

5 July 2019

Amaze, Yellow Ladybugs  
and Different Journeys

# Submission to the **Royal Commission** into Victoria's Mental **Health System**



## Table of Contents

Autism and mental health: an introduction.....	3
Summary of recommendations.....	5
About the organisations.....	6
What is autism?.....	8
Methodology.....	9
Part 1: Understanding of autism and co-occurring mental health conditions: stigma and discrimination.....	11
Part 2: Drivers behind poor mental health outcomes.....	15
Part 3: Barriers to autistic people experiencing good mental health.....	19
Part 4: The needs of family members and carers.....	28
Part 5: Attraction, retention of, and support for the mental health workforce.....	29
Part 6: Social and economic participation of autistic people.....	35
Part 7: Reform priorities for Victoria’s mental health system.....	39
Closing.....	41
Appendix A: Case Study – Orygen Youth Health.....	42
Appendix B: Case Study – Victorian Dual Disability Service.....	44
References.....	46

## Autism and mental health: an introduction

**There are approximately 55,000 autistic people in Victoria, with many more undiagnosed. Every individual experiences autism differently – but research and consultation with our communities reveals an alarming commonality within the autism community: poor mental health.**

Mental health in the autistic population is a deeply concerning issue, with between 50-70% of autistic people experiencing co-existing mental health conditions.

Evidence shows that autistic people are more likely to have experiences that can exacerbate a mental health condition. Autistic people also often experience comorbid medical conditions that can present a significant personal burden.

The poor current health, social and economic outcomes for autistic people in Australia indicate the urgency of greater supports for this cohort across the board, with an acute need in mental health.

- Premature mortality rates are over two times higher for autistic people than the general population.
- In 2015, the unemployment rate for autistic people was 31.6%, more than six times that of the general population.
- 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.
- 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 from the community.

This submission is informed by academic research, an online community consultation survey and a roundtable discussion with mental health and autism professionals and researchers. This extensive consultation exposed and explored the many barriers faced by autistic people in accessing and navigating Victoria's mental health system, including but not limited to:

- misdiagnosis
- difficulties in navigating the mental health system
- mental health practitioners' inadequate knowledge of autism
- lack of appropriate services, and prohibitive costs associated with services

- lack of mental health supports for carers of autistic people with mental health conditions.

While knowledge about autism and mental health is increasing within the mental health sector, this understanding is neither complete nor consistent across the sector. Insufficient autism training, an absence of information and guidance for supporting autistic people with mental health conditions, and an unsupportive mental health system are just some of the barriers mental health professionals encounter in providing support to autistic people with mental health conditions.

When autistic people are offered appropriate and sensitive supports, it improves wellbeing and community participation outcomes for those individuals and creates a culture of inclusion and acceptance in our mental health system.

This submission highlights the issues affecting autistic Victorians every day within our mental health systems and makes four practical, community-led recommendations to develop specific, specialised mental health supports for autistic people.

## Summary of recommendations

### Recommendation 1

A service model be developed that sets out how the mental health system can provide appropriate support to autistic people. The service model should:

- be underpinned by the notion that autistic people must have access to continuous care throughout their lives, with key aspects of this care including a multi-disciplinary team of specialists and case management
- ensure that information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area, is made accessible to health practitioners, as well as the general public
- ensure that professionals across all sectors, including the mental health, health, disability, justice and education, are aware of, and have access to, appropriate training in autism and mental health
- ensure that carers of autistic people are provided with appropriate mental health support.

### Recommendation 2

A clinical practice model be developed to support mental health in autistic people generally, and for adolescents and adults more specifically.

### Recommendation 3

The Victorian Government supports research into autism and mental health by:

- establishing a mental health and autism research fund
- funding a Mental Health and Autism Summit, to bring together mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and opportunities for service collaboration.

### Recommendation 4

The Victorian Government works towards eliminating restrictive practices across all service systems and sectors in Victoria, including the mental health system, and advocates for a nationally consistent framework for eliminating restrictive practices.

## About the organisations

**Amaze, Yellow Ladybugs and Different Journeys welcome this Royal Commission and support its aim to provide the community with a clear and ambitious set of actions that will change Victoria's mental health system and enable Victorians to experience their best mental health.**



**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.

Amaze works to ensure that the voices of autistic people, their families and carers are at the centre of all our work. In preparing this submission, Amaze sought the stories and ideas of the Victorian autism community, and their powerful experiences are present throughout this document.



**Yellow Ladybugs** is an autistic-led non-government organisation dedicated to the happiness, success and celebration of autistic girls and women. Yellow Ladybugs runs regular social events which bring autistic girls together in an inclusive and sensory-friendly setting. These events help foster a sense of connection, belonging and pride for autistic girls.

Yellow Ladybugs is also working to change the common misconceptions about autism, to ensure autistic girls and women are supported according to their needs, and to build a society that values and empowers all autistic individuals. Yellow Ladybugs has a strong advocacy role in highlighting the many challenges autistic girls and women face, including barriers to diagnosis, exclusion in school and employment, and access to services.

Yellow Ladybugs welcomes the opportunity to participate in the Royal Commission and is committed to ensuring that the mental health-care needs of autistic girls and women are specifically addressed as part of this inquiry.



**Different Journeys** is a peer led organisation of people with Autism Spectrum Disorder (ASD), their families and supporters. Different Journeys works in partnership with community groups and services.

Different Journeys believes that everyone needs to find their tribe - other people who speak the same language and just 'get' each other.

By creating opportunities for people with ASD to engage with other members of their tribe, we can change their worlds. Different Journeys addresses isolation, prejudice and ignorance with connections, hope and community. The journey for families, teens and adults with ASD is made better by connecting with the world and not feeling so alone.

## What is 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 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 Australian 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.<sup>1</sup>
- 85% of Australians have personal contact with an autistic person.<sup>2</sup>
- Autism is the largest National Disability Insurance Scheme (NDIS) diagnostic group – representing 29% of all participants receiving an individual funding package<sup>3</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.



## Methodology

**The direct, lived experience of autistic people, their families and carers is central to this submission.**

Extensive consultation was undertaken to support its development and ensure that it captured the voices of the Victorian autism community – including the issues they are facing and how they would like these issues to be addressed. The consultation also extended to health professionals and researchers with expertise in autism and mental health.

The findings and recommendations in this submission are focused on Victoria; recommendations in relation to Commonwealth programs, such as Medicare and the National Disability Insurance Scheme, have not been included.

### Community consultation survey

Amaze, Yellow Ladybugs and Different Journeys developed an online community consultation survey asking about the experiences of autistic people and their families and carers with the mental health system ('the community consultation survey'). This survey was designed to be autism-friendly, and was co-designed with autistic people.

Questions were asked in relation to diagnosis, access to support, supports utilised, and how the mental health system could be improved. The families and carers of autistic people were also provided with an opportunity to share their experiences with the mental health system.

A range of closed questions and questions allowing free text answers were used, which provided space for more detailed answers and experiences to be shared. Participation was anonymous and consent was sought to use the information provided in this submission.

A mix of qualitative and quantitative data was obtained. With a total of 293 responses from Victoria, there was a substantial volume of qualitative information provided, which is shared in this submission.

### Amaze Mental Health Professional Round Table

Amaze hosted a round table discussion ('Amaze Mental Health Professional Round Table') for 11 mental health practitioners and researchers with expertise working with autistic and neurodiverse people. The exchange enabled these experts to explore and discuss how Victoria's mental health system does and does not support these clients, and the ways it could better support the mental

health needs of autistic people in the future. Information from this round table discussion has been used in the submission.

