

## Amaze Position Statement

# Mental Health

### Key points

- **Approximately 50 – 70% of autistic people experience co-occurring mental health conditions, most commonly depression, anxiety disorders and/or obsessive compulsive disorder.**
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- **A range of barriers currently prevent autistic people accessing adequate mental healthcare, including a lack of autism recognition, understanding and expertise across mainstream health and mental healthcare services, as well as a lack of coordination and collaboration across a range of sectors.**
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- **Amaze recommends that, in partnership with autistic people and the autism community, the Victorian Government:**
    - Develop a strategy for autism and mental health in an updated State Autism Plan (as recommended in the Victorian Parliament's *Inquiry into services for people with autism spectrum disorder – Final Report, 2017*). It should aim to enhance training and professional development of mental health service professionals and staff, provide quiet spaces in public hospitals and healthcare facilities, provide funding to increase the capacity of mental health and community health services to support autistic people with a co-occurring mental health condition and improve service co-ordination and collaboration across sectors.
    - Facilitate a multi-media campaign to reduce the stigma of autism and mental health and raise community understanding.

# 1. Background

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>1</sup> The estimated prevalence of mental health conditions among autistic people varies due to methodological variations between studies, but is in the range of approximately 50 – 70%.<sup>2</sup> There is emerging evidence that the prevalence of mental health conditions, such as anxiety and depressive disorders, may be higher among autistic females than autistic males.<sup>3</sup>

Studies into autism and mental health have tended to focus on autistic people without intellectual disabilities.<sup>4</sup> For example, 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>5</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>6</sup> In 2012, the Autism Advisory Board on ASD conservatively estimated that around 100,000 autistic people in Australia had a co-occurring mental health condition.<sup>7</sup> In the UK, it has been reported that a leading cause of early death among autistic people is suicide.<sup>8</sup> A recent Swedish study found that adults with autism (and no additional learning disability) are over 9 times more likely, relative to the general population, to commit suicide.<sup>9</sup>

It is important to note that many autistic people experiencing mental health conditions may not actually know or feel confident knowing whether they are experiencing a mental health condition.<sup>10</sup> As such, the prevalence may be higher.

## 2. Current experiences.

Autistic people have a basic human right, like any other Australian, to accessible and person-centred mental health services.<sup>11</sup> However, autistic people currently face significant barriers when seeking to access a diagnosis of, and support for, mental health conditions. These barriers can include a lack of autism recognition and understanding by mental health practitioners, communication difficulties (particularly when a person is non-verbal), sensory sensitivities and a lack of coordination and collaboration between mental health, mainstream health, disability services and other sectors, including education, employment, justice and housing.<sup>12</sup>

Some mental health services, and health services with mental health units, have sought staff training to support their understanding and management of autistic patients (particularly in hospital settings, for the purpose of behaviour support). However, there remains no co-ordinated approach to ensuring all mainstream health and mental health professionals and staff can access the level of autism knowledge and skills required to diagnose, meaningfully treat or facilitate the treatment of (i.e. through appropriate referral pathways) mental health conditions in autistic people. Barriers to training and professional development are known to include location, cost and organisational priority.<sup>13</sup>

While some resources are available online to help assist health professionals working with autistic people, they can be difficult to find and quality assess, and/or are not widely publicised or targeted across mainstream health and healthcare professionals.<sup>14</sup>

A lack of autism recognition and understanding, together with a lack of sector collaboration across mental health services has led to mental health services 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>15</sup> As a result, mental health conditions are often not diagnosed or adequately treated, resulting in poor health, an increased risk of suicide and other poor education, social and employment outcomes.<sup>16</sup> Although it should also be noted that among females, autism has historically been under-diagnosed, with women and girls often being misdiagnosed, or solely diagnosed with conditions such as learning disabilities, anxiety and/or eating disorders (with some undergoing unnecessary interventions and/or taking unnecessary medications).<sup>17</sup> A lack of autism knowledge can also result in misunderstanding of behaviours across autistic males and females, increasing the risk of restrictive practices and the overprescribing of medications.<sup>18</sup>

As noted above, not all autistic people will recognise that they are experiencing a mental health condition or feel comfortable disclosing their mental health condition to healthcare or other professionals. They may also choose not to seek support from family and friends due to concerns of stigma and/or burdening those closest to them.<sup>19</sup>

