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Select Committee on Mental Health and Suicide Prevention

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### Select Committee Inquiry on Mental Health and Suicide Prevention

#### Amaze seeks to create a better future for autistic people

Amaze is a community organisation established over fifty years ago by autistic people and their families. We work to build understanding of autism, influence policy change for autistic people and provide independent, credible information and resources to individuals, families, professionals, government and the wider community. We are closely connected with the autistic community through our national help line Autism Connect, our peer support networks and community capacity building initiatives.

We welcome this inquiry by the Select Committee on Mental Health and Suicide Prevention. This short submission argues that autism needs to be considered core business for the mental health sector, including by:

- Identifying autism as a priority group in the next National Mental Health & Suicide Plan
- Expanding access to Medicare rebated autism assessments for those aged over 13 years
- Establishing a National Centre of Excellence for mental health and autism
- Building autism proficiency in federally funded mental health infrastructure
- Increasing the autism knowledge and skills of the mental health workforce

Our submission is informed by the lived experience of autistic people and their families and carers. Quotes and results are taken from the largest consultation survey of the autism community ever conducted in Australia. This survey of almost 4000 autistic people and their families/carers was commissioned by the Australian Autism Alliance (of which Amaze is a partner) in 2020. We also draw from Amaze's engagement with the autistic community to inform Victoria's Mental Health Royal Commission.<sup>1</sup>

Amaze endorses the more comprehensive submission to this Inquiry made by La Trobe University's Olga Tennison Autism Research Centre (OTARC).

#### Autism is one of the biggest disability groups

Autism is a high prevalence condition. In 2018 the ABS reported that 1.3% of males, 0.4% of females and 3.2% of children aged 5-14 years had an autism diagnosis; though actual prevalence in the community is much higher as only a small proportion of autistic adults have been formally diagnosed. Autistic people comprise the biggest cohort of participants in the NDIS.<sup>2</sup>

<sup>1</sup> Amaze, 2019. Submission to the Royal Commission into Victoria's Mental Health System. Available at: <https://www.amaze.org.au/wp-content/uploads/2019/09/Amaze-Yellow-Ladybugs-Different-Journeys-Submission-RCVMHS.pdf>

<sup>2</sup> 31% of participants have autism as a primary diagnosis, a further 5% as a secondary diagnosis.

## There is an extreme mental health crisis among autistic people

The challenges of mental illness are starkly felt by autistic people, with heartbreaking consequences.

These statistics are staggering:

- The majority of autistic people (50-70%) experience co-occurring mental health issues – particularly depression and anxiety. The Autism Alliance’s 2020 Autistic community survey revealed 75-83% of respondents reporting mental health conditions.
- The autistic community experiences high rates of suicide, with a ninefold increased risk of premature death by suicide compared to the general population.<sup>3</sup> Research involving a cohort of 50 autistic adults found a 36% suicide attempt rate, compared to 4.6% in the general population.<sup>4</sup>
- The high incidence of mental ill health has been linked to autistic people being more than twice as likely as non-autistic people to die before turning 75, with a life expectancy of 20-36 years shorter than the general population.<sup>5</sup>

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*The stark health inequities faced by autistic people presents a burning platform for action from all levels of government to arrest what is an unacceptable gap in mental health outcomes for a significant population group.*

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Despite the high prevalence of mental illness, autistic people face widespread and persistent challenges in accessing autism-informed mental health care. The 2020 Autism Alliance survey reveals a major disconnect between appropriate mental health care and the availability of services able to meet the needs of autistic people:

- The majority (58%) of autistic adult respondents report that they were previously diagnosed with another condition which their doctor/psychologist/psychiatrist advised was incorrect after they were diagnosed as autistic.
- 69% of adult autistic respondents experienced considerable difficulties finding clinical mental health support that is autism responsive and expressed low confidence in health professionals’ understanding of autism.
- 90.5% of autistic adults respondents reported challenges in accessing healthcare due to anxiety caused by the environment.
- 84.4% of autistic adults reported access challenges related to sensory sensitivities.
- Over one-third of survey respondents reported not been able to access mental health support.

*“A lot of mental health professionals (even those who claim to specialise in autism) seem to have a limited understanding of how autism can affect people, especially women/girls. I often feel like I'm*

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<sup>3</sup> Hirvikoski T et al 2015. Premature mortality in autism spectrum disorder. Available at: <https://pubmed.ncbi.nlm.nih.gov/26541693/>

<sup>4</sup> Paquette-Smith, M. et al, 2014. History of suicide attempts in adults with Asperger syndrome. Available at: <https://pubmed.ncbi.nlm.nih.gov/25113892/>

<sup>5</sup> Hirvikoski T et al 2015. Premature mortality in autism spectrum disorder. Available at: <https://pubmed.ncbi.nlm.nih.gov/26541693/>;  
Guan J, Li G. Injury mortality in individuals with autism. Available at: <https://pubmed.ncbi.nlm.nih.gov/28323463/>

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*being treated as someone who "just needs more confidence" rather than a person with complex needs and difficulties."*

Mental health practitioners have self-identified barriers to providing appropriate care to autistic people. Major reasons include limited access to training and professional development in autism, a lack of readily available information about supporting autistic people with mental health conditions and disconnected support and service systems<sup>6</sup>.

