

Submission  
No 50

**INQUIRY INTO EQUITY, ACCESSIBILITY AND  
APPROPRIATE DELIVERY OF OUTPATIENT AND  
COMMUNITY MENTAL HEALTH CARE IN NEW SOUTH  
WALES**

**Organisation:** NeuroAccess

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### **Portfolio Committee No. 2 - Health: Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales**

**Dear Committee Chair,**

I would like to take this opportunity to thank the NSW Government for launching this much needed inquiry into the equity, accessibility and appropriate delivery of outpatient and community mental health care in NSW.

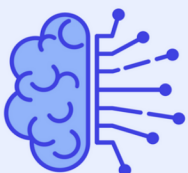
#### **About Me**

My name is Annie Crowe and I am a proud disabled neurodivergent woman, NSW resident and small business owner. I am also a human rights lawyer and consultant specialising in neurodivergent accessibility (or neuroaccessibility).

In 2022, I publicly defined *neuroaccessibility* to mean when the needs of neurodivergent people are specifically considered, and products, services, environments and systems are built or modified so that they can be used by people of all neurotypes.

I also founded Eating Disorders Neurodiversity Australia in May 2022 and have helped developed the recently launched National Eating Disorder Strategy and continue to consult with the National Eating Disorder Collaboration on mental health care accessibility.

Furthermore, I supervise and mentor mental health professionals across Australia, and internationally, seeking expertise in supporting neurodivergent clients. Most importantly, I bring my lived experience as a NSW resident who has not only interacted with the State health system but also supported many neurodivergent and disabled NSW residents who continue to need mental health care and services.



### **Lived Experience and Self-Advocacy**

Earlier this year I was taken to my local emergency department via ambulance after calling 000 due to mental distress and suicidality (I have posted about this on my LinkedIn and Instagram). I had an overwhelmingly positive experience, mostly due to my ability to self-advocate and my vast experience communicating with health professionals and articulating my access needs in health settings.

The majority of the disabled and neurodivergent community are not as privileged to have these positive interactions and non-traumatic experiences with the NSW and broader State and Territory health systems.

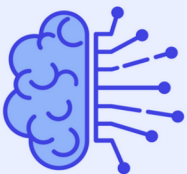
I believe robust and accessible community mental health is critical for **upstream suicide prevention** and reducing the need to rely on emergency services and downstream supports.

### **Inaccessible Community Mental Health Care**

Currently, we are limited to community mental health being restricted by location and many using group settings for therapy - both of which pose accessibility challenges to the disabled and neurodivergent community.

To briefly expand on this, location specific care isn't only a limitation to regional and rural participants, it's also limiting for those with physical and neurodevelopmental disabilities (including Autism and ADHD) - from a sensory, social and executive function lens.

Furthermore, group settings cause many neurodivergent people much distress and are often based on therapies that are targeted at neurotypical people, and less than ideal or effective for the neurodivergent community (see **resources** for information on CBT and how it is not ideal for autistic people).



## **Senate Autism Inquiry Report 2022**

According to the Senate Inquiry Report *Services, support and life outcomes for autistic Australians*, released in March 2022, autistic people are more likely to attempt or die by suicide than other groups. For example, while autism affects only one per cent of the population in the UK, up to 11 per cent of people who die by suicide in the UK may be autistic.

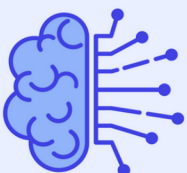
In one recent Australian study of autistic people without intellectual disability, 66 per cent reported suicidal ideation and 35 per cent reported suicide plans or attempts—about five times higher than the general population.

This may reflect the high rate of co-occurring psychiatric conditions among autistic people, with between 69–79 per cent of autistic people experiencing at least one mental health condition during their life.

The committee heard that depression, anxiety disorders and/or obsessive-compulsive disorder are the most common mental health conditions experienced by autistic people, with anxiety and depressive disorders particularly common among autistic females and males at higher risk of suicide. Autistic mothers are also at a higher risk of experiencing pre- and post-natal depression than non-autistic mothers.

