



**Mental
Health
Council**
OF TASMANIA

www.mhct.org

Submission to the draft National Autism Strategy

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AUTHORISED BY:

Connie Digolis

Chief Executive Officer

cdigolis@mhct.org

03 6224 9222

0418 431 995

Level 6, 39 Murray Street
Hobart TAS 7000

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About Us

The [Mental Health Council of Tasmania](#) (MHCT) is the peak body representing the mental health and wellbeing needs of all Tasmanians, and the community organisations that work with and support them. We work closely with government to amplify the voices of our members and Tasmanian communities, to provide input into public policies and programs. We advocate for reform and improvement within the Tasmanian mental health system. Our purpose is to strengthen and advocate for our communities and service providers to support the mental health and wellbeing of all Tasmanians, and our vision is that every Tasmanian has access to the resources and support needed for good mental health and wellbeing.

Background

The MHCT welcomes and supports the draft National Autism Strategy. We found it confronting to learn that autistic people have a life expectancy more than 20 years shorter than the general population, are nine times more likely to die by suicide, and have a high chance of suffering from mental illness.

We know from the peak independent body [Autism Tasmania](#) that autism touches the lives of many Tasmanians. An estimated 2-3 percent of Tasmanians are autistic (11,400 –17,100 people). Nearly every Tasmanian knows someone who is autistic, and around one in four people have an immediate or extended family member who is autistic.¹

MHCT welcomes the draft National Autism Strategy's framework of improving life outcomes for autistic people and their families by focusing on social and economic inclusion; diagnosis, services and support; and health and mental health. We also support the actions being developed through the National Roadmap to Improve the Health and Mental Health of Autistic People.

Summary of MHCT's recommendations in this submission

1. The National Strategy and the National Roadmap should consider current data highlighting the prevalence of mental illness among people with autism. This will focus attention on the complex treatment needs of this community.
2. People with comorbid conditions should be included in formulating the National Roadmap.
3. Autism has varying levels of impact on families and carers. The National Roadmap should try to fill a gap in the existing research on interventions that can support caregivers.
4. The Department of Social Services should lead a campaign to raise public awareness of the National Strategy, so it is not overshadowed by the NDIS Review and impending state and federal responses to the recommendations from the Disability Royal Commission.
5. The National Strategy and National Roadmap must strive to make autism diagnosis and treatment accessible and affordable in rural and regional Australia. Public waitlists in Tasmania exceeded 18 months in 2021-22 for children needing an autism assessment and diagnosis.¹
6. The National Roadmap will need a strong plan to address workforce shortages and skills, especially in rural and regional Australia.
7. The National Strategy and National Roadmap should reference the Australian Child Maltreatment Study from 2023 given that recent public inquiries have shown increased rates of abuse in children with disability.

Comorbidity

MHCT recommends a clear focus on the high rates of mental illness among people with autism in the National Strategy and the National Roadmap (noting that autism is a developmental condition, not a mental illness). A U.S. study from 2008 for example showed 70 percent of children aged 10-14 had at least one comorbid disorder and 41 percent had two or more.² Advocacy group Amaze Australia says current evidence shows 50–80 percent of autistic people experience mental health conditions.³ Aspect, Australia’s largest service provider for people with autism, says surveys show up to 46 percent of children with autism aged from 3-16 years and 70 percent of children from 10-14 have at least one mental health condition.⁴

Using the best available data on how frequently people with autism experience mental illness will help governments, the medical community, and mental health organisations understand that this cohort requires tailored treatment from a highly trained and empathic workforce.

MHCT notes the National Roadmap is being driven by the autistic and autism community and will consider key outcome areas such as best practice models of care and support to navigate the health and mental health systems. The limited draft documents we have seen don’t refer to people with autism and lived experience of mental illness as being part of the working groups.

MHCT recommends people with comorbid conditions, and their family members or friends take part because of the important insight they will bring, both in terms of living with more than one condition but also their struggle in getting treatment.

Families and carers

Autism can impact on the mental wellbeing of families and carers. Parents providing care to a child or adult with autism are at higher risk of adverse mental health outcomes such as chronic stress, depression, and anxiety.^{5 6}

A scoping review published only late last year noted there had been little research on the impact of family members caring for someone with autism. The researchers could not find a single study that showed evidence of interventions to reduce or prevent caregiver burden.⁷

Our colleagues at Mental Health Families and Friends Tasmania (MHFFTas) highlighted these strains, and others, in their submission to the Department of Social Services on the draft National Autism Strategy. They noted family and friends were unrecognised and unacknowledged in areas where they are vital to the success of the National Strategy or have their rights and needs overlooked.

