

30 October 2023

Department of Social Services
GPO Box 9820
Canberra ACT 2601

Submission online via Department of Social Services website

Re: headspace National submission – National Autism Strategy

headspace National welcomes the opportunity to provide input into the development of the National Autism Strategy.

headspace is the National Youth Mental Health Foundation, providing early intervention mental health services to 12- to 25-year-olds. headspace has 154 centres across Australia in metropolitan, regional and remote areas, and provides online and phone support services through eheadspace.

Our work builds the mental health literacy of young people and reduces stigma associated with mental health and the associated barriers to seeking help. headspace can help young people with mental health, physical health (including sexual health) alcohol and other drug services, and work and study support. Our work also involves supporting schools and their communities with expert advice and guidance on how to support their communities following major events. At the heart of all our services are young people, their needs and the needs of those who support them.

Our submission focuses on providing mental health prevention and early intervention services for autistic young people, as part of key theme 4 of the National Autism Strategy – specifically the National Roadmap to Improve the Health and Mental Health of Autistic People.

Many autistic young people experience mental health challenges and mental ill health. Responding effectively to these needs requires accessible services that provide neurodiversity-affirming care that is tailored to the needs of each autistic young person. Our submission highlights that it is important that the National Autism Strategy includes a focus on improving the capacity of the youth mental health system to meet the needs of autistic young people.

The Strategy (along with the National Roadmap) need to identify and support ways to ensure autistic young people have access to timely, inclusive and effective mental health services. This requires:

- **additional capacity to provide integrated, holistic mental health services to autistic young people** – sustainable, long-term investment is required to ensure the system has the capacity to meet the needs of autistic young people, from primary through to tertiary level services
- **building and supporting the workforce** – to have the skills and confidence to deliver accessible and effective mental health interventions to autistic young people, with adaptations that cater for their cognitive, communication, social and sensory needs
- **accessible services that incorporate lived experience perspectives** – autistic young people need to feel that they are visible, heard and understood when accessing services.

headspace National would welcome the opportunity to discuss any aspects of our submission further. I look forward to the development of the strategy.

Yours faithfully



Jason Trethowan
Chief Executive Officer

headspace National submission: National Autism Strategy

Introduction

headspace National welcomes the opportunity to contribute to the development of the National Autism Strategy.

Our submission notes the importance of access to affordable assessment, diagnosis and post-diagnosis support, then focuses on key theme 4 of the National Autism Strategy – specifically the National Roadmap to Improve the Health and Mental Health of Autistic People. In particular, we consider the strategies and approaches required to better support mental health outcomes for autistic young people.

In preparing this submission, we consulted with:

- members of the headspace Youth National Reference Group (hY NRG)
- members of the headspace National Family Reference Group (FRG)
- experienced clinical professionals from across the headspace network.

Our submission highlights approaches and investment needed under the National Autism Strategy, to improve mental health prevention and early intervention for autistic young people.

Access to affordable assessment, diagnosis and post-diagnosis support

Key takeaways

- Many young people continue to experience barriers to assessment and diagnosis services.
- Post-diagnosis services are critical to support autistic young people, but system capacity is low.

The rate of autism diagnoses have increased in Australia in recent decades.¹ This can be attributed to a range of factors, including improved approaches to diagnosis, and better awareness and understanding of autism in the community.² 'Diagnostic substitution', where changes to diagnosis standards and practices mean an individual is now diagnosed with autism rather than a mental health disorder, may also contribute to the increase.³

Autism assessments may need to be considered when working with young people experiencing poor mental health. Members of the hY NRG and FRG noted that traits of autism can overlap with symptoms of poor mental health, making it difficult to distinguish between mental ill health and different ways of experiencing the world. A member of the hY NRG group highlighted the importance of considering autism when working with young people with anxiety, depression and disordered eating (including conditions such as avoidant/restrictive food intake disorder):

Since the underrepresented phenotype of autism seen in females is covered by anxiety, depression and eating disorders, many young female autistics get overlooked for a diagnosis or misdiagnosed because of these.

¹ Australian Institute of Health and Welfare. (2017) Autism in Australia. www.aihw.gov.au/reports/disability/autism-in-australia/contents/autism, accessed 12 October 2023.

