

23 January 2020

# AMAZE SUBMISSION

In response to the Productivity Commission's Mental  
Health Draft Report

## **Amaze**

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## About Amaze



**Amaze** is the peak body for autistic people and their supporters in Victoria. Established in 1967, today Amaze represents a community of more than 55,000 autistic Victorians in shaping a better future for autism.

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) improve over time.
- Opportunities for meaningful participation and valued contribution increase for autistic people.

### About autism

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

#### Autism facts:

- In 2018, the ABS determined there were 205,200 autistic Australians, a 25.1% increase from 164,000 in 2015. It found that males were 3.5 times more likely than females to be diagnosed with autism, with prevalence rates of 1.3% and 0.4% respectively<sup>i</sup>. However, the true prevalence of autism in Australia is likely to be much higher given the large numbers of autistic adults who remain undiagnosed.
- 85% of Australians have personal contact with an autistic person.<sup>ii</sup>
- Only 29% of Australians feel they have a good understanding of how to support an autistic person, with only 4% of autistic people and their families agreeing that people in the community know how to support them.<sup>iii</sup>
- Autism is the largest National Disability Insurance Scheme (NDIS) disability group – representing 30% of all participants receiving an individual funding package.<sup>iv</sup>

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 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.

# Summary of recommendations

## Recommendation 1.

That the Productivity Commission consider the high rates of mental health conditions experienced by autistic people during its inquiry and in developing final 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. This would include research into developing best practice service models to meet the mental health needs of autistic people.
- 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 discuss research priorities, capacity building requirements and service collaboration.
- A National Clinical Trial network into mental health and suicide prevention funded by the Australian Government, should include research on autism and mental health.

## 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. The findings should then be filtered into:

- A National Autism Strategy.
- The Sixth National Mental Health Plan and implementation plan (due in 2023).
- Funding agreements for mental health service providers.

## Recommendations arising directly from the Productivity Commission Draft Report

### **Recommendation 5**

The Productivity Commission recommend that all training and skill development in mental health, across all sectors, include training on autism and mental health.

### **Recommendation 6**

The Productivity Commission adopt a definition of 'complex support needs' that is sufficiently broad and flexible to capture existing definitions of complex support needs.

### **Recommendation 7**

The Productivity Commission recommend that an increased number of MBS-rebated sessions be available as a matter of priority for those who require them.

### **Recommendation 8**

The Productivity Commission recommend that improvements to emergency mental health service experiences should take into account the needs of autistic people.

# 1. Introduction

The Productivity Commission has a track record in assisting government, the private sector and the community sector to navigate seemingly intractable systemic and structural issues. This Inquiry has the potential to make a significant practical contribution to the long-term reform agenda for mental health.

There are many strengths in the Productivity Commission's Draft Report (Draft Report). However, we are concerned that the draft report does not specifically examine the high level of co-occurring mental health conditions in autistic people, or the impacts this co-occurrence has for access to appropriate mental health diagnosis, services and supports. The Draft Report also fails to consider the productivity impacts or direct costs to government (particularly through the NDIS) related to mental health conditions among autistic people.

Autism and mental health is increasingly being recognised in research and by governments locally and internationally as a distinct area of policy and reform. The following key points reflect the need for this focus.

- **50% to 70%** of autistic people experience a co-occurring mental health condition, with indications the prevalence could be higher.<sup>v</sup>
- There **is an elevated risk of death from suicide for autistic people** compared to the general population<sup>vi</sup>.
- A 2019 Australian study found that the largest increase in risk of death for autistic people was associated with comorbid mental health conditions.<sup>vii</sup>
- An Australian study has found **up to 30%** of patients with anorexia are autistic or display high levels of autistic traits, and **that standard eating disorder treatment options and settings may need to be modified to better accommodate autistic females.**<sup>viii</sup>

In light of a growing body of research and a strong evidence base, the co-occurrence of autism and mental health (and unique barriers to mental health diagnosis, services and supports for this cohort) need to be explicitly considered in the Productivity Commission's Report on Mental health to ensure the final recommendations are comprehensive and effective for all of the community.