Stakeholders also observed that autistic people who identify as LGBTQ+ are also more likely to experience mental health issues than the heteronormative population. It was suggested that the issues experienced by this group were magnified by the intersection of autism, mental health, gender and sexual identity.

However, participants also stressed that mental health problems are not inevitable for autistic people and instead can be the result of, or made worse by, discrimination and isolation. As an example, some submitters pointed to the mental health impacts of using masking behaviours in order to 'blend in'.



Furthermore, the Senate Inquiry Report *Services, support and life outcomes for autistic Australians*, noted that autistic people face a number of challenges when trying to access mainstream health care services.

These include:

- difficulties navigating a complex service environment;
- a lack of autism knowledge and understanding;
- diagnostic overshadowing and co-occurring conditions; and
- a lack of autism-friendly health care environments.

Multiple submitters argued that health care settings must improve accessibility for autistic people. Suggested actions included:

- introducing autism-friendly universal design principles across major health infrastructure, including quiet, low-sensory emergency departments, waiting and treatment rooms in public hospitals;
- implementing longer consultation times and reduced wait times for autistic people (expedited triage of care);
- giving patients the option to make appointments online, and providing training for health professionals on how to adjust their communication to meet the needs of their autistic patients;
- encouraging broader uptake of existing initiatives to reduce communication barriers, such as the care passports and communication boards;
- adapting measures that are in place to improve health care responsiveness for other cohorts (for example, actions to address cultural needs include alternative signage and modified clinic times and locations);
- adapting autism-specific initiatives from other sectors for use in health care settings (for example, Coles 'quiet hour'); and
- funding further research into how to improve the accessibility of health care services for autistic people.

Many of these suggestions for increased health care accessibility could extend to reforms to community mental health services.

## Autism and Suicide

**7 x**

Autistic people overall are 7 times more likely to die by suicide than non-autistic people.<sup>1</sup>

**13 x**

Autistic women are 13 times more likely to die by suicide than non-autistic women.<sup>1</sup>

**28 x**

Autistic children are 28 times more likely to contemplate or attempt suicide compared to non-autistic children.<sup>1</sup>

**75%**

75% of autistic adults have at least one mental health diagnosis.<sup>2,3</sup>

**66%**

Furthermore, 66% of autistic people report lifetime suicide ideation, plan, or attempt.<sup>4</sup>

Autistic people are also more than 3 times more at risk of self-harm.<sup>4</sup>

- 1 [https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/workshops-\(wave-4\)/wave-4-workshop-2/suicide-and-autism---slides.pdf?sfvrsn=bf3e0113\\_2&fbclid=IwAR1\\_5yquHnFDzLdUB8Pw4TaAi4HASFo\\_7XAberpOVaoDkqUw5ONlxlv64XU](https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/workshops-(wave-4)/wave-4-workshop-2/suicide-and-autism---slides.pdf?sfvrsn=bf3e0113_2&fbclid=IwAR1_5yquHnFDzLdUB8Pw4TaAi4HASFo_7XAberpOVaoDkqUw5ONlxlv64XU)
- 2 [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Autism/autism/Report/section?id=committees%2Freportsen%2F024412%2F77833&fbclid=IwAR3TviDuy0UxL\\_pGX-mY2lnUHFlz\\_79NkxOPc4F-QzC\\_pZyo7Q9SFurYQg](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Report/section?id=committees%2Freportsen%2F024412%2F77833&fbclid=IwAR3TviDuy0UxL_pGX-mY2lnUHFlz_79NkxOPc4F-QzC_pZyo7Q9SFurYQg)
- 3 [https://journals.sagepub.com/doi/full/10.1177/13623613211067928?fbclid=IwAR1x1\\_12MMnDfwiHOMnEQqGJyDWhilqLiOYA7nbMx6OA88aDQgGduUX2Ss](https://journals.sagepub.com/doi/full/10.1177/13623613211067928?fbclid=IwAR1x1_12MMnDfwiHOMnEQqGJyDWhilqLiOYA7nbMx6OA88aDQgGduUX2Ss)
- 4 <https://www.nationalelfservice.net/learning-disabilities/autistic-spectrum-disorder/self-harm-autism-higher-risk/?fbclid=IwAR2LbCfEV-boNTf3f4Q8EUPfej91mW6ydK8FU2ArUJr5TJg6mQN35sPCYA>

These statistics were gathered by Eating Disorders Neurodiversity Australia and originally posted on social media in 2022.