² Goodwin, C. (2023) Why autism rates are rising. Psychology Today, www.psychologytoday.com/au/blog/parenting-translator/202305/why-autism-rates-are-rising, accessed 12 October 2023.

³ King, M. & Bearman, P. (2008). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology*, 38(5): 1224 – 1234.

For a lot of autistic people, our traits are anxiety or eating disorders or depression. We get misdiagnosed; it can come from a lack of education.

However, young people continue to face barriers in accessing autism assessment and diagnosis services. These barriers include limited numbers of clinicians who can provide assessments, and limited public or low-cost assessments. Many low-cost services have long wait times, which in turn places greater burden on young people and their families.

Members of the hY NRG and FRG highlighted the importance of access to affordable diagnoses and follow-up support:

Low-cost psychiatrists. Low-cost medications. Increased accessibility to supports, like psychiatrists, to get diagnosis, medications, supports, whatever the individual needs.

[We need] free or heavily subsidised diagnosis for people of all ages. Easier to access support in navigating getting services like the NDIS.

In particular, 'girls' go under the radar in regards (sic) to diagnosis and they are seen as 'quiet' or 'shy' which societally is 'normal' and accepted or even promoted. There is correlation between this lack of diagnosis and validation and poor or deteriorating mental health.

Post-diagnosis services are also critical – and system capacity is low. Autistic young people and their families can find it difficult to navigate the system and to access appropriate and adequate support services, particularly when experiencing mental ill health.

Autism, mental health and risk of suicide

Key takeaways

- Autistic young people are more likely to experience co-occurring mental ill health, compared to young people who do not have autism.
- In addition, autistic young people are at higher risk of suicide, with studies showing autistic young people can be seven times more likely to attempt suicide.
- Siblings of autistic young people are also at higher risk of mental ill health and suicide.

Many young people experience anxiety, depression or other mental health issues or conditions. Autistic young people are even more likely to experience co-occurring mental ill health – particularly anxiety and depression.

One recent Australian study found almost one third of autistic young people met the clinical cut-off for both anxiety and depression disorders.⁴ Research shows autistic young people are also at higher risk of developing other disorders, including bipolar and mood disorders, schizophrenia, and disruptive, impulse-control and conduct disorders.⁵ In addition, autistic young people are likely to have high rates of other neurodevelopmental differences such as attention/hyperactivity, language and learning differences.

Autistic young people are also at higher risk of suicide. In a large study in Sweden, researchers reviewed the medical records of a group of 54,000 autistic people, comparing these to 271,000 people who do not have autism.⁶ The study found higher levels of suicide attempts and death by

⁴ Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I, Cai, R. Y., Dissanayake, C., Richdale, A.L., Trollor, J. (2020). Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(9), 3155-3165.

⁵ Hassain, MM., Khan, N., Sultana, A., Ma, P., et al. (2020). Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. *Psychiatric Research*, 287, article 112922.

⁶ Hirvikoski, T., Boman, M., Chen, Q., D'Onofrio, B.M., et al. (2020). Individual risk and familial liability for suicide attempt and suicide in autism: a population based study, *Psychological Medicine*, 50(9), pp. 1463-1474.

suicide among autistic people. In particular, one in ten autistic people with ADHD (but not intellectual disability) had attempted suicide, a rate seven times higher than people who did not have autism. Other studies, while not looking at such a large group of people, have also found a higher risk of suicide attempts in people with autism.⁷ Researchers also looked at autism and autistic traits in people who died by suicide in England, and found 10% likely had undiagnosed autism.⁸

Many factors impact on autistic young people's mental health. Experiences of stigma, discrimination and marginalisation can lead to increased psychological distress and poorer mental health. Many autistic young people will mask or camouflage to fit in with others around them, or to sub-consciously respond to the threat of discrimination or harm. Masking is also associated with mental ill health and increased risk of suicide (independently of mental ill health).⁹

A young person's identity as autistic overlaps with other aspects of their identity – including gender, and sexual orientation. A young person may be both neuro- and gender-diverse, and this can amplify or intensify mental health challenges.¹⁰ Gender identity and sexuality are more varied among autistic young people compared to people who are not autistic.¹¹ While these relationships are not well understood, the intersection of these identities can present a cumulative risk of both mental ill health and suicide for gender diverse autistic people.¹²

Mental ill health among siblings of autistic young people

Many studies have found that siblings of an autistic young person are at higher risk of mental ill health and suicide.¹³

In addition, as highlighted by members of members of hY NRG and FRG, family members may also be neurodivergent, often without diagnosis due to stigma, lack of knowledge or inability to access assessment services:

Listening, supporting and understanding the family's perspective and helping them to improve their own support [needs to improve].