### Research literature

The findings of contemporary Australian and international peer reviewed evidence has also been included in the submission.

## Part 1: Understanding of autism and co-occurring mental health conditions: stigma and discrimination

### 1.1 Autism and mental health conditions

**There are approximately 55,000 autistic people in Victoria, with many more undiagnosed. Poor mental health is a common feature in the autistic population with between 50-70% of autistic people having co-existing mental health conditions,<sup>4</sup> though there are indications the prevalence may be higher.**

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>5</sup>. Comorbid medical conditions are also common in autistic adults, which present a significant burden and may increase a person's vulnerability to some mental health disorders<sup>6</sup>.

A large national survey of autistic adults in Australia (without intellectual disabilities) in 2013 found that 71% of those surveyed experienced a mental health condition, with less than half stating that they were receiving sufficient support to manage their condition<sup>7</sup>. Other studies have reported that up to 50% of young autistic adults (without intellectual disabilities) experience anxiety, and that up to half experience depression<sup>8</sup>.

In 2016, a Dutch study found that 79% of their autistic sample met criteria for a psychiatric disorder at least once in their lives<sup>9</sup>. In 2012, the Autism Advisory Board on Autism Spectrum Disorders conservatively estimated that around 100,000 autistic people in Australia had a co-occurring mental health condition<sup>10</sup>. It is important to note that many autistic people experiencing mental health conditions may not know or feel confident knowing whether they are experiencing a mental health condition<sup>11</sup> – 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; some will undergo unnecessary interventions and/or take unnecessary medications<sup>12</sup>. 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<sup>13</sup>.

Within the health profession and amongst researchers, there is a growing recognition, awareness, and better understanding of the prevalence of mental health conditions and autism<sup>14</sup>. However, there is still a wide disparity in this knowledge and understanding, which is elaborated on in Sections 3 and 5 of this submission.

*Table 1* sets out the mental health diagnoses of participants to the community consultation survey who answered positively to the question 'Have you been diagnosed with a mental health condition by a doctor or other mental health professional?'. Anxiety and depression were the most frequently cited mental health conditions.

Anxiety	90%
Depression	80%
PTSD or complex-PTSD	23%
Eating disorder	8%
Bipolar Affective Disorder	6%
Psychosis	1%
Other (incl. OCD, panic disorder, borderline personality disorder)	19%

*Table 1* Mental health condition diagnosis (n=80)

## Recommendation

The Victorian Government support research into autism and mental health by:

- Establishing a mental health and autism research fund
- Funding a Mental Health and Autism Summit to bring together mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and service collaboration.

## 1.2 Autism and suicide

**A 2019 Australian study found that the premature 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<sup>15</sup>.**

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 autistic people compared to the general population<sup>16</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>17</sup>. These findings alert the urgent need for health promotion and management of concurrent mental health conditions for autistic people.

Responses to the community consultation survey indicate that even when autistic people were suicidal they did not get the informed care they needed.

“The crisis worker who yelled at me for being suicidal was a low point.”

“When younger (19) I had a serious (near fatal) suicide attempt, and spent several weeks in a general hospital ward. I had no psychiatric assessment or support and no mental health follow up after discharge. Only the physical symptoms were treated.”

“When you want to die; finding the will to seek help is a big deal, you shouldn’t have to jump through hoops to get the actual help.”

“It’s been incredibly difficult to access what little support I have, and it’s taken a lot of fighting for it on my behalf. I can understand how and why so many people end up committing suicide because it really does take far too much effort on the patient’s behalf to access relevant support.”

### 1.3 Stigma

Recently, researchers have found that social stress autistic people experience in relation to stigma was predictive of higher levels of psychological distress and lower levels of emotional, psychological, and social well-being<sup>18</sup>.

Results from the community consultation survey also indicate 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.

“Being diagnosed with depression has a huge stigma attached to it, so I don’t tell people. I also don’t admit I have anxiety because I think people will look at me differently.”

“

“I’ve deliberately stayed under the radar and away from diagnosis because even though my son copped the diagnosis and my dad probably was autistic, the stigma surrounding something regarded as a disability is huge and I don’t want to jeopardize my employment prospects. I’m already diagnosed with [m]ajor [d]epression, last thing [I] need is to add autism to the list.”

## Part 2: Drivers behind poor mental health outcomes

### 2.1 Key drivers for mental health conditions and prevalence with autistic people

Evidence shows that autistic people are more likely to have experiences that can exacerbate a mental health condition, including:

- sensory challenges that impact their wellbeing
- high levels of intolerance of uncertainty
- comorbid medical conditions that can present a significant burden<sup>19</sup>
- significantly more likely than their non-autistic peers to be suspended or excluded<sup>20</sup> and targets of bullying<sup>21</sup> in school
- high levels of social isolation - research previously commissioned by Amaze found that 51.6% of autistic people and their families agreed they are socially isolated<sup>22</sup>
- poorer education<sup>23</sup> and employment outcomes<sup>24</sup>.

*Table 2* shows the response rate to the community consultation survey question asking what has made autistic peoples' mental health worse. Social interactions, sensory sensitivities/processing and relationships were the most frequently selected answers.

Social interactions	79%
Sensory sensitives/processing	76%
Relationships	70%
Work	68%
School	67%
Lack of meaning, purpose or fulfilment	62%
Financial circumstances	60%
Health care (including mental health)	56%
Family	53%
Isolation from friends and family	52%
Physical health	48%
Housing	25%
Sexuality	20%
Gender	13%
Other	10%

*Table 2* Responses to the question 'Have any of these things made your mental health worse?' (Tick all that apply) (n=79)

Additional information provided by participants noted that their mental health was also made worse due to the lack of appropriate accommodation and (for carers) lack of respite.

One autistic trait that was frequently listed as having significant negative mental health impacts was cognition and poor executive functioning, particularly where this led to difficulties in work, study, housekeeping and organising their lives. Participants explained that executive difficulties resulted in low education attainment and employment, discomfort in their living environments, and distress about housing and health stability.



“Executive function challenges impact on just about every part of life. Having the confidence and feelings of self-worth to be able to follow up friendships is hard when you are depressed and anxious, so you get isolated and that just makes it harder.”

## 2.2 Feeling different

**Participants’ responses to the community consultation survey painted a clear picture of how autistic people with mental health conditions can feel they are ‘different’ or ‘wrong’.**

Social isolation and social anxiety were also themes that were repeatedly raised, with participants feeling anxious about communicating with others and feeling exhausted after social interactions, noting that they were often ‘masking’<sup>25</sup> in an attempt to fit in.



“Autism causes my [m]ental [h]ealth issues. When I am forced out of my comfort zone or in a sensory overloaded environment my [m]ental [h]ealth deteriorates.”

“I often feel “different” to other people and get anxious in many situations. This contributes to my mental health because it is difficult to get out of the house, to feel self-worth and to feel satisfaction in day-to-day tasks.”

“Trying to emulate a normal person, but continually getting it wrong, makes you question your value as a person.”



A number of participants linked their mental health conditions to their autism, noting in particular that sensory sensitivities contributed to feelings of anxiety.

The interaction between autism and mental health is not well understood. A recent study found that almost 50 per cent of the poorer mental health of adolescents with disability is due to bullying by peers<sup>26</sup>. More research is needed to understand how stigma, discrimination and bullying relating to autism impacts on mental health. Research into the effects of autistic traits, such as sensory sensitivities, on mental health is also required.