### **Autistic Mental Health and Medicare**

Currently in Australia, the Better Access initiative provides Medicare benefits for mental health services provided by GPs, other medical practitioners, psychologists, social workers and occupational therapists.

The current structure of the Medicare benefits does not enable health care providers to support the health needs of Autistic people with more complex health needs.

What hope does our community mental health care have to provide for this?

Access to health is a fundamental human right. Our mainstream community and outpatient mental health supports should be accessible for people with disability.

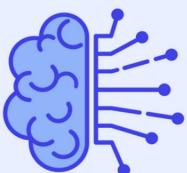
The apparent inability of mental health services to address the needs of Autistic people with mental health conditions is particularly concerning given autistic people's vulnerability to suicide.

### **NDIS and Mental Health**

As an NDIS participant and a consultant who helps NDIS providers and participants access and understand the complex scheme, I see the very real disconnect in services and the separation of disability and mental health.

The NDIS doesn't support Autistic people with mental health challenges, which the NDIA view as a medicare and health responsibility. However, being a disabled person with mental health challenges means we have specific access needs that are not met or even considered by mainstream mental health system that is made for non-disabled people without access needs.

Community mental health care services should connect with NDIS supports and ensure this vulnerable, disproportionately affected population has adequate, equitable, accessible support.



In May, I spoke at the National Suicide Prevention Conference about the risk of Autistic Suicide.



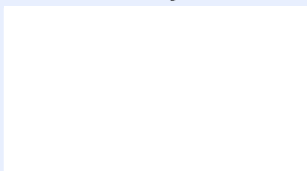
As a multiple disabled neurodivergent woman who has personally experienced suicidality and poor mental health in the past, I now spend all my time ensuring my community do not need to live this way. This topic is close to my heart.

I have a neurodivergent husband and son, and come from a multigenerational neurodivergent family and a strong line of military service - which intersects with suicide prevention (in the veteran community).

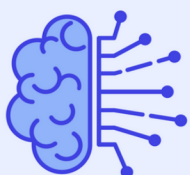
I want my son so grow up in a world where he can find adequate mental health support services, and I want NSW to lead the way. The Victorian Government continues to move faster than all other States and Territories in disability and mental health policy and practice. Let's change this and ensure that this inquiry isn't just including LGBTQ+, CALD, Remote/Regional/Rural communities, but also the disability and neurodivergent community.

I am available to speak to the committee and provide more examples (and possible solutions) of what I see in our community, including my many disabled, neurodivergent clients who deserve to have their basic human rights met with accessible mental health care.

Sincerely,



**Annie Crowe**





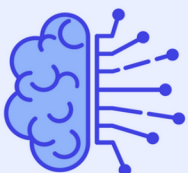
## References and Recommended Reading

### Autism Senate Inquiry

- [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Autism/autism/Report](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Report)