Families around an individual who have a diagnosis may also have those types of traits, but they just go without the support. They may not admit they have the same issues.

The support system around autistic young people is likely to be autistic, both diagnosed and undiagnosed. Especially parents and other support people that are older in age, are unlikely to be diagnosed ... This is important to consider, because it means the people supporting them may have their own struggles, and also, may struggle to recognise these struggles, as well as struggle to navigate systems and get help for their young people.

⁷ Newell, V., Phillips, L., Jones, C., Townsend, E., et al. (2023). A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. *Molecular Autism*, 14: 12.

⁸ Cassidy, S., Au-Yeung, Sh., Robertson, A., Cogger-Ward, H., et al. (2022). Autism and autistic traits in those who died by suicide in England. *British Journal of Psychiatry*, 221(5).

⁹ Women With Disability Australia. (2023). *The experiences of Autistic women and girls*. Written by Sophie Cusworth, Senior Policy Officer, Women With Disabilities Australia (WWDA): Hobart, Tasmania.

¹⁰ George, R. & Stokes, M.A. (2018). A quantitative analysis of mental health among sexual and gender minority groups in ASD. *Journal of Autism Development Disorder*, 48(6): 2052-2063.

¹¹ Ibid.

¹² Women With Disability Australia. (2023). *The experiences of Autistic women and girls*. Written by Sophie Cusworth, Senior Policy Officer, Women With Disabilities Australia (WWDA): Hobart, Tasmania.

¹³ Jokiranta-Olkonieni, E., Cheslack-Postava, K., Sucksdorff, D. et al. (2016). Risk of psychiatric and neurodevelopmental disorders among siblings of probands with autism spectrum disorders, *Journal of American Medical Association*, 73(6): 622-629; Lin, H.C., Cheng, C-M., Huang, K-L, Hsu, J-W. et al. (2022). Developmental and mental health risks among siblings of patients with autism spectrum disorder: a nationwide study. *European Child & Adolescent Psychiatry*, 31: 1361-1366.

headspace mental health prevention and early intervention services for autistic young people

Key takeaways

- headspace seeks to provide inclusive, accessible and neuroaffirmative mental health care for autistic young people, offering supports when and how each young person wants them.
- Autistic young people value headspace's integrated, holistic approach across mental health, physical health, work and study and alcohol and other drugs services.

At headspace, our goal is to provide a space where all young people aged 12 – 25 years can access mental health, health, drug and alcohol and vocational supports – whether this be a physical space, in a centre, or virtually, via phone or internet. This includes autistic young people and those who suspect they may have autism, who may be experiencing poor mental health related to loneliness, social exclusion, experiences of bullying, and other challenges young people experience.

As a mental health prevention and early intervention service, headspace aims to provide autistic young people with access to a range of free or low-cost mental health supports. This includes opportunities for social connection and acceptance. For example, many headspace centres run Dungeons and Dragons social groups, both in person and online, providing an inclusive space for autistic young people. headspace's Online Communities also provide accessible and inclusive social opportunities.

Autistic young people can also be referred to GPs, psychiatrists or other health care professionals for vocational support (via Work and Study) or drug and alcohol counselling. This integrated, holistic approach to care is highly valuable to autistic young people.

In 2022-23, 1,717 young people accessing headspace centres had an autism diagnosis (recorded as either a primary or a secondary diagnosis).¹⁴ Among this cohort of young people:

- 42% identified as female, 46% identified as male and 12% identified as gender diverse
- 66% were aged 12 to 17 years, and 34% were aged 18 to 25 years.¹⁵

This data is likely to be an underrepresentation of the number of autistic young people accessing headspace services for to support their mental health, as it does not include four groups of young people:

- young people who identify as autistic but do not have a formal diagnosis
- young people who have an autism diagnosis but did not disclose this to headspace
- young people who may have autistic characteristics but have not sought or considered a diagnosis
- young people who accessed headspace's online programs, such as eheadspace (where diagnoses are not recorded).