### 2.3 Physical environment and its impact on autistic people

**Autistic people face a range of barriers to accessing services across sectors, including the mental health sector, due to a lack of “autism friendly environments”<sup>27</sup>.**

For autistic people, access issues can relate to:

- Structure or physical features of the built environment: including lighting, acoustics, odours, colours, spatial features, flooring and other design elements. They may also include the way information is conveyed, for example a lack of provision for non-verbal communication or signs<sup>28</sup>.
- Cognitive and/or social differences: including a need for routine/predictability and sensory processing difficulties, such as delayed or single channel processing (i.e. may not be able to process all sensory input, such as hearing, seeing and feeling where their body is in space, simultaneously)<sup>29</sup>.
- 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<sup>30</sup>.

The *Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder* recommended the inclusion of quiet rooms and spaces in Victorian hospitals and other healthcare settings to better accommodate autistic people<sup>31</sup>.

Furthermore, autistic people would be better supported to access healthcare and mental health services if they were provided with: support for transitions and new experiences (e.g. social stories); additional time for consultations; and adjustments by mental health service practitioners and staff to communication styles<sup>32</sup>.

When designing mental health services and facilities, the needs of autistic people – with respect to acoustics, lighting, sensory spaces etc. – should be taken into account<sup>33</sup>.

## 2.4 Restrictive Practices

**Current evidence concludes that restrictive practices have a negative effect on health, wellbeing and quality of life for people with disability<sup>34</sup>, and can give rise to serious adverse consequences, including increasing behaviours of concern, post-traumatic stress, serious injury and death<sup>35</sup>.**

Restrictive practices involve the use of interventions and practices that have the effect of restricting the rights and freedoms of movement of an autistic person. These primarily include restraint (chemical, mechanical or social) and seclusion<sup>36</sup>, but also include psycho-social restraint, consequence driven strategies and environmental restraint<sup>37</sup>.

Currently, autistic people (and people with disability more generally) who display 'challenging behaviours' or 'behaviours of concern' may be subjected to restrictive practices in a variety of settings including: schools, disability services, supported accommodation and group homes, hospitals, mental health facilities and prisons.

Significant steps have been taken towards eliminating restrictive practices in disability service settings,<sup>38</sup> this approach should be replicated in the mental health sector.

### Recommendation

That the Victorian government work towards eliminating restrictive practices across all service systems and sectors in Victoria, including the mental health system, and advocates for a nationally consistent framework for eliminating restrictive practices

## Part 3: Barriers to autistic people experiencing good mental health

### 3.1 Access to the right services

**The difficulty in accessing the right mental health supports was a major theme raised by autistic people and their carers and families.**

In the community consultation survey, 73% (n=81) of autistic participants reported finding it hard or very hard to find the right services to help them with their mental health.

Lack of knowledge from service providers about mental health and autism	79%
Cost/lack of finances	66%
Lack of appropriate services	59%
Too hard - overwhelmed or burnout	53%
Not being believed e.g. about being autistic, mental health symptoms	47%
Too hard - executive functioning challenges	43%
Too many competing priorities e.g. carer role	43%
Location/distance of support services	29%
Did not get funding support i.e. NDIS	28%
Stigma	19%
Other (most frequent responses: Difficult to find professionals I trust, lack of access to child care)	26%

**Table 3** Responses to the question 'What made it hard to seek help or support for your mental health?' (Tick all that apply) (n=58)

90% (n=181) of participants who are caring for an autistic person found it hard or very hard to find the right services for the person they are caring for.

During the Amaze Mental Health Professional Round Table, mental health practitioners also described their frustration at how difficult it was to find the right services and specialists to help support autistic people with their mental health. The factors that both the community consultation survey participants and participants at the Amaze Mental Health Professional Round Table felt contributed to the difficulty in accessing the right services:

## Misdiagnosis

Early, correct diagnosis of autism alongside assessment and diagnosis of mental health conditions is essential so that the right supports can be provided.

There is substantial evidence that investment in the early years of children's health, development and wellbeing is the most cost-effective means of tackling long-term health conditions and health inequity<sup>39</sup>; however, 54% (n=74) of the community consultation survey participants have been, or felt that they have been, misdiagnosed either in relation to autism and/or their mental health conditions.

There were reports of incomplete diagnosis as well as misdiagnosis. The most common misdiagnosis described by participants was bipolar disorder, schizophrenia and borderline personality disorder. Some participants said that due to them being female, they did not fit the male stereotypical presentation, and were inappropriately refused an autism diagnosis.

“At 15 I was treated for depression but [received] no formal diagnosis. At 28 I was diagnosed with Borderline Personality Disorder which I don't agree with. Now I am 49 and have a young daughter with autism I know all along I have had autism.”

“The life-long depression and anxiety I have been treated for were just symptoms of an underlying undiagnosed autism.”

“As a woman I have observed that autism is not accepted. My brothers received childhood diagnoses and I did not. I was simply "difficult", "attention seeking" etc.”

A 2018 UK study found that participants who identified as autistic or possibly autistic were less likely to agree with their mental health diagnoses<sup>40</sup>.

Participants' main reasons for disagreement were:

- they felt their autism characteristics were being confused with mental health conditions by healthcare professionals
- they perceived their own mental health difficulties to be an outcome of their autism.

Participants attributed perceived misdiagnoses to healthcare professionals' inadequate knowledge of autism and the professionals' knowledge of how to adapt their practice to better communicate with the participants – which in turn prevented them from receiving appropriate support<sup>41</sup>.

The study highlighted the need for autism training for healthcare professionals and the need to develop tools and interventions to accurately diagnose and effectively treat mental health conditions in autistic individuals<sup>42</sup>.

There is also evidence suggesting that autistic women and girls are often misdiagnosed, or solely diagnosed with conditions such as learning disabilities, anxiety and/or eating disorders (with some consequently undergoing unnecessary interventions and/or taking unnecessary medications)<sup>43</sup>.

### Difficulty navigating the mental health system

Many community consultation survey participants described the difficulties in navigating the mental health system.

This difficulty was attributed to the lack of information about where to get help and what questions to ask and of whom, and needing to act as 'project managers' to co-ordinate appointments and fill out required forms. Many autistic participants also noted that they struggled with executive functioning,<sup>44</sup> which made navigating the system even harder.

At the Amaze Mental Health Professional Round Table mental health and autism health professionals also spoke about their difficulties in navigating the system and finding people with the right expertise to support their clients. The lack of co-ordination between sectors, specifically mental health and the disability, justice and education sectors was frequently cited as a barrier to accessing appropriate supports.

“When my daughter was first diagnosed, I felt like I was just flailing about not really knowing what I should be doing. It was like I needed a "project manager" to tell me exactly who she needed to see when, what referrals and plans to apply for and to organise it all for me: it was very convoluted, confusing and overwhelming.”

“I work in the health sector and navigating the Public Health system, DHHS and NDIS has been a nightmare. I still feel my daughter is not being cared for as she should. The mental health system lacks facilities for complex patients who need to be in a safe environment where they can be cared for by caring [and] understanding staff.”

### Lack of appropriate services

It was acknowledged at the Amaze Mental Health Professional Round Table that there are gaps in the mental health system, that there is a lack of services available, and that services/support can suddenly disappear (due to lack of funding or practitioners leaving the service temporarily or permanently) leaving autistic people with mental health conditions without support.

With the transition to the NDIS, it was noted that a 'whole workforce' has seemingly disappeared. Experienced case managers are gone and Victoria's Department of Health and Human Services disability services are being replaced with an inexperienced NDIS workforce. There is a risk that children and families will be re-traumatised when treatments and supports that can be so difficult to access in the first place are suddenly no longer available.