In Victoria, Child and Adolescent Mental Health Services (CAMHS) and Child and Youth Mental Health Services (CUYMHS) currently provide public services for children and young people experiencing mental health challenges. They are also funded to conduct multidisciplinary assessments and diagnosis of autism. However due to a lack of resources, CAMHS and CUYMHS (and indeed most mental health services) mainly focus on supporting people experiencing acute mental health crisis and withdraw services once the initial mental health crisis is over. When long term support is offered it is often not suited to autistic people, or seeks to treat autistic people in a way that can fail to acknowledge their positive self-identity as an autistic person.<sup>20</sup> They also lack the resources to engage in cross-sector collaboration and coordination with other service providers.<sup>21</sup> There are also two dual disability health/mental health services in Victoria. Dual disability is a term used for people with an intellectual disability and a mental health condition. Autistic adults with an intellectual disability and a mental health condition and/or epilepsy technically do not have a dual disability. At present, there isn't a term to describe this which has an impact on services, research and policy.<sup>22</sup>

### 3. What needs to be done?

In June 2015, the Victorian Parliament's Family and Community Development Committee released its *Inquiry into service for people with autism spectrum disorder – Final Report* (Victorian Parliament's report, 2017).<sup>23</sup> Among the 101 recommendations in this report, the Committee recommended that the Victorian Government update its State Autism Plan and in that plan “develop a strategy for public and mental health services to accommodate the needs of people with Autism Spectrum Disorder, including the roll out of autism specialists in the public health system”.<sup>24</sup>

Amaze welcomed the Victorian Government's commitment in December 2017, in its response to the Victorian Parliament's report, to develop a strategy for building autism competency across mainstream workforces, including mental health, to better equip them to respond positively to autistic people.<sup>25</sup> This strategy must also focus on raising recognition and understanding of autism and mental health (including its commonality, particularly among autistic women) and service collaboration and co-ordination. In developing this strategy, the government should consult and engage closely with autistic people, their families/carers and autism organisation. Involving autistic people will increase their confidence in mental health services, ensure they are specifically tailored to the needs of the autistic community and make these services as accessible as possible.<sup>26</sup> As a first step, autistic people should be consulted about their mental health needs and current barriers to support.<sup>27</sup>

#### a. Increasing recognition and understanding.

Amaze supports the recommendation in the Victorian Parliament's report, 2017, that “[t]he updated State Autism Plan make provision for training and professional development of public hospital staff and mental health clinicians in the awareness and understanding of ASD presentations”.<sup>28</sup> A multi-media campaign would also be beneficial to reduce stigma and raise community awareness of autism and mental health.<sup>29</sup>

Existing online resources for mental health and healthcare professionals should also be widely publicised across sectors and targeted to peak bodies, such as the Australian Medical Association.<sup>30</sup> For example, Australia's Cooperative Research Centre for Living with Autism (Autism CRC) has recently developed an information resource for health and mental health professionals which includes information on understanding and supporting sensory, communication and processing differences.<sup>31</sup> In the UK, the “Know your Normal” campaign, recently launched by Ambitious about Autism (UK), demonstrates the value of a purpose built website to raise community awareness and provide a tool box for autistic people needing mental health support, as well training for (and creating linkages between) education and health professionals.<sup>32</sup>

The value of neurodiversity and a patient's positive self-identity as an autistic person must also be recognised by mental health and healthcare professionals as this may influence the types of interventions and treatments preferred by the patient. Acknowledgement of individual preferences and self-identify are key to developing positive therapeutic relationships.<sup>33</sup>

#### b. Capacity building across health and mental health services.

Capacity building is urgently required across sectors to improve their ability to support autistic people with co-occurring mental health conditions.