The rationale and evidence to support this request is outlined in this submission and builds on arguments from our response to the Issues Paper.

## 2. Factors supporting the case for examining autism and mental health

The prevalence of autism in Australia, the high proportion of NDIS participants identifying autism as their primary disability and the higher rates of mental health conditions experienced by autistic people compared to the general population, warrant significantly more research and policy reform to support the needs of autistic people with co-occurring mental health conditions.

### (a) Co-occurrence of autism and mental health conditions

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 disorder and obsessive compulsive disorder.<sup>ix</sup> In particular, the research indicates:

- **50% to 70%** of autistic people experience a co-occurring mental health condition, with indications the prevalence could be higher.<sup>x</sup>
- There **is an elevated risk of death from suicide for autistic people** compared to the general population.<sup>xi</sup>
- A 2019 Australian study found that the largest increase in risk of death for autistic people was associated with comorbid mental health conditions.<sup>xii</sup>
- An Australian study has found **up to 30%** of patients with anorexia are autistic or display high levels of autistic traits, and **that standard eating disorder treatment options and settings may need to be modified to better accommodate autistic females.**<sup>xiii</sup>

Autistica, the United Kingdom's leading autism research charity, reports that **more than six in ten autistic people have considered suicide**, and **more than three in ten autistic adults have attempted suicide.**<sup>xiv</sup> An Australian study has also found that the leading cause of death for autistic people was 'injury and poisoning', which includes accidents, suicide, and self-harm<sup>xv</sup>. In contrast, the leading cause of death in the comparison group of people from the general population was cancer.<sup>xvi</sup>

A study has also found that in addition to risks markers for suicide shared with the general population, camouflaging and unmet support needs appear to be risk markers for suicide that are unique to autistic people.<sup>xvii</sup>

Further research and increased awareness of the high rate of mental health conditions for autistic people is necessary to ensure that all autistic people are able to obtain appropriate support when it is needed.

## Autistic people and mental health risks

Autistic people experience many of the risk factors for poor mental health that have been identified in the Draft Report at significantly high rates than the general population.

These include:

- **Experiencing financial stress and/or compromised financial security:** Recent data released by the Australian Bureau of Statistics indicates that the unemployment rate for autistic people is more than three times the rate for people with disability and almost eight times the rate of people without disability.<sup>xviii</sup>
- **Difficulties at school:** As Amaze, Yellow Ladybugs and Different Journeys submitted to the Royal Commission into Victoria's Mental Health System, evidence indicates that at school, autistic students are significantly more likely than their non-autistic peers to be suspended or excluded<sup>xix</sup>, to suffer depression and anxiety<sup>xx</sup> and to under-perform academically relative to their level of intelligence.<sup>xxi</sup> Exclusion and bullying in school also has long term adverse impacts on mental health and community participation<sup>xxii</sup>.
  - **32% of autistic people attain a year 10 level of education or below** compared with 17% of the general population.<sup>xxiii</sup>
- **Social Isolation:** Research undertaken for Amaze found that **51.6% of autistic people** and their families agreed they are socially isolated with almost four in ten often not leaving their homes.<sup>xxiv</sup>
- **Stigma:** Results from a community consultation survey undertaken by Amaze with Yellow Ladybugs and Different Journeys indicated there is significant stigma associated with autism and separately, with having a mental health condition. Of the participants who found it hard or very hard to find the right services to support their mental health, **19% attributed this difficulty to the stigma associated with either autism or mental health conditions.**<sup>xxv</sup>

Given the Productivity Commission identified the increased risk of each of these factors on mental health, the experiences of autistic people across all of the domains indicates that there is a critical need to ensure the Commission considers the experiences of autistic people with mental health in developing its final report and recommendations.