“MHFFTas believe that this Strategy can set an example for other strategies at a national or state level in respecting families and friends, highlighting their rights, needs, and experiences.

Moreover, it is an opportunity for the Strategy to go one step further from just recognising families and friends, but actually implementing the supports and addressing the barriers for families and friends,” said their submission.

MHCT recommends the National Roadmap try to fill this gap for family members.

Awareness

MHCT is concerned that the draft National Strategy will be overshadowed by inevitable attention on the NDIS Review and impending state and federal responses to the 222 recommendations from the Disability Royal Commission. For example, at a recent conference on disability in Tasmania, not a single speaker referred to the draft National Autism Strategy. Given the interconnection between the draft strategy, the NDIS Review and the DRC recommendations, MHCT strongly recommends that these reforms are considered in unison to support a well-considered and integrated response to disability reform.

MHCT recommends that the Department of Social Services and other organisations conduct a campaign to raise awareness of the draft National Autism Strategy. Specific communications could help all relevant parties understand the linkages between these three major pieces of work – especially individuals and their family members. This will help reduce anxiety and confusion going forward.

Access & Affordability

The draft strategy notes that support for autistic people is provided through an often-complex mix of disability supports funded by the NDIS, non-NDIS-funded mainstream and community services and supports, as well as informal supports provided by families, carers, and other networks. The draft recognises high levels of unmet demand, and service gaps and inadequacies. The cost of services is a concern for many, as well as the lack of information and support when navigating services, including the NDIS. This lack of service integration across sectors, and poor understanding of autism in both community and professional settings, and workforce shortages, were commonly identified barriers, says the draft.

MHCT would suggest these problems are magnified in Tasmania, a state with generally poorer health outcomes and lower incomes than the rest of Australia.

The fact the NDIS doesn’t pay for an autism assessment is reflected in lengthy wait times of approximately 18 months for children under 18 to be seen by the Tasmanian Autism Diagnostic Service (TADS), the state service provider.

TADS needs a referral from a paediatrician, a specialist who is difficult to book in public settings

in Tasmania. Paying \$2,000-\$3,000 for a private assessment is beyond the reach of many Tasmanians.

[In its submission](#) to the Department of Social Services, Autism Tasmania stressed the need to reduce public waiting lists to no more than three months for children needing autism assessment and diagnosis. It also suggested attention be paid to the supports and tools offered to carers and families awaiting a result.

MHCT strongly believes no child (or their family) should be penalised from getting an early diagnosis and treatment because of the cost of an assessment. This becomes an even bigger financial burden when families have more than one child with autism.

As such, MHCT recommends the National Strategy and National Roadmap puts a priority on making assessments more accessible and affordable in rural and regional areas such as Tasmania.

Ongoing treatment is another issue.

[An MHCT survey](#) of 450 people last year showed 92 percent of respondents faced barriers to accessing mental health services for themselves or a person they support. The top four barriers related to cost or availability. Nearly 60 percent of people said they delayed accessing mental health support due to cost in the last 12 months in Tasmania. And 43 percent said they, or a person they supported, had been on a waitlist for six months. Of those who waited six months or more, 80 percent were offered no interim support.⁸

Our survey did not ask specifically about people with autism or if they cared for someone with autism. But we suggest the results underscore the importance of making sure the National Autism Strategy and National Roadmap focus on the significant challenges of treatment of autism in rural and regional Australia. As Autism Tasmania notes, there is little support, outside of the NDIS, for autistic Tasmanians.

Workforce

Autism Tasmania notes myriad workforce challenges, including:

- ▶ shortages and high workforce turnover.
- ▶ little choice between service providers.
- ▶ long waitlists.
- ▶ allied health professionals leaving the public system to join private NDIS services.

- ▶ low understanding of autism among key workforces, including NDIS planners and care workers.
- ▶ long waitlists for psychology and mental health supports and lack of in-patient mental health beds.
- ▶ limited availability of paediatric psychiatrists and allied health professionals with the skills and experience to undertake assessments.
- ▶ misdiagnosis, particularly when there are intersecting mental health conditions.
- ▶ autism frequently goes undiagnosed or misdiagnosed in First Nations communities.
- ▶ inconsistency in quality of assessment, including those using on-line services.
- ▶ MHCT has also been told about an acute shortage of occupational and speech therapists in Tasmania who can work with autistic people.