Without autism expertise and more adult diagnosis, mental health workers will reasonably assume that they are dealing with a non-autistic person (given that 97%+ of the population are not autistic) and diagnose and treat accordingly. Misdiagnosis leads to significant wasted public expenditure as well as personal harm. When an autistic person is treated for schizophrenia or FASD (for example) the cost of treatment is largely wasted and can even be harmful to the recipient.

### Covid-19 has exacerbated mental health challenges for many autistic people

The Covid-19 pandemic has exacerbated the mental health challenges faced by autistic people. Restrictions imposed to reduce the spread have dramatically affected people's social functioning and disrupted everyday routines. In the 2020 Autism Alliance Survey many respondents detailed their challenges with social isolation, mental health needs and the compounding effects of social restrictions during the pandemic.

Research conducted by Dr Liz Pellicano and colleagues on the impact of the pandemic on autistic people indicated that while some autistic people had positive experiences in lockdown (e.g., appreciating the 'slowing down' of pressurised routines and the move to online engagement), many autistic people reported a decline in their overall mental health, and felt worryingly unsupported during the pandemic.<sup>7</sup>

The pandemic was particularly stressful for autistic young people, and Amaze is particularly concerned about the long-term impacts of extended schooling disruptions on autistic students. Around 70% of families responding to Amaze's Victorian-based *Learning in Lockdown Survey* reported their children experienced deteriorating mental health during school disruptions<sup>8</sup>.

As Australia begins to adjust to the post-pandemic 'new normal', it is clear the autistic community will need significant mental health support. This need includes assisting those whose mental health deteriorated during lockdown; and supporting those who found the lockdown a welcome change to 're-enter' normal life.

<sup>6</sup> Amaze, 2019. Submission to the Royal Commission into Victoria's Mental Health System. Available at: <https://www.amaze.org.au/wp-content/uploads/2019/09/Amaze-Yellow-Ladybugs-Different-Journeys-Submission-RCVMHS.pdf>

<sup>7</sup> Available at: <https://www.amaze.org.au/wp-content/uploads/2020/08/Reflections-on-learnings-on-schooling-during-COVID-19-Amaze-and-ACD-Aug-2020.pdf> and <https://www.sydney.edu.au/content/dam/corporate/documents/sydney-policy-lab/everyday-experiences-of-autistic-people-during-covid-19-report-july-2020.pdf>

<sup>8</sup> Available at: [Amaze-Learning-in-Lockdown-Report-Term-3-Sept-2020.pdf](https://www.amaze.org.au/wp-content/uploads/2020/08/Amaze-Learning-in-Lockdown-Report-Term-3-Sept-2020.pdf)

## A dedicated approach is needed in the next iteration of the National Mental Health & Suicide Plan

Despite the high prevalence of autism and the huge proportion of autistic people experiencing mental ill-health, autism remains conspicuously absent in major mental health reports and plans including in the Fifth National Mental Health and Suicide Prevention Plan.

This is of great concern given autistic people are at far greater risk of co-occurring mental health conditions and have a significantly higher risk of premature death by suicide than the general Australian population. Autistic suicide rates are comparable to Australia's First Nations communities<sup>9</sup> and the LGBTIQ+ community.<sup>10</sup> We are aware these rates may be exponentially higher for individuals with autism who fall into one or more of these groups.

The next iteration of the National Mental Health and Suicide Prevention Plan is due in 2022. This provides a critical opportunity to elevate autism to one of the key 'Priority Groups'. Enshrining autism as a Priority Group under the Plan would ensure the development of autism specific approaches and initiatives by national, state and territory governments, with measurable goals.

### Recommendations:

1. **Identify autism as a 'Priority Group' in the next iteration of the National Mental Health and Suicide Plan**

## Barriers to autism assessment and diagnosis must be urgently addressed

There is a strong correlation between undiagnosed autism, misdiagnosis, mental health and self-harm.