## (b) Vulnerable groups and Autism

The Commission should recognise the particular challenges faced by autistic women, girls and LGBTIQ+ with mental health conditions.

### Autistic Women/Girls and mental health

Studies have indicated that:

- Autistic women displayed current mental health symptoms at a more severe level than non-autistic women.<sup>xxvi</sup>
- Autistic women received mental health diagnosis at an earlier age than non-autistic women<sup>xxvii</sup>
- Autistic women were more likely to die from suicide than women who are not autistic.<sup>xxviii</sup>

The Productivity Commission should give attention to the high prevalence of mental health conditions in autistic women and girls, and why there is a need to develop thorough screening tools and encourage further research and development of mental health service responses for this cohort.

Recent data released by the ABS indicates that the ratio of autistic males to autistic females is contracting. In 2015, males were 4.1 times more likely to be autistic than females. In 2018, the ratio of was 3.5:1.<sup>xxix</sup> It is widely accepted that autistic girls and women (particularly those without an intellectual disability) are likely to be underrepresented in the prevalence and incidence data on autism, primarily due to the different ways in which their autism characteristics can present, compared to autistic boys/men, plus historical gender biases in autism screening and diagnostic tools.<sup>xxx</sup>

There is an urgent need for practitioners to be aware of the high rates of mental health conditions in autistic people, and in particular, when working with autistic women.

### LGBTIQ+ and Autism

Amaze notes that the Productivity Commission acknowledges that different groups may have different mental health outcomes, including Australians who identify as LGBTIQ+.

The National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia has noted that there is growing evidence that being transgender or gender diverse is more common in autistic children, adolescents and adults compared to the broader population.<sup>xxxi</sup>

Amaze notes and supports the Royal Commission into Victoria's Mental Health System acknowledgement of the need for mental health services to understand intersectionality<sup>xxxii</sup>, to ensure that individuals receive treatment that meets their needs. This understanding should be adopted across the mental health sector.

### 3. Barriers to autistic people accessing appropriate diagnosis, services and supports

There are significant barriers faced by autistic people in accessing appropriate mental health services.

#### (a) Lack of understanding of autism and autism training for the mental health sector workforce

Lack of understanding is a significant barrier to improving outcomes for autistic people with a mental illness and to their economic and community participation. There is a crucial need to continue to improve the skills of the mental health workforce regarding autism.

The Victorian *Parliamentary Inquiry into Services for People with Autism Spectrum Disorder* found that autistic people face significant barriers when seeking to access a diagnosis of, and support for, mental health conditions, including a lack of autism recognition and understanding by mental health practitioners, as well as communication difficulties (particularly when a person is non-verbal) and sensory sensitivities<sup>xxxiii</sup>.

Amaze notes that the Productivity Commission Draft Report has referenced the work of the National Institute for Health and Care Excellence (NICE) in the United Kingdom, stating that NICE 'uses rigorous processes and evidence to establish what healthcare provides good value for money'.<sup>xxxiv</sup> The NICE Guidance for Autism spectrum disorder in adults: diagnosis and management, includes guidance regarding interventions for coexisting mental disorders.

They note;

*'Staff delivering interventions for coexisting mental disorders to adults with autism should:*

- *have an understanding of the core symptoms of autism and their possible impact on the treatment of coexisting mental disorders*
- *consider seeking advice from a specialist autism team regarding delivering and adapting these interventions for people with autism.*<sup>xxxv</sup>

This guidance recognises the importance of the mental health sector having an understanding of autism and access to specialised advice when providing mental health support to autistic people.

Further research into how to best meet the mental health needs of autistic people is required.