Difficulties in finding appropriate services and long waitlists was a major theme in the community consultation survey responses. Responses also specifically noted the lack of services for autistic adults and the lack of services in regional areas.

“Long wait times for appropriate specialists. Short wait times for inappropriate ones. Try the short wait, suffer. Then when going for the long wait time people, it's still hit or miss, but it takes years to figure out the service isn't working. Try again. More years of confusion and frustration. At this point I'm so burned out on the system I just gave up.”

“The local "public" hospital (the only one in my town) is privately owned and told me my son is "not considered severe needs" so refused to help. I've heard MULTIPLE stories from friends and relatives about how little help this town is with any mental health issue.”

“Despite much searching I am yet to find a psychologist in Ballarat who has a genuine interest in autism who treats adults. I have found in the past many mental health professionals don't truly know our unique needs.”

### Lack of service provider knowledge of autism

73% (n=81) autistic participants reported finding it hard or very hard to find the right services to help them with their mental health. Of that cohort, 79% attributed this to 'lack of knowledge from service providers about mental health and autism' (refer to *Table 3*).

Participants suggested that the attitudes and knowledge of mental health professionals was the most significant factor in their support and care.

The provider's willingness to accept and support their individual autistic experience and support needs had the biggest impact on *improving* their mental health. In contrast, participants described the impact of ignorant and inconsistent mental health care to be destructive to their mental health.

Many participants to the community consultation survey highlighted a lack of knowledge specifically in relation to autistic girls and women. Participants also noted that mental health providers did not have the knowledge to treat mental health conditions in an autistic person with a dual disability, or complex needs.

“There is a deep lack of understanding and knowledge about autism in adult women.”



“In my experience most professionals such as psychs are empathetic but they just don't understand the complexities. They will try and treat the anxiety but also try and treat the autism like it is a mental health disorder and that it can be "cured". There may be a select few psychologists who have the expertise but they are hard to book and cost a lot of money so it becomes treatment for the privileged... if you live in the city and have money you have a little more chance of being treated by som[e]one who gets it. Out in regional Victoria there is NOTHING !! Even if you have the money to spend there are just no professionals to see who are experienced in autism.”

Similarly, the *Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder* found that autistic people currently 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>45</sup>.

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<sup>46</sup>. 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<sup>47</sup>.

The *Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder* concluded that there are a lack of professionals specialising

in autism and mental health and this gap needs to be addressed<sup>48</sup>. Specialists are required to improve the treatment of mental health conditions in autistic people and should 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<sup>49</sup>.

An evidence based “best practice service model” should be developed to identify how to best meet the varying age-related mental health needs of autistic people<sup>50</sup>.

When people find the right provider, and can afford to see them for as long as they want to, they report feeling supported to manage the challenges of their life. One of the most important criteria for successful support was when the provider understood autism, and accepted how it uniquely impacted the person’s life.



“Now I have found a psychologist who understands autism properly and we work really well together but it’s taken a really long time to find him.”

### Lack of rapport with service providers

The community consultation survey participants described finding a practitioner they could trust enough to talk openly to as a barrier to getting appropriate mental health support.



“It took quite a few goes with different professionals to find the right one; and even she didn’t identify my autism. I’d like to go back to her but I can’t afford it; the gap payment [is] nearly \$100 per appointment.”

### Cost

The expense associated with accessing mental health services was frequently raised by participants to the Community Consultation Survey. There was a frustration about the lack of financial support to access services, and this particularly related to limited funding for psychology.





It's expensive, I don't get NDIS, I care for two ... children, I'm mentally unwell, all the supports I used to access disappeared, ten Psychologist sessions isn't enough, I can[t] drive due to meds, I need support to leave the house, the public system knocked me back, after constantly being rejected it was easier to give up trying."

"It is expensive to get ongoing help. The mental health plan only covers 10 visits which is not enough, and even then you are still out of pocket for psychologists."

## Recommendation

That a service model be developed that sets out how the mental health system can provide appropriate support to autistic people. The service model should:

- ensure that information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area, is made accessible to health practitioners, as well as the general public
- ensure that professionals across all sectors, including the mental health, health, disability, justice and education, are aware of, and have access to, appropriate training in autism and mental health.

### 3.2 Usefulness of mental health supports that are being accessed

**Community consultation suggests that supports autistic people find most useful for their mental health are peer support and informed, respectful one-on-one support from a mental health professional.**

Participants communicated that when they engaged with their peers they felt understood and accepted – they did not feel so alone. Online support played a substantial role in peer support, as it is widely accessible and participants could find people with shared life circumstances.

There was generally positive feedback about psychologists – participant feedback indicated that they understand, accept and support autistic people well.

“

“My psychologist initially diagnosed me and was extremely knowledgeable in autism and mental health issues (they specialise in Autism).”

Community consultation survey participants offered mixed experiences of psychiatrists, commonly expressing they felt neurodiversity was not understood, accepted or supported by these professionals.

“

“The psychiatrist just checks in on medication and did my assessment.”

“My current psychiatrist is brilliant - he actually listens to me and believes me.”

Many of the comments about general practitioners highlighted the importance of this role; however, a pervasive lack of knowledge about autism and limited time had a detrimental effect on mental health outcomes. People expressed much gratitude and appreciation when they had good support and rapport with their general practitioner.

“

“My original GP has been very supportive in linking me in with Psychologist, since she retired and I was transferred over to a new Dr he refuses to believe me and made it very hard to get services and support and doesn't understand disability nor will he support me in getting the supports I need – find[ing] a good GP is very very hard.”

Some participants commented that hospital interactions had been ineffective, traumatic or destructive and that they had felt profoundly misunderstood and unsupported when they had attempted to obtain care. They also spoke of the lack of understanding about the causes of their distress behavior.

“

“Hospital emergency wards are useless, [I] have been once and there was no follow up, and if anything it just made me more likely to not seek help in the future.”

The need for appropriately trained mental health professionals in schools was frequently raised in community consultation.

“

“Improve autistic and mental health services in schools!!!!”

“We are now forced home schoolers as she wasn’t coping at school or being supported effectively.”

On 8 May 2019, the Victorian government announced that it will be ‘rolling out mental health professionals in Victorian government schools to give students the support they need...’<sup>51</sup> More than 190 mental health professionals will be employed in government schools to offer counselling, early interventions services, and coordination support for students with complex needs. It is imperative that these mental health professionals have knowledge of treating mental health in autistic students.

### 3.3. Accommodation and other practical support

Many participants to the community consultation survey described the following as contributors to their mental health condition and/or as barriers to accessing mental health support: Unstable accommodation, inability to drive, lack of personal supports for childcare and transport, un- and under-employment, and concurrent physical health issues.

“

“There is literally no other suitable option for people like me with no support from my family or friends, or income to secure accommodation on my own. Autism is central to my lack of stable housing & the two combined have kept me in a perpetually [r]isk [a]verse mentality for most of my life.”

## Part 4: The needs of family members and carers

**Responses from carers and family members of autistic people in the community consultation survey clearly indicate the mental health system is failing to appropriately support carers.**

Participants noted that the role of caring can be exhausting and, often, a struggle. Academic research similarly shows that caring for autistic children is challenging, affects family life, and can result in psychological distress, depression, anxiety among parents<sup>52</sup>.

The community consultation survey results indicate that carers can be so overwhelmed in navigating an unsupportive system for those for whom they care, that their capacity to navigate it for themselves is limited.