At headspace, our goal is to ensure young people can access the right supports, when they need them and how they want them. headspace aims to provide inclusive and accessible neuroaffirmative mental health care for young people, where autistic young people feel welcome, accepted and validated and can access care that meets their individual needs.

At headspace, we are working to improve accessibility and build capacity to provide neurodiversity-affirming care for autistic young people. In particular, we are ensuring all headspace staff have

¹⁴ headspace National (2023). Unpublished service data.

¹⁵ headspace National (2023). Unpublished service data.

access to contemporary training and professional development on neurodiversity and providing mental health early intervention to autistic young people.

While many autistic young people access headspace services, our network also experiences challenges when supporting autistic young people. Our responses below provide insight into these challenges and offer potential solutions.

Challenges for young autistic people in accessing mental health care and treatment

Key takeaways

- Separate disability and mental health systems make it difficult to navigate services and access the care and support autistic young people need, increasing the risk young people ‘fall through the gaps’.
- How well mental health services provide accommodations and adaptations that cater for the cognitive, communication, social and sensory differences for autistic young people varies.
- When autistic young people access mental health services, they can find their needs are overlooked due to stigma, discrimination or the clinician assuming that their symptoms are due to autism, not poor mental health.

The risk of poor mental health among autistic young people makes mental health prevention and early intervention incredibly important. While there have been improvements in recent years (such as more mental health clinicians talking about neurodiversity), many autistic young people struggle to find the support they need to manage and improve their mental health.

It can be difficult for autistic young people to access any care, and what is available can be costly, have long wait times and vary by location (by state and by region). Key issues include:

- **stigma and ‘over-shadowing’ can mean mental health needs are overlooked** – despite high rates of mental ill health among autistic people, many mental health services will attribute the challenges faced by autistic young people to disability, rather than poor mental health.

This can be due to stigma and a lack of awareness of the needs of autistic young people. ‘Overshadowing’ can also contribute, where a health care worker attributes symptoms to autism rather than a co-occurring mental health challenge. For example, clinicians may assume symptoms of depression are due to challenges with social interactions, or anxiety is assumed to be emotional lability.

This can mean that autistic young people are turned away from services and not offered supports that may improve their mental health.

- **lack of accessible care that is appropriately tailored to the needs of the autistic young person** – there is variation in how well services (and staff) can provide accommodations and adaptations that cater for the cognitive, communication, social and sensory differences of each autistic young person.

This can include a lack of adaptations to the physical space (for example, a lack of sensory adjustments such as noise and light levels). It can also include adaptations to mental health care – from initial engagement through to providing therapies. Choice of therapeutic approaches can be important, and increased use of structure and visual augmentation, increased parent involvement, using concrete examples, and other adaptations can be helpful.

Members of the hY NRG and FRG highlighted the importance of therapeutic approaches that are adapted to the needs and preferences of the individual, in a way that feels right to them. For example, one person may find using checklists in a therapeutic session helpful, others will find it ‘babyish’. It also includes being age-appropriate:

There is a large amount of infantilisation when seeking help – particularly experiences with speech therapists and OTs. This is really hurtful and can be harmful particularly to someone's mental health.

Clinicians really need to have better education on neurodiversity. How you support a young person with autism or ADHD can be very different. And if you don't know what you are doing, it can be so harmful.

- **lack of research on adapting mental health therapies for autistic young people** – while autistic people view adaptations as important, much of the research is focused on tailoring cognitive behavioural therapies. More research on other therapies, and lead by autistic researchers is needed. This also needs to consider intersectionality with cultural, gender, and sexual diversity. As a member of hY NRG noted:

I think we are starting to identify less visible groups such as gender diverse, women, people of colour, but we definitely need to do so much better.