As discussed above, Amaze welcomes the Victorian government's commitment to develop a strategy for building autism competency across mainstream workforces, including mental health. An increase in funding to public mental health services and community services will be essential to build their capacity to provide services for autistic people with a co-occurring mental health condition.<sup>34</sup>

The Victorian Parliament's report, 2017, also concluded that there are a lack of professionals specialising in autism and mental health and this gap needs to be addressed. Amaze agrees that specialists are required to improve the treatment of complex mental health conditions in autistic people. Specialists should also be supported to build capabilities across mainstream health and mental health services to improve their 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>35</sup> An evidence based "best care service model" should be developed to identify how to best meet the varying age-related mental health needs of autistic people.<sup>36</sup>

Autistic people may also be better supported to access often busy healthcare and mental health services through the creation of quiet rooms (to help autistic people manage sensory difficulties), support for transitions and new experiences (such as through social stories), additional time for consultations and adjustments by mental health service practitioners and staff to communication styles.<sup>37</sup> When designing mental health services and facilities, the needs of many autistic people with respect to acoustics, lighting, sensory spaces etc. should always be taken into account.<sup>38</sup>

Accordingly, Amaze also supports the recommendations in the Victorian Parliament's report, 2017, that "[t]he Victorian government ensure all new and existing public hospitals and healthcare facilities have provision for dedicated quiet spaces for people with ASD in emergency departments and other inpatient and outpatient areas".<sup>39</sup>

### **c. Service collaboration and coordination, and cross sector understanding.**

Better service collaboration and coordination is needed across sectors (including the mainstream health, disability, mental health, education, employment, justice and housing sectors) to build professional knowledge of autism, provide clearly defined pathways of care and improve participation, health and wellbeing outcomes for autistic people.<sup>40</sup>

Amaze supports the recommendation in the Victorian Parliament's Report, 2017, that "[t]he Victorian Government include, as a key element of the updated State Autism Plan, the integration and coordination of government funded services for people with ASD".<sup>41</sup> Indeed, the Plan should prioritise the coordination and collaboration of all services that interface with autistic people.

Following any person's diagnosis of autism (child or adult), a coordinated approach should be taken to surveillance of their mental health (across all sectors that interface with that person) to identify and treat any emerging mental health issues as early as possible.<sup>42</sup> A systematic, rather than ad hoc, approach is required to information sharing and cross referrals between services.<sup>43</sup>

Online networks should aim to link and build the knowledge of professionals across sectors, including the education, disability, health and mental health sectors.<sup>44</sup> Early identification, monitoring and prevention of mental health conditions should also be prioritised across schools, with funding for multidisciplinary services to build their capacity to identify, monitor and meet the support needs of autistic students with emerging or existing mental health conditions.<sup>45</sup>

Autistic participants in Australia's National Disability Insurance Scheme (NDIS) should have access to service co-ordinators knowledgeable in mental health and autism to provide appropriate advice regarding services and pathways. Their NDIS package of supports should also include adequate funding to access mental health services and support their community engagement. All autistic people, including those who are not Participants in the NDIS (i.e. do not qualify for an individual package of supports) should have access to sound advice regarding mainstream and specialist services and pathways through NDIS Information, Linkages and Capacity funded activities. Autistic people who are not Participants in the NDIS should also have access to other government funding streams to support their mental health needs and access appropriate services.<sup>46</sup>

## 4. Key recommendations

1. Australian Governments engage with autistic people and the autism community to build their understanding of mental health and autism, current barriers to diagnosis and support and how healthcare services may better tailor their supports to autistic people.
2. The Victorian Government, in partnership with autistic people and the autism community, adopt the recommendations in the Victorian Parliament's Report, 2017, that it:
  - a. Develop a strategy for autism and mental health in an updated State Autism Plan which includes the roll out of autism specialist mental health services and a strategy for autism training and professional development of mental health service professionals and staff.
  - b. Ensure all public hospital and healthcare facilities provide dedicated quiet spaces.
  - c. Increase funding to mental health and community health services so they have the capacity to provide services and support for autistic people with a co-occurring mental health condition.
  - d. Improve autism recognition and understanding, together with improved service co-ordination and collaboration across sectors.
3. The Victorian Government, in partnership with autistic people and the autism community, facilitate a multi-media campaign to reduce the stigma of autism and mental health and raise community understanding.

## Endorsed by:



## Attribution:

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**Shaping the future  
for Autism.**

## 5. References

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- <sup>22</sup> For more information, see the Victorian Dual Disability Service (a joint mental health initiative between St Vincent's Hospital Melbourne and Melbourne Health) at <https://svhm.org.au/home/our-services/departments-and-services/v/victorian-dual-disability-service> and the Centre for Developmental Disability Health at <http://www.cddh.monashhealth.org/>.
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