The extra cost and time commitment involved with getting mental health support for themselves were repeatedly noted as barriers accessing that support. Some carers noted that they accessed counselling sessions through Carers Victoria, which were beneficial.



“I think the system doesn't care for carers. I know carers are expected to be capable of reaching out for help if they need it, but no-one has once asked me how I am doing. As a carer, I will not be reaching out for any help, such as counselling, because I have not got time and it's yet another thing to pay for. Even with medicare rebates for psychology, it's another \$80 to find per session. After paying for all my child[’s] needs (and another child), there just isn't the money for me to see someone as well.”

“There has been no support for me as a carer”

“There really is no help offered for carers of children with mental health issues. We have 3 children in our family all struggling at times with mental health. As their carer, I too have suffered although in silence as there is no time for me to seek help, I cannot afford it and as far as I am aware there is no help for carer which is really hard”

### Recommendation

That a service model be developed that ensures that carers of autistic people are provided with appropriate mental health support

## Part 5: Attraction, retention of, and support for the mental health workforce

### 5.1 Building an autism-competent mental health workforce to support autistic people

**The Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder found that autistic people face significant barriers to accessing support for their mental health needs, largely due to a low level of understanding of autism by mental health practitioners<sup>53</sup>.**

The Inquiry made a number of recommendations, including making provisions for training and professional development of public hospital staff and public mental health clinicians in the awareness and understanding of autism presentations<sup>54</sup>.

It was noted at the Amaze Mental Health Professional Round Table that within the health profession and amongst researchers, there is a growing recognition, awareness, and better understanding of the prevalence of mental health conditions and autism. One participant described a conference they had recently attended, where sessions on mental health and autism were filled to capacity<sup>55</sup>.

However, it was also noted at the Amaze Mental Health Professional Round Table that perceptions of autism, within the broader community as well as the mental health sector, are 'as broad as the spectrum'<sup>56</sup>. There is a need for mental health professionals to better understand the complexity of autism presentation. For example, these professionals need to understand the effect of, and take into account, co-morbidities and differences in gender.

The following are the key areas that need to be addressed in order to better support the mental health workforce:

#### Training

Demand for mental health services for autistic people has increased markedly, yet the number of services available has not increased to match this demand.

During the Amaze Mental Health Professional Round Table it was suggested that some mental health professionals may not provide services to autistic people with mental health conditions because they do not know how to help. Key specialists, including paediatricians, do not receive formal training in autism, nor do nurse practitioners. A paediatrician at the Amaze Mental Health Professional Round Table stated that even after undertaking her training at the Royal Children's Hospital she received no training and little exposure to autism. In her

early years of practice, she built her knowledge via seeking out evidenced based information and advice from the Amaze Autism Advisor service.

Due to lack of funding, there are also very few clinical placements for psychologists that provide the opportunity to work with autistic people with mental health conditions in a supervised and supportive environment.

Training in autism and mental health can address this barrier, and provide mental health professionals with the knowledge and confidence to be able to provide these services. With additional funding, current training programs for health professionals could be expanded, which would help to increase the supply of mental health services and supports to autistic people.

There are programs in Victoria that currently provide training to health professionals in relation to autism and mental health. For example, Mindful, Centre for Training and Research in Developmental Health, The University of Melbourne, provides autism training that is available to all mental health clinicians in the public and private sector and professionals working with autistic children and young people. This training covers autism assessment, diagnosis, mental health comorbidities and a range of intervention strategies. Mindful has trained over 1000 clinicians in the last 12 months alone. Mindful's ongoing funding from the Mental Health Branch, Department of Health and Human Services is uncertain and due to limited funding, this program has not yet been evaluated

The Neurodevelopmental Stream at Orygen Youth Health (OYH) also provides autism training to those in mental health and related sectors, including mental health clinicians, teachers, wellbeing staff at schools, and private practitioners. Despite the importance of these training services, they are not funded. A case study in relation to the training provided by OYH is included in *Appendix A*.

### **A mental health system that supports practitioners**

Training is the first step in building knowledge and awareness of autism within the mental health sector. However, the system must also provide appropriate access to training, and support for trained practitioners. Support can be provided through offering appropriate, supervised placements, a mentoring system, or by facilitating the use of multi-disciplinary teams of specialists who can work together.

The Centre for Autism Spectrum Disorders and the Child Development Centre in the Nationwide Children's Hospital in Columbus, Ohio provide an example of a model that utilises a multi-disciplinary team to provide comprehensive, multidisciplinary care focusing on diagnosis of autism, evidence based treatment,

education, research and advocacy for autistic children<sup>57</sup>. To ensure their knowledge is shared with the broader health profession and community, the practitioners in the team spend time in community clinics and also work closely with relevant professionals across sectors, for example, teachers. The Child Development Centre autism services are part of the Autism Treatment Network (ATN) and therefore adheres to the ATN guidelines for assessment, diagnosis, and treatment<sup>58</sup>.

### Navigating the mental health system

Not only do autistic people and their carers find it hugely difficult to navigate the mental health system, but health professionals also find this challenging.

Some health professionals have taken on pseudo case management roles, spending extensive time researching services and specialists, to ensure that their clients are referred to and linked in with the right support.

Practitioners taking on these types of roles could be better supported by:

- having a practice nurse or a social worker who is able to assist them with these task
- working in a multi-disciplinary team with other health professions who provide expertise and support
- having access to a centralised online database that provides details on services and specialists with expertise in mental health and autism.

### A clinical practice model

Having a model, or guide, that provides information on treatment of mental health conditions in autistic people would greatly assist practitioners who have had limited experience in treating mental health in autistic people.

During the Amaze Mental Health Professional Round Table concerns were raised about the use of medication, such as Risperidone, to manage challenging behaviours in autistic children as a first line response instead of first seeking support from mental health services. A clinical practice guideline could set out appropriate use of medication for autistic people.

A clinical practice model for autism and mental health could be developed in a number of ways, for example:

- the model could provide for the creation of a specialised clinic that focuses specifically on autism and mental health;
- the model could be developed so that it can be used by the whole mental health workforce when treating mental health conditions in autistic people ;

- the model could create a specialised clinic that focuses specifically on autism and mental health, but that also includes an outreach element where the clinic's health practitioners provide support and expert advice in other community and clinical settings as a secondary consultation service.

There are examples of successful treatment models that could provide a base for a treatment model for practitioners to use in relation to autism and mental health. For example, the Mental Health Intellectual Disability Initiative – Youth (MHIDI-Y), provides a specialist, community-based mental health assessment and treatment service for children and youth aged from birth to 25 years who have an intellectual disability and severe mental illness<sup>59</sup>.

The Victorian Dual Disability Service (VDDS) at St Vincent's Hospital in Melbourne is another treatment model that could inform a treatment model for mental health and autism with intellectual disability. The VDDS provides assessment, diagnosis, consultation-liaison, treatment support for mental health conditions and education to public mental health services across Victoria in relation to people with neurodevelopmental disorders. The service is part of the public mental health services sector, funded by the Mental Health Branch of the Department of Health and Human Services. Part of VDDS's success can be attributed to all team members being highly experienced, having specific training in mental health and neurodevelopmental disorders, and being willing to engage with autistic people and be flexible according to their needs. *Appendix B* contains a case study on the VDDS model.

## Recommendation

That a service model be developed that sets out how the mental health system can provide appropriate support to autistic people. The service model should:

- ensure that information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area, is made accessible to health practitioners, as well as the general public
- ensure that professionals across all sectors, including the mental health, health, disability, justice and education, are aware of, and have access to, appropriate training in autism and mental health.

