



## Annie Crowe

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

#### **Supplementary Questions**

**Dear Committee Chair,**

We 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 and for the opportunity to present at a public hearing.

Please find our response to the supplementary questions below.

#### **Question 1: Is there a centralised pathway that is integrated with both State and federally funded services that enables people to access the care they need at the time they want it?**

We are not aware of a centralised pathway that is integrated with both State and federally funded services.

Furthermore, there is much confusion among consumers and services providers as to what funding or systems can be used to support the mental health of people with disability, and more specifically neurodivergent people.

Currently, the main pathways are:

1. NSW Emergency departments, which are only for crisis care and often do not have appropriate follow up or referral pathways; and
2. General Practitioners, which can complete a Mental Health Care Plan that allows for medicare subsidised psychology.

The National Disability Insurance Scheme (NDIS) supports some people with psychosocial disability, although this is being phased out in the next two years. One third of NDIS participants are Autistic, and need mental health support.

NDIS is clear that it only supports disability and that mental health is a Department of Health and Medicare problem.

However, the separation of disability and mental health is not so simple. People with a disability need accessible mental health care that is more specific than what would support the general population.

We would like to see more of a collaborative and flexible approach to funding for mental health care for people with a disability, especially the Autistic community who are far more likely to need mental health supports (75% of autistic adults have at least one mental health diagnosis). This would require more collaboration between NSW State and Federal Government, especially connecting NDIS participants with mainstream mental health care that acknowledges and fully supports extra accessibility needs.

We would also recommend more State funding towards disability, neurodivergence and Autistic-led organisations and peer-networks. Including supporting lived experience education to services providers and carers in order to ensure the needs of these vulnerable groups are prioritised over often misguided and inappropriate research which does not prioritise lived experience.

Finally, we recommend all NSW Emergency departments have a sensory safe room for Autistic patients presenting in a mental health crisis. Additionally, all ambulance and police personnel should be trained in co-regulation and deescalation specifically for neurodivergent people to reduce trauma, harm and incidents that result from a lack of understanding and accessibility.

## **Question 2: How would the people you represent e.g consumers and mental health carers describe their ability to navigate the system and its varied pathways to service access?**

The people NeuroAccess represent consumers who are neurodivergent, disabled Australians and their families. This group would describe their ability to navigate the system and its varied pathways to service access as painful, complicated and almost impossible.

Between managing disability support needs and accessing the education system and workforce, which are both highly inaccessible to Autistic people, our community has little resources (emotional, energy and financial) left to navigate a complex health system that rarely considers or acknowledges their access needs, let alone meets those needs.

Often our community reach out to other families and friends who understand Autistic and neurodivergent lived experience to find out how they have navigated the system and pathways to service access.

They also often rely on allied health professionals, who many see as a part of disability support, for advice and guidance to navigate the system.

The lack of clarity and collaborative systems at both the State and federal level often leaves our community of consumers feeling lost and hopeless when seeking mental health care services.

Additionally, many Autistic and neurodivergent consumers do not reach out for help due to the highly inaccessible systems that do not provide any reasonable adjustments for them. This is a major contributing factor to the suicide rates of Autistic people.

Autistic people overall are 7 times more likely to die by suicide than non-autistic people and Autistic women are 13 time more likely to die by suicide than non-autistic women.<sup>1</sup>

<sup>1</sup> [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\\_7XAbeRpOVaoDkqUw5ONlxiv64XU](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_7XAbeRpOVaoDkqUw5ONlxiv64XU)



### **Question 3: Do any of these challenges or enablers extend to when a carer or consumer is wanting to escalate their concerns when health is deteriorating in the community?**

#### **a. Can you tell us about their experience of this?**

Our mental health system is based on reactionary care, not proactive and preventative care. Most funding is directed at upstream suicide prevention (i.e. at crisis point) and not downstream suicide prevention (i.e. proactive mental health support).

Therefore, by the time consumers ask for help it's often already too late for meaningful mental health support and instead focuses on crisis prevention or harm reduction.

The wait times for psychological and psychiatric treatment are so substantial that many consumers either deteriorate to the point of needing crisis management or turn to unsafe self-medication practices (i.e. substance abuse, eating disorders, etc.).

The best help Autistic consumers and their carers find when seeking mental health support in the community is finding professionals and services that understand neurodivergence and the nuances that supporting Autistic people in distress need. This often looks like co-regulation and understanding that things that distress Autistic people often do not impact the non-Autistic (or Allistic) population. These stressors can be as simple as bright lights and loud noises or as complex and communication misunderstandings due to a disconnect in language, tone, expression and other reasons why there are barriers to Autistic to Allistic communication (see Double Empathy Problem<sup>2</sup> for more on this barrier).

Most of the challenges come from a completely lack of awareness and understanding of Autistic access needs from healthcare providers. There is a growing number of openly Autistic mental health professionals who could help increase education and professional development for the field more broadly and save many Autistic lives.

<sup>2</sup> <https://reframingautism.org.au/miltons-double-empathy-problem-a-summary-for-non-academics/>



**Question 4: Does your organisation have a direct line of contact to the NSW Department of Health?**

**a. If so, what division/section is your direct line of contact?**

No, it does not.

**Question 5: How many people (measured as full-time equivalents) work for your organisation on either a paid or voluntary basis?**

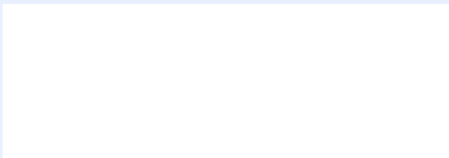
2.5 FTE. NeuroAccess is a private (sole-trader) consulting business focused on building accessibility for neurodivergent people, we are lead by Annie Crowe Human Rights Lawyer and some support staff.

**Question 6: Does your organisation receive any funding or support, in any form, from the Commonwealth Government?**

**a. If so, what was the amount in the 2021/2022 financial year?**

**b. If so, what was the amount in the 2022/2023 financial year?**

No, it does not.



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