Workforce shortages have impacted the public and community mental health sector in Tasmania for years. As a small snapshot, seven community member organisations told MHCT last year they were trying to fill roughly 22 FTE positions. Those roles ranged from psychologists, mental health nurses to social workers. There were more than five FTE vacant roles for psychologists alone. Some of the varied positions had been vacant for 6-12 months.

MHCT recommends the National Roadmap address workforce issues by consulting with state governments, professional bodies, and universities to ensure graduates will be available to meet demand for services in the years to come. The University of Tasmania does not offer undergraduate degrees for example in occupational or speech therapy, only a Masters in both. The National Roadmap will also need to address the challenge of recruiting and retaining skilled people in rural and remote areas such as Tasmania. This might involve training and financial incentives.

Child Maltreatment

The Disability Royal Commission highlighted that autistic people were vulnerable to abuse, neglect, and discrimination. The recent Commission of Inquiry into the Tasmanian Government's Responses to Child Sexual Abuse in Institutional Settings noted children with disability are three times more likely to experience child sexual abuse than other children and that the rates are even higher for female children and children with intellectual and behaviour-related disabilities.

MHCT recommends the draft National Autism Strategy and National Roadmap take into account the [Australian Child Maltreatment Study](#) from 2023.

This study – while it did not refer to children with autism -- showed child maltreatment was endemic in Australia. [A more recent study](#) estimated the alarming proportion of mental health

conditions caused by childhood maltreatment, which includes sexual abuse, physical violence and witnessing domestic abuse. It found 41 percent of suicide attempts, 35 percent of self-harm and 21 percent of cases of depression in Australia were caused by child maltreatment. More than 1.8 million cases of depression, anxiety and substance use disorders in Australia – almost a quarter of the total number – could be prevented if child maltreatment was eradicated, the study showed.⁹

References

- ¹Autism in Tasmania: State of the State 2023. A systems view of the array of local, state, and national programs and policies, that influence the life outcomes for Autistic Tasmanians. Autism Tasmania. <https://www.autismtas.org.au/wp-content/uploads/2023/10/StateOfTheState-V7.pdf>
- ² Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample. *Journal of the American Academy of Child & Adolescent Psychiatry*. Volume 47, Issue 8, P921-929, August 2008. [https://www.jaacap.org/article/S0890-8567\(08\)60059-3/abstract](https://www.jaacap.org/article/S0890-8567(08)60059-3/abstract)
- ³ <https://www.amaze.org.au/about-autism/mental-health/>
- ⁴ <https://www.aspect.org.au/uploads/documents/Fact%20Sheets/Aspect-Research-mental-health-wellbeing.pdf>
- ⁵ Catalano D, Holloway L, Mpofu E. Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review. *Int J Environ Res Public Health*. 2018 Feb 14; 15(2):341. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5858410/>
- ⁶ Herrema R, Garland D, Osborne M, Freeston M, Honey E, Rodgers J. Mental Wellbeing of Family Members of Autistic Adults. *J Autism Dev Disorder*. 2017 Nov; 47(11):3589-3599. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5633644/>
- ⁷ Dückert, S., Gewohn, P., König, H. et al. Multidimensional Burden on Family Caregivers of Adults with Autism Spectrum Disorder: a Scoping Review. *Rev J Autism Dev Disord* (2023). <https://link.springer.com/article/10.1007/s40489-023-00414-1>
- ⁸ Access and Affordability: Mental Health Services in Tasmania: Highlighting the experience of Tasmanians. Mental Health Council of Tasmania. 2023. <https://mhct.org/wp-content/uploads/2023/07/MHCT-Access-and-Affordability-Report-2.pdf>
- ⁹ Grummitt L, Baldwin J, Lafoa’l J. Burden of Mental Disorders and Suicide Attributable to Childhood Maltreatment. The Matilda Centre for Research in Mental Health and Substance Use, The University of Sydney, Sydney. *JAMA Psychiatry*. May 2024. <https://jamanetwork.com/journals/jamapsychiatry/article-abstract/2818229>