That a clinical practice model be developed to support mental health in autistic people generally, and for adolescents and adults more specifically.



## 5.2 Continuity of care

**Autism and mental health practitioners at the Amaze Mental Health Professional Round Table noted that positive outcomes for clients are more likely to occur when practitioners are able to provide continuous care.**

Continuity of care is essential for all people with mental health conditions, and particularly for autistic people, who often find change and transition to be particularly challenging. Continuing care for an autistic person would ideally start from diagnosis in early years (2+ years) and continue for that person's lifetime. There is substantial evidence that investment in the early years of children's health, development and wellbeing is the most cost-effective means of tackling long-term health conditions and health inequity<sup>60</sup>.

The provision of continuity of care could involve a multi-disciplinary team of specialists, including a case manager, to support an autistic person throughout their lifetime. The members of this care team are expected to change to suit the autistic person's needs. For example, having a maternal health nurse as a part of a team will be beneficial for early diagnosis and early intervention. The multi-disciplinary team could work with the autistic person and their family to develop a plan for support and treatment, to provide education about what to expect during different life stages, and to provide contacts who can be accessed efficiently if, and when, crisis occurs.

### Recommendation

That a service model be developed that sets out how the mental health system can provide appropriate support to autistic people. The service model should be underpinned by the notion that autistic people should have access to continuous care throughout their lives, with key aspects of this care including a multi-disciplinary team of specialists and case management.

## 5.3 Interaction of mental health system with other mainstream systems

There is no coordinated approach between mental health, 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<sup>61</sup>.

This lack of a coordinated approach was showcased in the recent Victorian Ombudsman report, *Investigation into the imprisonment of a woman found unfit to stand trial*. The report highlighted the case of 'Rebecca', an autistic woman imprisoned for 18 months, despite being found unfit to stand trial, simply because there was nowhere else for her to go.

This report underlined the 'service gap' between mental health and disability. Rebecca's changing diagnosis meant she was no longer eligible for help under the Mental Health Act, but she could not get help under the Disability Act. Professionals agreed she needed support, but no one could agree on who was responsible. For Rebecca, this led to her imprisonment<sup>62</sup>.

The siloed approach to mental health and disability is likely to be exacerbated by the transition of disability funding for supports and services from the states to the National Disability Insurance Agency (NDIA). The Victorian government needs to work closely with the NDIA to ensure that people with disability are able to access appropriate mental health services.

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<sup>63</sup>.

## Part 6: Social and economic participation of autistic people

### 6.1 Social and economic outcomes for autistic people

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

- Premature 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<sup>64</sup>.
- 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<sup>65</sup>.
- 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<sup>66</sup>.
- 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<sup>67</sup>.

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

*Table 4* shows the response to survey question about whether an autistic person felt that their mental health made it harder to do certain activities. The most frequent responses were 'social interaction', 'enjoying life' and 'friendships'.

Social interaction	93%
Enjoying life	86%
Friendships	79%
Employment	74%
Family relationships	67%
Financial wellbeing	65%
Self care	62%
Education	59%
Physical health	53%
Other	11%

*Table 4. Responses to the question 'Does your mental health condition make it harder to do any of the following' (Tick all that apply) (n=76)*

## 6.2 Education

Evidence indicates that at school, autistic students are significantly more likely than their non-autistic peers to be suspended or excluded<sup>68</sup>, targets of bullying<sup>69</sup>, to suffer depression and anxiety<sup>70</sup> and to under-perform academically relative to their level of intelligence.<sup>71</sup> Exclusion and bullying in school also has long term adverse impacts on mental health and community participation<sup>72</sup>.

These experiences and outcomes not only prevent autistic students from achieving a level of educational attainment that 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<sup>73</sup>.

Participants to the community consultation survey noted that their autistic traits impacted on their engagement with education due to 'very poor at time management and organisation' with several participants saying that they were unable to keep up with part time or full time workload.



"I didn't understand what teachers wanted, even when I asked again, I didn't understand the explanation, if [I] asked again everyone thought I was dumb and I still didn't understand. I found it difficult to work in groups."

## 6.3 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%)<sup>74</sup>.**

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<sup>75</sup>.

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<sup>76</sup>. 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.

Participants to the community consultation survey advised that poor mental health impacts their capacity to work where anxiety and depression reduces motivation. There were also comments made about how autistic traits impact employment success; for example, poor time management and organisation was reported to leave people feeling unable to cope. Furthermore, social demands, discomfort with work politics and a lack of accommodations and adjustments made work difficult for many participants.



“I don't know how to "sell myself" at the interview. I don't know how to defend myself from the bullying & mind games of the workplace when I actually get a job.”

## 6.4 Social isolation

**Participants to the community consultation survey noted that they felt socially isolated. This isolation was often attributed to the difficulties experienced in executive functioning and interacting socially, which made participants feel anxious and exhausted.**



“Executive function challenges impact on just about every part of life. Having the confidence and feelings of self worth to be able to follow up friendships is hard when you are depressed and anxious, so you get isolated and that just makes it harder.”

It is well known that social isolation can lead to poor mental health, education, social and economic outcomes<sup>77</sup>. 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

- 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<sup>78</sup>.

## 6.5 The economic costs associated with autism

In 2011, Synergies Economic Consulting's report for the AEIOU Foundation on the economic costs of autism in Australia estimated that the annual economic costs of autism in Australia were between \$8.1 billion (low prevalence) and \$11.2 billion (high prevalence)<sup>79</sup>.

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.

Synergies Economic Consulting also conducted a literature review that revealed 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<sup>80</sup>.

## Part 7: Reform priorities for Victoria's mental health system

### 7.1 Key findings

The following are the key findings from consultation and research thus far that inform the recommendations below.

- Autistic people experience higher prevalence of mental health conditions as well as poor social and economic outcomes in comparison to the general population.
- There is a systemic lack of long term, accessible and autistic informed mental health supports and services.
  - There is inconsistency and disparity in health professionals' understanding and knowledge in relation to autism and mental health.
  - There is a particular lack of knowledge in relation to autistic girls and women.
  - Continuity of care across the lifespan (early years, child, youth, adult, ageing) is essential, particularly for autistic people who can find transitions particularly challenging.
  - The difficulties in accessing autistic informed mental health supports and services are exacerbated in regional areas.
- Navigating the mental health system to find the right supports and specialists is difficult for autistic people, their families and carers, as well as health care professionals. These difficulties are even more challenging for autistic people who have executive functioning or communication challenges.
- There is no existing treatment model in relation to autism and mental health, however there are models such as MHIDI-Y for children or the VDDS that could inform a treatment model.
- When cognitive or sensory autistic traits are supported, mental health and whole life participation and fulfilment increases.

### 7.2 Recommendations

We intend to continue to consult with our communities throughout the Royal Commission process in order to provide specific recommendations for change. The recommendations below provide a starting point for changes that can be made to the mental health system to better support autistic people experiencing mental health conditions and their carers and families.

### Recommendation 1

That a service model be developed that sets out how the mental health system can provide appropriate support to autistic people. The service model should:

- be underpinned by the notion that autistic people should have access to continuous care throughout their lives, with key aspects of this care including a multi-disciplinary team of specialists and case management
  - ensure that information specifically in relation to autism and mental health, including where to access services and supports and which practitioners specialise in this area, is made accessible to health practitioners, as well as the general public
  - ensure that professionals across all sectors, including the mental health, health, disability, justice and education, are aware of, and have access to, appropriate training in autism and mental health
- ensure that carers of autistic people are provided with appropriate mental health support.