*"A lack of understanding leads to misdiagnosis and treating things like depression and anxiety long term. I have been seeing psychologists since I was a child and psychiatrists since my 20s. It took until I was 37 for it to be picked up that I'm autistic, now I'm finally on a path that helps me so much more. I didn't understand autism myself to ever recognise it in me."*

Access to autism diagnosis can deliver substantial benefits, including to mental health and wellbeing. Autistic respondents to the 2020 Autism Alliance survey reported significant advantages of receiving a diagnosis:

- "Helped me understand myself" (91%)
- "Helped me understand my needs [and] explain my needs to others" (82.5%)
- "Helped me deal with feelings of being different/inadequate" (80%)
- "Helped give me a sense of belonging" (80.7%)

<sup>9</sup> 4.2% compared to 1.5% in the non-indigenous population. See <https://www1.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-c-toll-toc~mental-pubs-c-toll-str~mental-pubs-c-toll-str-3~mental-pubs-c-toll-str-3-1>

<sup>10</sup> Suicide rates of up to 14x higher rates than their heterosexual peers. See <https://www.beyondblue.org.au/docs/default-source/default-document-library/bw0258-lgbti-mental-health-and-suicide-2013-2nd-edition.pdf?sfvrsn=2>

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There are significant systemic barriers to accessing an autism diagnosis, including federal funding constraints. *Medicare rebates for autism assessment are available only for children under 13 years* (and these rebates only partially covers the costs). Young people and adults seeking a diagnosis face prohibitively high costs (often between \$2000-\$4000), which is a key contributing factor to the high rate of undiagnosed autistic adults.

This policy also has a gendered impact. It disproportionately impacts girls and women, as they tend to be diagnosed later than boys – often not until adolescence or adulthood.<sup>11</sup>

In 2020, the Medicare Benefits Schedule (MBS) Taskforce recommended rebated autism assessment services should be extended to people up to 25 years of age.<sup>12</sup> The Government has yet to act on this recommendation. While Amaze welcomes this recommendation, we believe there is a strong case to remove the age cap for publicly funded assessments altogether, including as part of addressing the high rates of mental ill health and suicide in the autistic community.

**Recommendations:**

- 2. Immediately increase the age limit for autism assessment from 13 to 25 years of age. This is consistent with the recommendation of the MBS Taskforce to improve access to autism assessment**
- 3. Provide a Medicare rebate for access to autism diagnosis for all who need it, across the lifespan**

### Autism must be considered core business for our mental health system

#### A Centre of Excellence in Autism in Mental Health is needed

Autism proficiency needs to be a core capability of Australia's Mental Health system. To build such capability, we recommend establishment of a national Centre of Excellence in Autism and Mental Health. This would strengthen understanding of the intersection of autism and mental health, research and advise on best practice, and enable mental health practitioners to improve their knowledge of autism through access to resources, tools and professional development. It ought to also embed the lived experience of autistic people to ensure co-production of system improvements, including the development of self-help strategies and resources for preventing and managing mental ill-health for autistic people.

#### Public and community mental health services need to be autism proficient

Our public and community mental health settings must do better at improving accessibility and service responsiveness for autistic people.

A promising initiative in Victoria is the inclusion of specialist autism coordinators in all Child & Adolescent Mental Health Services and Child & Youth Mental Health Services. They advise on the need for an autism assessment and appropriate models of care for those with both autism and a

<sup>11</sup> La Trobe University Olga Tennison Autism Research Centre. Response to the Select Committee on Autism Inquiry into the services, supports and life outcomes for autistic people in Australia. July 2020. Submission number 55, pg. 8

<sup>12</sup> <https://www.health.gov.au/resources/publications/taskforce-findings-allied-health-reference-group-report>

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mental health condition, taking a multidisciplinary approach. However, the demand for these services far outstrips their current capacity, and the autistic community are crying out for more support. Following Victoria's Mental Health Royal Commission, the service system is being significantly restructured.<sup>13</sup> The new Infant Child & Family Mental Health & Wellbeing Hubs will include autism expertise and capacity for publicly funded autism assessments for children.

Such an approach is both scalable and could be replicated across the nation's federally funded mental health settings including:

- in *headspace* Centres to facilitate assessment of adolescents and young adults.
- Head2Help - the newly established COVID-19 mental health clinics.

### The mental health workforce needs to be trained in autism

There is a strong need to extend, quality assure and mandate training in autism for the mental health workforce whether employed in public, community or private sector settings. The adult mental health workforce needs particular attention given the historic absence of investment in autism competence in these settings and the large number of undiagnosed autistic adults who are intersecting with the mental health system.

*"There should be more autistic health workers who understand our needs"*

#### Recommendations:

4. **Establish a National Centre of Excellence in Autism and Mental Health**
5. **Embed specialist autism advisors – with expertise in autism and mental health – within public and community mental health services, including *headspace* and HeadtoHelp**
6. **Extend, quality assure, and mandate training in autism for all mental health services; alongside the introduction of a new system of accreditation that enables autistic people to easily identify mental health practitioners with proficiency in autism.**

Amaze stands ready to assist the Select Committee in its work. Nicole Rees (Amaze Executive Manager, Policy and Advocacy and Deputy CEO) can be contacted at [nicole.rees@amaze.org.au](mailto:nicole.rees@amaze.org.au) to discuss this submission.

<sup>13</sup> <https://finalreport.rcvmhs.vic.gov.au/wp-content/uploads/2021/01/Fact-Sheet-%E2%80%93-Infant-child-and-youth-mental-health-and-wellbeing-services.pdf>