## (b) Training across sectors in Autism and Mental Health

Amaze notes that the Productivity Commission has identified a need to improve training and ensure skills align with the community requirements in mental health across a broad range of sectors including through:

- Education: *Information Request 18.2*
- The National Mental Health Workforce Strategy: *Draft Recommendation 11.1*
- Improved Mental Health training for Doctors: *Draft Recommendation 11.5*
- The Promotion Mental Health Specialisation as a Career option: *Draft Recommendation 11.6*

In all areas where it is recommended that training and skills be improved, it is crucial that this training includes an understanding of autism and mental health. The need for appropriate training and awareness of the prevalence of coexisting mental health conditions in autistic people by the entire mental health system critical given the Productivity Commission's consideration of the 'no wrong door approach.'<sup>xxxvi</sup> The higher risk of one or more co-occurring mental health conditions than the general population, risk of suicidality; and increased mortality rate for autistic people compared to the general population shows that there is a critical need that all training in relation to mental health includes gaining an awareness of autism.

### **Recommendation 5**

The Productivity Commission recommend that any training and skill development in mental health, across all sectors, includes training on autism and mental health.

## (c) Screening Tools and Questionnaires

There is a need to examine the appropriateness of mental health screening tools and questionnaires for autistic people. Amaze and Deakin University have conducted a research survey of autistic women and non-autistic women regarding the accessibility of commonly used mental health questionnaires, such as the Depression Anxiety Stress Scales (DASS-21). Information collected through this survey will aid in the development of a resource for autistic women, and to assist doctors to understand how they can support autistic women with their mental health.

The establishment of a mental health and autism research fund would ensure that this type of research could be further encouraged so that any screening tool that determines the level of care provided to an individual is accessible and appropriate, to ensure that early intervention is provided.

## (d) Complex Support Needs

Amaze welcomes the Productivity Commission's acknowledgment that individuals with complex needs may require additional assistance to obtain necessary supports.

Amaze has undertaken a review of academic and grey literature<sup>1</sup> which has revealed that there is no single agreed definition of 'complex support needs'. Existing definitions generally include reference to individual needs that either span multiple domains and/or involve high levels of need in one or more areas (e.g. multiple diagnoses), as well as reference to environmental considerations (e.g. service and system context, socioeconomic disadvantage etc.).<sup>xxxvii</sup>

These definitions are similar in that they do not provide a precise definition. They tend to include several factors that would define a person as having complex support needs. The factors listed are not exhaustive. This is a useful approach because it ensures some flexibility while providing examples of types of factors that should be taken into account.

As a result of this grey literature review, Amaze has reached the following definition of where an autistic person has complex support needs, as being someone:

- Whose support needs span multiple domains (i.e. health, mental health, other disabilities, justice etc.); and/or
- Who have high levels of need in one or more areas; and/or
- Who are more vulnerable or at a great risk of vulnerability than the broader autistic community.

Amaze considers that complex support needs may be indicated by a number of factors, including the presence of multiple disabilities, coexisting mental health issues, experiences of trauma and neglect, factors of complexity within a family unit.

Amaze recommends that the Productivity Commission adopt a similar definition of 'complex support needs' that allows sufficient flexibility to capture existing definitions of complex support needs across sectors, and to ensure consistency.

### **Recommendation 6**

The Productivity Commission adopt a definition of 'complex support needs' that is sufficiently broad and flexible to capture existing definitions of complex support needs.

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<sup>1</sup> Grey literature are materials and research produced by organisations outside of the traditional commercial or academic publishing and distribution channels. Common grey literature publication types include reports, working papers, government documents, white papers and evaluations

## (e) Autism and the cost of mental health care

Amaze notes that the Draft Report has recognised the lack of flexibility of the Better Access program, and the limitations of the current number of capped MBS-rebated psychological therapy sessions per calendar year.

The costs of mental health care can be a barrier to accessing support. Feedback received through the Amaze, Yellow Ladybugs and Different Journeys community consultation survey indicated that a limit of 10 psychologist appointments was insufficient.<sup>xxviii</sup>

We have concerns about the continuing impact on individuals who currently require the support of a psychologist if they are to await the outcome of a trial and evaluation of the merits of increasing the number of MBS-rebated sessions. For those individuals who require additional sessions with a psychologist, the number of rebated sessions available to them should be increased as a matter of priority.