### Recommendation 2

That a clinical practice model be developed to support mental health in autistic people generally, and for adolescents and adults more specifically.

### Recommendation 3

That the Victorian government support research into autism and mental health by:

- establishing a mental health and autism research fund; and
- funding a Mental Health and Autism Summit to bring together mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and service collaboration.

### Recommendation 4

That the Victorian government work towards eliminating restrictive practices across all service systems and sectors in Victoria, including the mental health system, and advocates for a nationally consistent framework for eliminating restrictive practices.



## Closing

Amaze, Yellow Ladybugs and Different Journeys appreciate the opportunity to provide this submission and highlight the mental health support needs of autistic people.

We look forward to participating in the Commission's hearings and reviewing your findings and recommendations.

If you have any questions or we can provide further information in support of this submission, please contact Fiona Sharkie, Amaze Chief Executive Officer, via email [REDACTED] or phone [REDACTED].

## Appendix A: Case Study – Orygen Youth Health

**Orygen Youth Health (OYH) is a tertiary mental health service that provides care to young people aged 15-25, in Melbourne's west.**

The Neurodevelopmental Stream provides advice and training to clinicians both within OYH and across the sector, and assists with diagnostic assessment and care of clients who are diagnosed with autism or may be autistic. The Neurodevelopmental Stream consists of a coordinator, a psychiatrist and a psychologist - all are part-time roles.

In regards to autism, OYH receives young people in two main cohorts: Those who already have a diagnosis of autism and have a comorbid psychiatric illness.

People who present to OYH with a psychiatric illness and are not yet diagnosed with autism but may be autistic.

Concerning the first cohort, people are referred to the Neurodevelopmental Disorders Stream by clinicians throughout OYH who are looking after a young autistic person and need assistance on how best to: meet the person's needs, understand their difficulties, work with them on their mental health difficulties. For the second cohort, the Neurodevelopmental Stream advises clinicians on how to gather further information on the client, and make a diagnostic assessment if needed. They also work with the client and their family or carer to first discern if it is an appropriate time in their life to proceed with the diagnostic assessment.

OYH has realised the considerable need for mental health clinicians who not only understand mental health but are also knowledgeable about autism. This is because of the significant number of people with neurodevelopmental disorders who have comorbid mental health problems: autistic people are more likely to have mental health problems than the broader population, and their needs for mental health support are great. Around 1/70 - 1/100 young people who present to OYH with mental health issues are also autistic or undiagnosed.

The service has identified the need to up skill clinicians to become knowledgeable about autism. OYH provides guidelines to mental health clinicians on young autistic people and comorbid mental disorders. The Neurodevelopmental Stream also works with the OYH to provide training programs to those in mental health and related sectors, including mental health

clinicians, teachers, wellbeing staff at schools, and private practitioners. This is crucial work, but the training services are not funded.

Despite the numbers of autistic people presenting to OYH increasing significantly over the past few years, funding is insufficient to meet the need. This creates immense pressure as clinicians are increasingly under resourced and need to both assess and treat clients but also train people across the sector to understand autism.

## Appendix B: Case Study – Victorian Dual Disability Service

**The Victorian Dual Disability Service (VDDS) is a joint mental health initiative between St Vincent’s Hospital Melbourne and Melbourne Health that services the state of Victoria. At a state wide level, the VDDS is responsible for developing a model of best practice.**

The VDDS also provides assessment, diagnosis, consultation-liaison, treatment support for mental health conditions and education to public mental health services across Victoria in relation to people with co-occurring intellectual and neurodevelopmental disabilities.

The VDDS consists of a team of four experienced senior clinicians, three psychiatrists and one nurse practitioner.

The service is part of the public mental health services sector, funded by the mental health branch of the Department of Health. Funding is reviewed and renewed on an annual basis.

Each person referred by the VDDS gets a comprehensive biopsychosocial and developmental assessment by an experienced senior clinician. The VDDS is able to service people in their homes or a suitable location for the individual. All assessments are peer-reviewed and followed by a detailed treatment plan. This includes a 3-month follow up assessment.

In the past four years, 448 autistic people were referred to the VDDS by mental health services - equivalent to 23% of total referrals.

Health of the Nation Outcome Scales (HoNOS) is an instrument that provides a general measure of the severity of mental health symptoms (the highest number being equal to most severe symptoms). It is used for all mental health service outcomes in Australia. The mean HoNOS total for those referred to the VDDS service at the point of assessment is 19. At 3-month follow up the mean score is 12, showing a significant reduction in items relating to aggression, self-harm and psychiatric symptoms.

The VDDS is a successful service because all team members are highly experienced, have specific training in mental health and neurodevelopmental disabilities, and are willing to engage with autistic people and be flexible according to their needs. They have experience working with people with highly complex needs. All clinicians actively seek out additional training to remain current with research in the field, and ensure the VDDS is developing a model of best practice.

## References

---

- <sup>1</sup> 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>.
- <sup>2</sup> Amaze, Strategic Directions to 2040 and Strategic Plan 2018-2021, 2018.
- <sup>3</sup> NDIS National Dashboard as at 30 June 2018. <https://www.ndis.gov.au/medias/documents/national-dashboard-aug18/National-Dashboard.pdf>
- <sup>4</sup> Australian Advisory Board on Autism Spectrum Disorders 2012, The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward. Discussion paper, December 2012
- <sup>5</sup> 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.
- <sup>6</sup> Ibid.
- <sup>7</sup> Autism Spectrum Australia (Aspect) 2013. We Belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism, April 2013.
- <sup>8</sup> Lugnegard T et al 2011. Psychiatric comorbidity in young adults with a clinical diagnosis of Asperger syndrome. Research in Developmental Disabilities 2011;32:1910 – 17; Green et al 2000. Social and psychiatric functioning in adolescents with Asperger syndrome compared with conduct disorder. J Autism Dev Disord. 2000; 30:279-93.
- <sup>9</sup> 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.
- <sup>10</sup> Australian Advisory Board on Autism Spectrum Disorders 2012. The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward. Discussion paper, December 2012.
- <sup>11</sup> 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>.
- <sup>12</sup> 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>.
- <sup>13</sup> Autism Spectrum Australia (Aspect). We Belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism, April 2013.
- <sup>14</sup> Amaze Mental Health Professional Round Table.
- <sup>15</sup> Hwang YI et al 2019. Mortality and cause of death of Australians on the Autism Spectrum. International Society for Autism Research, 2019, p1-10.
- <sup>16</sup> Hirvikoski T et al 2015. Premature mortality in autism spectrum disorder. The British Journal of psychiatry, 207(5); Kirby A.V. et al 2019. A 20-Year Study of Suicide Death in a Statewide Autism Population. Autism Research 12, p658-666.
- <sup>17</sup> Autistica. Understanding suicide in autism. Available from <https://www.autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism>.

