including anxiety, depression and positive well-being over 12 months.²³ The study found that mental health and well-being remained stable over time, and concluded that more research is required to understand the mental health and well-being outcomes in employed autistic adults. The results of this study suggest that a whole of life approach to improving life outcomes associated with autism is required, employment is just one contributing factor.

¹⁵ Barnard, J. et al 2000, Inclusion and autism: Is it working? London: The National Autistic Society.

¹⁶ Van Roekel, E. et al 2010, Bullying among Adolescents with Autism Spectrum Disorders: Prevalence and Perception. *Journal of Autism and Developmental Disorders*, 40(1), 63-7.

¹⁷ Kim, J. A. et al 2000, The prevalence of anxiety and mood problems among children with autism and Asperger Syndrome. *Autism*, 4 (2), 117-132.

¹⁸ Ashburner, J. et al 2010, Surviving in the mainstream: Capacity of children with Autism Spectrum Disorders to perform academically and regulate their emotions and behaviour at school. *Research in Autism Spectrum Disorders*, 4(1), 18-27.

¹⁹ Wolke D and Lereya S 2015. Long-term effects of bullying. *Arch Dis Child Sept*, 100(9), 879-885.

²⁰ ABS, 2017, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015. <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>.

²¹ Australian Bureau of Statistics 2016. Autism in Australia. Survey of Disability, Ageing and Carers: Summary of Findings. See <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>.

²² Australian Government 2011. National Disability Strategy 2010 to 2020. An initiative of the Council of Australian Governments, available at <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020>.

²³ Hedley D, et al 2019. Predictors of Mental Health and Well-being in Employed Adults with Autism Spectrum Disorder at 12-month Follow-up. *Autism Research*, 12:3, p. 482.

Social Isolation

It is well known that social isolation can lead to poor mental health, education, social and economic outcomes.²⁴

Australian research has found that autistic people and their families suffer from social isolation, with:

- 51.6% agreeing that they feel socially isolated;
- 40.6% agreeing that they have lost friends because of the way those friends have responded to their or their family member's autism; and
- 39.3% agree that they sometimes feel unable to leave the house because they are worried about people behaving negatively towards them because of their or their family member's autism.²⁵

The built environment and its impact on autism

Autistic people face environmental barriers when seeking to access and participate in Australian society. These barriers can limit inclusion and participation across a range of public and private places, including in school, employment and recreational activities.

The barriers faced by autistic people when seeking to access built and natural environments can relate to:

- Structural or physical features of the built environment: including lighting, acoustics, smells, colours, spatial features, flooring and other design elements. They may also include the way information is conveyed, for example a lack of non-verbal communication by event staff or signage.²⁶
- Cognitive and/or social differences: including a need for routine/predictability, and sensory processing difficulties such as delayed or single channel processing (i.e. not being able to process all sensory input, such as hearing, seeing and feeling where their body is in space, simultaneously).²⁷
- Commonly co-occurring mental health conditions: in particular, anxiety can escalate in new/unknown environments or situations, or when an unexpected event or sudden change occurs in the environment.²⁸

This section outlines that there are significant barriers to autistic people achieving optimal outcomes to improve their social and economic participation and that mental health conditions for autistic people is an important barrier that impacts life outcomes. It is important to note that addressing mental health is one part of the whole of life approach required to improve life outcomes for autistic people across the board. That is why the Australian Autism

²⁴ National People with Disabilities and Carer Council 2009. Shut out: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report. Commonwealth of Australia.

²⁵ Jones S et al. 2017, Experiences of Autistic People and their Families, Centre for Health and Social Research, Australian Catholic University

²⁶ Shell, S 2016. Why buildings for autistic people are better for everyone. Forte Building Science.

²⁷ American Psychiatric Association 2013. *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC.

²⁸ Kerns C, et al 2014. Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44:11, p. 2851-2861, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5441227/pdf/nihms859304.pdf>.

Alliance is calling for a National Autism Strategy to improve life outcomes for autistic people, with improving mental health a priority within the strategy.

6. Increasing awareness, capacity building and collaboration across sectors

The need for greater understanding of autistic mental health

It is not clear why autistic people experience such a high prevalence of mental health conditions. In addition, there is limited understanding about what the best practice responses to support autistic people with mental health conditions are.

Amaze recommends that an autism mental health research fund be established to continue to build understanding of the mental health of autistic people. This could be supported by an Autism and Mental Health Summit to bring together mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and service collaboration.