### Other helpful resources on neurodivergent mental health

- Supporting Autistic Girls and Gender Diverse Youth  
<https://yellowladybugs.myshopify.com/products/supporting-autistic-girls-and-gender-diverse-youth>
- Supporting the Mental Health of Autistic Girls and Gender Diverse Young People
  - Hard copy: <https://yellowladybugs.myshopify.com/products/hard-copy-resource-supporting-the-mental-health-of-autistic-girls-and-gender-diverse-young-people>
  - Digital version: <https://yellowladybugs.com.au/Document?documentId=2>
- Guidelines for Selecting a Neurodiversity-affirming Mental Healthcare Provider
  - <https://reframingautism.org.au/guidelines-for-selecting-a-neurodiversity-affirming-mental-healthcare-provider/>
- EDNA and NEDC Report on Eating Disorders and Neurodivergence
  - <https://nedc.com.au/eating-disorders/types/neurodivergence/>
- Autism Alliance Australia
  - <https://australianautismalliance.org.au/wp-content/uploads/2020/09/comprehensive-submission-Australian-Autism-Alliance-Senate-Inquiry-into-Autism-Aug-2020.pdf>
- Amaze
  - <https://www.amaze.org.au/about-autism/mental-health/>
- Aspect
  - <https://www.autismspectrum.org.au/uploads/documents/Fact%20Sheets/Aspect-Research-mental-health-wellbeing.pdf>
- National Autistic Society UK
  - <https://www.autism.org.uk/advice-and-guidance/topics/mental-health>



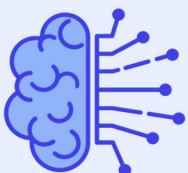
## Recommended Reading

### Other helpful resources on neurodivergent mental health (cont)

- Double Empathy
  - <https://reframingautism.org.au/miltons-double-empathy-problem-a-summary-for-non-academics/>
- Supporting mental health: What young Australian autistic adults tell us
  - [https://www.autismcrc.com.au/sites/default/files/resources/SASLA\\_Supporting-mental-health\\_Resource.pdf](https://www.autismcrc.com.au/sites/default/files/resources/SASLA_Supporting-mental-health_Resource.pdf)

### Autism and Suicide

- Role of poor mental health support in autism and suicide
  - <https://www.ncl.ac.uk/press/articles/latest/2022/04/conversationautismsuicide/>
- COVID-19, social isolation and the mental health of autistic people and their families
  - [https://www.researchgate.net/publication/353763608\\_COVID-19\\_social\\_isolation\\_and\\_the\\_mental\\_health\\_of\\_autistic\\_people\\_and\\_their\\_families\\_A\\_qualitative\\_study](https://www.researchgate.net/publication/353763608_COVID-19_social_isolation_and_the_mental_health_of_autistic_people_and_their_families_A_qualitative_study)
- Study reveals high rate of possible undiagnosed autism in people who died by suicide
  - <https://www.cam.ac.uk/research/news/study-reveals-high-rate-of-possible-undiagnosed-autism-in-people-who-died-by-suicide>
- Autism and Suicide: A National Crisis (UK)
  - [https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/workshops-\(wave-4\)/wave-4-workshop-2/suicide-and-autism---slides.pdf?sfvrsn=bf3e0113\\_2](https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/suicide-prevention/workshops-(wave-4)/wave-4-workshop-2/suicide-and-autism---slides.pdf?sfvrsn=bf3e0113_2)



## Recommended Reading

### Autistic people and CBT (Cognitive Behaviour Therapy)

- Why Doesn't Standard Talking Therapy Work for Autistic People?
  - <https://www.dralicenicholls.com/why-doesnt-standard-talking-therapy-work-for-autistic-people/>
- Cognitive behavioral therapy may be only mildly effective for anxious, autistic children
  - <https://www.spectrumnews.org/news/cognitive-behavioral-therapy-may-be-only-mildly-effective-for-anxious-autistic-children/>
- Creating Autistic Suffering: Neuronormativity in mental health treatment
  - <https://emergentdivergence.com/2022/01/02/creating-autistic-suffering-neuronormativity-in-mental-health-treatment/>

### Books

- Autistic Masking by Amy Pearson and Kieran Rose
- Can't Not Won't by Eliza Fricker
- Trauma, Stigma, and Autism by Gordon Gates
- The Guide to Good Mental Health on the Autism Spectrum by Yenn Purkis and Emma Goodall

### Podcasts

- Princess and the Pea Podcast with Annie Crowe
- The Neurodivergent Woman
- The Neurodiversity Podcast
- Woman & ADHD
- Neurospiced by Eating Disorders Neurodiversity Australia