- 
- <sup>18</sup> Botha, M. & Frost, D.M. 2018. 'Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population'. *Society and Mental Health*.
- <sup>19</sup> 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.
- <sup>20</sup> Barnard, J. et al 2000, *Inclusion and autism: Is it working?* London: The National Autistic Society
- <sup>21</sup> 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
- <sup>22</sup> Jones S et al. 2017, *Experiences of Autistic People and their Families*, Centre for Health and Social Research, Australian Catholic University.
- <sup>23</sup> ABS (2017) 4430.0 Survey of Disability, Ageing and Carers: Autism in Australia
- <sup>24</sup> Ibid.
- <sup>25</sup> 'Masking' is where people try to hide being autistic in order to fit in with others.
- <sup>26</sup> King, T., Aitken, Z., Milner, A., Emerson, E., Priest, N., Karahalios, A., Kavanagh, A., & Blakely, T. 2018. 'To what extent is the association between disability and mental health in adolescents mediated by bullying? A causal mediation analysis'. *International Journal of Epidemiology* 1-12.
- <sup>27</sup> Victorian Parliament 2017. *Inquiry into Services for People with Autism Spectrum Disorder - Final Report*. Family and Community Development Committee. June 2017.
- <sup>28</sup> Shell, S (2016) *Why buildings for autistic people are better for everyone*. Forte Building Science.
- <sup>29</sup> American Psychiatric Association 2013. **Diagnostic and statistical manual of mental disorders** (5th ed.). Washington, DC
- <sup>30</sup> 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>
- <sup>31</sup> Victorian Parliament 2017. *Inquiry into Services for People with Autism Spectrum Disorder - Final Report*. Family and Community Development Committee. June 2017.
- <sup>32</sup> 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.
- <sup>33</sup> Australasian Health Infrastructure Alliance (AHIA), *Australasian Health Facilities Guidelines*, North Sydney, AHIA, 2015.
- <sup>34</sup> Report on the Inquiry into Abuse and Neglect against People with Disability in Institutional and Residential Settings.", Senate Community Affairs References Committee, 2015; Sigafoos J., Arthur M., O'Reilly M. (2003). *Challenging behaviour and developmental disability*. London, England; Singh, N. N., Lloyd, J. W., & Kendall, K. A. (1990). Non-aversive and aversive interventions: Introduction - in A. C.Repp & N. N. Singh (Eds.), *Perspectives on the use of non-aversive and aversive interventions for persons with developmental disabilities* (pp. 3-16). Sycamore, IL: Sycamore
- <sup>35</sup> McVilly, K, *Physical restraint in disability services: Current practices, contemporary concerns, and future directions*. A report commissioned by the Office of the Senior Practitioner. Melbourne: Department of Human Services, 2009; Paterson, B., Bradley, P., Stark, C., Saddler, D., Leadbetter, D., & Allen, D. Deaths associated with restraint use in health and social care in the UK: The results of a preliminary survey. *Journal of Psychiatric and Mental Health Nursing*, 10, 9-17, 2003.
- <sup>36</sup> National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector, Australian Government, 2014

<sup>37</sup> NDIS Quality and Safe Guarding Framework, Commonwealth Department of Social Services, 2016.

<sup>38</sup> National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018

<sup>39</sup> The Royal Australasian College of Physicians. 2019. 'Early Childhood: The Importance of the Early Years'. Position Statement. Available from: [https://www.racp.edu.au/docs/default-source/advocacy-library/early-childhood-importance-of-early-years-position-statement.pdf?sfvrsn=e54191a\\_4](https://www.racp.edu.au/docs/default-source/advocacy-library/early-childhood-importance-of-early-years-position-statement.pdf?sfvrsn=e54191a_4).

<sup>40</sup> Au-Yeung, S and Bradley, L et al. 2018. Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults.

<sup>41</sup> Ibid.

<sup>42</sup> Ibid.

<sup>43</sup> 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>.

<sup>44</sup> The technical definition of executive function is: the cognitive processes that help us regulate, control and manage our thoughts and actions. It includes planning, working memory, attention, problem solving, verbal reasoning, inhibition, cognitive flexibility, initiation of actions and monitoring of actions (<https://autismawarenesscentre.com/executive-function-what-is-it-and-how-do-we-support-it-in-those-with-autism-part-i/>).

<sup>45</sup> 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>.

<sup>46</sup> 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.

<sup>47</sup> 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.

<sup>48</sup> 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>.

<sup>49</sup> Australian Advisory Board on Autism Spectrum Disorders 2012. The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward. Discussion paper, December 2012.

<sup>50</sup> 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.

<sup>51</sup> Premier of Victoria. 2019. 'Expanding Mental Health Support to Victorian Students'. Media Release. Available from <https://www.premier.vic.gov.au/expanding-mental-health-support-to-victorian-students-2/>.

<sup>52</sup> Hoefman, R. et al. 2014. Caring for a Child with Autism Spectrum Disorder and Parents' Quality of Life: Application of the CarerQol. *Journal of Autism and Developmental Disorders*. 44(8) pp1933-1945.

<sup>53</sup> Victorian Parliament 2017. Inquiry into Services for People with Autism Spectrum Disorder - Final Report. Family and Community Development Committee. June 2017.

<sup>54</sup> Ibid.



- 
- <sup>55</sup> Amaze Mental Health Professional Round Table.
- <sup>56</sup> Ibid.
- <sup>57</sup> Nationwide Children's Hospital. 'Centre for Autism Spectrum Disorders'. Available from <https://www.nationwidechildrens.org/specialties/center-for-autism-spectrum-disorders>.
- <sup>58</sup> Nationwide Children's Hospital. 'Autism Treatment Network'. Available from <https://www.nationwidechildrens.org/specialties/center-for-autism-spectrum-disorders/autism-treatment-network>.
- <sup>59</sup> Alfred Heath. 2019. 'Neurodevelopmental stream', available from <https://www.alfredhealth.org.au/services/neurodevelopmental-stream>.
- <sup>60</sup> The Royal Australasian College of Physicians. 2019. 'Early Childhood: The Importance of the Early Years'. Position Statement. Available from: [https://www.racp.edu.au/docs/default-source/advocacy-library/early-childhood-importance-of-early-years-position-statement.pdf?sfvrsn=e54191a\\_4](https://www.racp.edu.au/docs/default-source/advocacy-library/early-childhood-importance-of-early-years-position-statement.pdf?sfvrsn=e54191a_4).
- <sup>61</sup> Australian Advisory Board on Autism Spectrum Disorders 2012, The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward. Discussion paper, December 2012.
- <sup>62</sup> Victorian Ombudsman 2018. Investigation into the imprisonment of a woman found unfit to stand trial.
- <sup>63</sup> Ibid.
- <sup>64</sup> Hwang YI et al 2019. Mortality and cause of death of Australians on the Autism Spectrum. International Society for Autism Research, 2019, p1-10.
- <sup>65</sup> 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>
- <sup>66</sup> 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>.
- <sup>67</sup> Jones S et al. 2017, Experiences of Autistic People and their Families, Centre for Health and Social Research, Australian Catholic University.
- <sup>68</sup> Barnard, J. et al 2000, Inclusion and autism: Is it working? London: The National Autistic Society.
- <sup>69</sup> 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.
- <sup>70</sup> 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.
- <sup>71</sup> 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.
- <sup>72</sup> Wolke D and Lereya S 2015. Long-term effects of bullying. Arch Dis Child Sept, 100(9), 879-885.
- <sup>73</sup> 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>.
- <sup>74</sup> 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>.
- <sup>75</sup> Australian Government 2011. National Disability Strategy 2010 to 2020. A collaborative 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>.

---

<sup>76</sup> 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.

<sup>77</sup> 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.

<sup>78</sup> Jones S et al. 2017, *Experiences of Autistic People and their Families*, Centre for Health and Social Research, Australian Catholic University

<sup>79</sup> Synergies Economic Consulting 2011. *Economic Costs of Autism Spectrum Disorder in Australia*. April 2011. Available at [a4.org.au/sites/default/files/Synergies\\_costsofautism\\_FINAL\\_170511.pdf](http://a4.org.au/sites/default/files/Synergies_costsofautism_FINAL_170511.pdf).

<sup>80</sup> Ibid.