- **lack of affordable and timely care** – cost can make it difficult to access mental health treatment services, including psychologists in private practice. Many services – including headspace – have long wait lists for accessing free or more affordable care. Timeliness for providing mental health early intervention is a long-standing issue.
- **separate systems for disability and mental health care** – in some jurisdictions governments have funded services for autism and other neurodevelopmental differences separately to services that respond to mental ill health. This makes it difficult for autistic young people and their families to navigate the system and to access the care they need. It also means that autistic young people 'fall through the gap' between a disability system that doesn't fund mental health supports, and mental health services that are poorly equipped to respond to the needs of autistic young people.

Improving early intervention mental health services for autistic young people

Key takeaways

- Autistic young people need mental health prevention and early intervention services that are accessible, integrated and provide neurodiversity-affirmative care.
- To achieve this, greater investment is required in:
 - system capacity to meet the needs of young people, including sustainable, long-term funding to meet the need for more complex mental health care
 - supporting the workforce to build capability, capability and confidence to adapt services to the communication, cognitive, social and sensory needs of autistic young people
 - improved representation of autistic young people in system design, service delivery and research on autism and mental health
 - addressing stigma and discrimination, by building community understanding of neurodiversity, and providing accurate and accessible information.

To better support and improve outcomes for autistic young people, change is required across the youth mental health system. Autistic young people need mental health early interventions that provide mental health care and autism-related supports in an accessible, coordinated, integrated approach. In developing and delivering mental health early intervention, services need to amplify the voice of autistic young people, and their experiences of mental ill health and accessing services.

Members of hY NRG and the FRG described a mental health system that provides appropriate care for autistic young people:

Minimal wait times.

Genuine caring for people as human beings. When it comes to being on the spectrum it needs to be considered that we mainly are seeing the world beyond the systems that have been created for us, a space where we navigate as human beings and not as robots within the system. For example: not having to always speak; not being judged for differences in moods, opinion, likes, dislikes, needs; being able to walk freely; being able to eat and use the toilet whenever we need; not being offended by straight forward comments and remarks; no judgements on fidgets and note taking.

Open hours other than standard 9 to 5.

It would be inclusive of us all, including families, and would have lived experience involved in all facets of the service provided.

Ability to provide access to other areas, whether through the centre or good handover and referral to other agencies.

The Department should consider including the following areas for change in the National Autism Strategy.

Increased capacity across the system

Connected, sustainable and long-term investment is required to build capacity across the youth mental health system to provide multi-disciplinary, integrated care for autistic young people. As a member of the headspace Family Reference Group noted:

[We need] wrap around care that is well educated on neurodiversity. GPs, specialists, psychiatrists, social workers, psychologists, receptionists etc.

This investment is required to:

- **increase capacity of mental health services for autistic young people** – additional capacity is required across the system, in both primary care services (providing prevention and early intervention) through to tertiary services for autistic young people with more complex or significant needs.

While the lack of capacity also impacts non-autistic young people, it has disproportionate negative impact on autistic young people given the high proportion experiencing mental ill health. Even where primary care services are available, there are often insufficient specialist services to refer individuals with more complex needs.

- **ensure access to integrated, multi-disciplinary care** – autistic young people need access to care that provides support for their autism and mental health needs in a holistic, integrated approach.

When they have more complex mental health needs, autistic young people also need access to specialist services. This needs to be integrated with primary care services, with sustainable, long-term funding.

- **increase the number of Better Access sessions for autistic young people** – the current Medicare funding for ten sessions is not well suited to meet the mental health needs of autistic young people. Mental health interventions can take a longer period of time to be effective for this group due to their cognitive, communication, social and sensory differences. The increase to 20 rebated sessions per calendar year is better suited to many autistic people.

More broadly, access to headspace services covered under the Medicare Benefits Scheme (MBS) is diminishing, creating a risk that autistic young people go without care due to lack of access or cost.

Improved support for workforce

The youth mental health workforce needs additional support to ensure they have the awareness, capability and confidence to adapt interventions and deliver neurodiversity-affirming care and support. Across the system, government needs to provide **additional support to improve the capacity and capability of the workforce to have a better understanding of autism and adapt mental health care and therapies** for autistic young people.

Many mental health workers find themselves delivering services to autistic young people but lacking the knowledge and confidence to appropriately tailor and adapt these services. For most, their training on autism will have been minimal, and focused on autism as a disability and in childhood. It may have been included in their professional pre-entry training, or they may have attended a short workshop or training session.