The need for increased awareness and capacity building within the mental health sector specifically as well as across sectors

Autistic people currently face significant barriers when seeking to access a diagnosis of, and support for, mental health conditions. These barriers can include a lack of autism recognition and understanding by mental health practitioners, communication difficulties (particularly when a person is non-verbal) and sensory sensitivities.²⁹

Mental health services are not taking responsibility for the mental health needs of autistic people, with many mental health practitioners often assessing an autistic person's mental health concerns as simply part of their autism, and redirecting the person to disability services.³⁰ This leads to mental health conditions often not being diagnosed or adequately treated, resulting in poor health, an increased risk of suicide, and other poor educational, social and employment outcomes.³¹

The Victorian Parliament's 2017 *'Inquiry into Services for People with Autism Spectrum Disorder - Final Report'* concluded that there are a lack of professionals specialising in autism and mental health and this gap needs to be addressed. Amaze agrees that specialists are required to improve the treatment of mental health conditions in autistic people. Specialists should also be supported to build capabilities across mainstream health and mental health services to improve the early identification and treatment of mental health conditions in autistic people, as well as developing and championing interventions adapted to the specific needs of autistic people.³² An evidence based "best practice service model"

²⁹ Victorian Parliament 2017. *Inquiry into Services for People with Autism Spectrum Disorder - Final Report*. Family and Community Development Committee. June 2017. Available at <https://www.parliament.vic.gov.au/fcdc/article/2588>.

³⁰ Foley K and Troller J 2015. Management of mental ill health in people with autism spectrum disorder. *Australian Family Practitioner*, 2015:44:11:p. 784 – 790.

³¹ Ibid. See also Australian Advisory Board on Autism Spectrum Disorders 2012, *The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward*. Discussion paper, December 2012; Cusack J et al 2017. *Personal tragedies, public crisis – The urgent need for a national response to early death in autism*. Autistica, supported by Deutsche Bank. UK.

³² Australian Advisory Board on Autism Spectrum Disorders 2012. *The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward*. Discussion paper, December 2012.

should be developed to identify how to best meet the varying age-related mental health needs of autistic people.³³

Autistic people would also be better supported to access often busy healthcare and mental health services through: the creation of quiet rooms (to help autistic people manage sensory difficulties); support for transitions and new experiences (such as through social stories); additional time for consultations; and, adjustments by mental health service practitioners and staff to communication styles.³⁴ When designing mental health services and facilities, the needs of many autistic people with respect to acoustics, lighting, sensory spaces etc. should be taken into account.³⁵

The need for better coordination and collaboration between sectors

There is no coordinated approach between mental health, mainstream health, disability services and other sectors, including education, employment, justice and housing, to ensure professionals across these sectors can access the level of autism knowledge and skills required to diagnose, meaningfully treat or facilitate the treatment of mental health conditions in autistic people. Barriers to training and professional development are known to include location, cost and organisational priority.³⁶

Better service collaboration and coordination is needed across sectors to build professional knowledge of autism, provide clearly defined pathways of care and improve participation, health and wellbeing outcomes for autistic people.³⁷

Dedicated funding to support capacity building and collaboration between mental health, autism, and other sector professionals and staff is also required. A national approach to autism and mental health is needed and could be incorporated into the next National Mental Health Plan as well as a National Autism Strategy.

³³ Ibid. See for example, Table 2. Recommended pharmacological and psychological treatment for mental ill health in adults with autism spectrum disorders in Foley K and Troller J 2015, Management of mental ill health in people with autism spectrum disorder. *Australian Family Practitioner*, 2015:44:11:p. 784 – 790 at p.786.

³⁴ Foley K and Troller J 2015. Management of mental ill health in people with autism spectrum disorder. *Australian Family Practitioner*, 2015:44:11:p. 784 – 790.; See also, submissions from Distinctive Options, The Lab Network and Smart Communities (Submission No.77), Austin Child and Adolescent mental Health Service to public hearing in Melbourne, 29/8/16.

³⁵ Australasian Health Infrastructure Alliance (AHIA), Australasian Health Facilities Guidelines, North Sydney, AHIA, 2015.

³⁶ Australian Advisory Board on Autism Spectrum Disorders 2012, The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward. Discussion paper, December 2012.

³⁷ Ibid.

7. Recommendations

Recommendation 1.

That the Productivity Commission consider the link between autism and mental health during its inquiry and in developing recommendations.

Recommendation 2.

That the Commonwealth commit to developing a National Autism Strategy to improve life outcomes for autistic people, including improving mental health as a priority.

Recommendation 3.

That the Commonwealth support research into autism and mental health by:

- establishing a mental health and autism research fund; and
- funding a Mental Health and Autism Summit – hosted by the Australian Autism Alliance in partnership with mental health peak organisations – to bring together mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and service collaboration.

Recommendation 4.

Australian Governments engage with autistic people and the autism community to build their understanding of mental health and autism, current barriers to diagnosis and support and how healthcare services may better tailor their supports to autistic people. This understanding should then be filtered into:

- A best practice service model to identify how to best meet the mental health needs of autistic people.
- A National Autism Strategy.
- The Sixth National Mental Health Plan and implementation plan (due in 2023).
- Funding agreements for mental health service providers.

Closing

We thank you again for the opportunity to provide this submission. We look forward to reviewing your findings and recommendations.

If you have any questions or we can provide further information, please contact Benjamin Biro, Amaze's Acting Manager, Policy and Advocacy

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