### **Recommendation 7**

The Productivity Commission should recommend an increased number of MBS-rebated mental health sessions be available as a matter of priority for those who require them.

## (f) Autism and mental health services experiences

Amaze welcomes the Productivity Commission's recognition of the need to improve the emergency mental health service experiences,<sup>xxix</sup> including by providing separate spaces for people with mental illness, or otherwise creating an environment more suitable to their needs.

Any improvements should also specifically take into account the needs of many autistic people with respect to sensory sensitivities, including acoustics and lighting when designing these spaces.<sup>xl</sup> Autistic people would also be better supported to access mental health services through the creation of quiet rooms, support for transitions and new experiences (such as through social stories); extended times for consultations and adjustments by mental health services practitioners and staff to their communication styles.<sup>xli</sup> It should be noted that such improvement would not only benefit autistic people, but such supports are also likely to benefit others accessing emergency mental health services.

### **Recommendation 8**

The Productivity Commission recommend that improvements to emergency mental health service experiences should take into account the needs of autistic people.

## 4. Increasing recognition of autism in research and by governments as a distinct area of policy and reform

The need to examine and improve the mental health support available to autistic people is increasingly being recognised in Australia at both a state and federal level. Some of these examinations include:

- Senate Select Committee on Autism (2019- ongoing)
  - Established to inquire into and report on the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy. Its Terms of Reference include the interaction between services provided by the Commonwealth, state and local governments, including health and mental health.<sup>xiii</sup>
- Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder (2015 -2017)
  - The Final Report includes a chapter on Health and Mental Health Services.<sup>xiii</sup>
- Victorian Autism Plan (2019)
  - Includes 'Increase understanding of health and wellbeing needs, including mental health needs, for autistic Victorians' as an outcome<sup>xiv</sup>
- Victorian Royal Commission into Victoria's Mental Health System (2019 –ongoing)
  - Interim report acknowledged the experiences of autistic people, including the increased risk of anxiety and depression, and the stigma experienced by autistic people.<sup>xiv</sup>

### Royal Commission into Victoria's Mental Health System

Amaze, Yellow Ladybugs and Different Journeys prepared a submission to the Royal Commission into Victoria's Mental Health System (Royal Commission) that incorporated information obtained through:

- A community consultation survey – designed to be autism friendly and co-designed with autistic people;
- Amaze Mental Health Professional Round Table; and
- Research literature.

The submission to the Royal Commission discusses the following issues:

- Comorbidity between autism and mental health conditions
- Autism and suicide
- Barriers to autistic people experiencing good mental health (including costs of accessing services)
- The most useful mental health supports identified by autistic people
- Training of the mental health workforce.

The Royal Commission's Interim Report has acknowledged the experiences of autistic people in the mental health sector, including the increased risk of anxiety and depression, and the stigma experienced by autistic people.<sup>xvi</sup>

The submission to the Royal Commission can be accessed through the [Amaze website](#).

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- <sup>xliii</sup> Parliament of Victoria, Family and Community Development Committee, Inquiry into Services for People with Autism Spectrum Disorder Final Report. Available at [https://www.parliament.vic.gov.au/images/stories/committees/fcdc/inquiries/58th/Autism/FCDC\\_58-03\\_Autism\\_report.pdf](https://www.parliament.vic.gov.au/images/stories/committees/fcdc/inquiries/58th/Autism/FCDC_58-03_Autism_report.pdf)
- <sup>xliv</sup> Victorian Autism Plan. Pg. 21. Available at <http://www.statedisabilityplan.vic.gov.au/victorian-autism-plan>
- <sup>xliv</sup> Royal Commission into Victoria's Mental Health Services, Interim Report. available at <https://rcvmhs.vic.gov.au/>
- <sup>xlvi</sup> Royal Commission into Victoria's Mental Health Services, Interim Report, pg. 211. available at <https://rcvmhs.vic.gov.au/>