While these can provide some basic information about the characteristics of autism, most undergraduate courses provide limited details about autism across the lifespan, co-occurring mental ill health, and how to adapt mental health interventions most effectively. As a member of the Family Reference Group said:

Outdated education is not only not helpful, but outright harmful.

Therapists must have a strong evidence-based approach, that is also be reflective of the autistic community, not just formal research – lived experience is evidence.

More in-depth training is available in some states (for example, the Victorian Department of Health funds Mindful to deliver autism training for mental health services, under the Victorian Autism Plan). However, demand for current options is high and not all health care workers have access.

Building accessible, representative and lived-experience driven services

Autistic young people need to feel that they are visible, heard and understood when accessing mental health services. This needs to go beyond stereotypical images of autism and incorporate the traits and needs of autistic young people of diverse sexual, gender and cultural identities.

As a member of the headspace Family Reference Group noted:

We need to look at what the autistic community is saying, because there is a lot that has harmed us and continues to harm us ... If a clinician is trained in this sort of stuff it will help all their clients. Not just autistic people have sensory issues. It helps everyone.

This includes the need for:

- **accessible spaces in headspace centres and other youth services** – mental health services need additional support to ensure services have appropriate spaces to meet the cognitive, sensory, social and communication preferences of autistic young people.
- **amplifying the voice of autistic young people in system design** – headspace has a deep commitment to participation of young people, family and friends in the delivery, design and evaluation of our services. This should be replicated for all services and systems for young people.
- **further research** on different ways autism and mental ill health can look, beyond stereotypical images of autistic young people, the intersection between autism and risk of suicide, and the most effective therapeutic approaches. In particular, additional support is required for lived experience led research.

Addressing stigma, normalising neurodiversity and credible sources of information

Beyond youth mental health services, building greater awareness about neurodiversity and addressing the stigma associated with autism will help support the mental health of autistic young people and encourage services to deliver neurodiversity-affirming care.

Stigma about autism has a significant impact on autistic young people. It can stop young people from accessing mental health care – and it can mean autistic young people are turned away from mental health services.

Government should consider:

- **improving community awareness about neurodiversity** - a broader community conversation about neurodiversity will help reduce stigma, in turn encouraging youth mental health services to provide neurodiversity-affirming care and support.
- **invest in access to credible, reliable information** – this is important to support awareness of autism, to reduce stigma and to support young people and families considering assessment. This needs to:
 - adopt a neurodiversity-affirming approach, validating the experiences of autistic young people,
 - be available where young people are (e.g.: social media)
 - be accessible (e.g.: using pictures, video formats etc)
 - incorporate lived experience stories.
- **provide additional training for school staff** – school educators and allied health professionals working in schools are in important positions to recognise autistic traits in young people, and to provide support to autistic young people. It is critical that people in these roles have access to training, beyond the stereotypical portrayal of autism. As a member of hY NRG noted:

Education systems need to do a lot better. It can be traumatic for young people. Classrooms need to be inclusive.

Essentially, the education of people outside the direct autism community needs major improvements. Teachers, GPs and the like who are seen as the 'gatekeepers' to be able to get a diagnosis formally need better education and better skills to support this.

Social media is increasingly driving awareness of autism and neurodevelopmental differences. Many young people and parents learn about the symptoms and characteristics of autism via social media – and may self-identify as autistic or seek a diagnosis based on the experiences of people within online communities. Many young people find they can truly express their full identity on social media; almost half (44%) of the young people surveyed in the 2022 National Youth Mental Health Survey agreed it is easier to express their opinions online than in person.¹⁶ For the autistic and neurodivergent community, social media is a key space to find, manage and maintain social connection.

Learning about autism via social media can also lead to challenges. Young people and their families can present to GPs or other services with self-referrals and self-diagnoses. This can be difficult when there is limited low-cost services available for GPs to refer young people to for assessment and diagnosis. It can also leave a young person feeling unsupported and or invalidated if they are assessed and their self-diagnosis is not confirmed.

¹⁶ headspace National (2023). National Youth Mental Health Survey.