

8 June 2023

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Submission online via Parliament of Australia website

Re: headspace National submission – Senate Community Affairs References Committee inquiry on Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD

headspace National welcomes the opportunity to provide a response to the inquiry into barriers to consistent, timely and best practice assessment of ADHD.

headspace is the National Youth Mental Health Foundation providing early intervention mental health services to 12- to 25-year-olds. headspace has more than 155 centres across Australia in metropolitan, regional and remote areas, as well as 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.

Attached are headspace National's responses to the Terms of Reference for which headspace can offer insight.

Our responses highlight:

- the importance of improving access to services and reducing out of pocket expenses for services and medication;
- the critical role professionals within schools play in identifying young people with ADHD and the importance of ensuring clear referral pathways for them;
- the importance of education that is tailored to a variety of audiences, including GPs, clinicians, families, teachers and the broader public;
- opportunities to strengthen training for clinicians in relation to ADHD diagnosis and management; and
- the need for greater national consistency and collaboration to better support young people with ADHD.

headspace National would welcome the opportunity to discuss any aspects of our submission further and we look forward to learning of the outcomes of this inquiry.

Yours sincerely,

Jason Trethowan
Chief Executive Officer

headspace National submission

Senate Community Affairs References Committee inquiry on Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD

Introduction

headspace National welcomes the opportunity to provide input into the inquiry on barriers to consistent, timely and best practice assessment of ADHD and support services for people with ADHD.

As a neurodevelopmental condition, characterised by differences in brain and cognitive development, ADHD symptoms are often lifelong, having a lasting impact on the people who are diagnosed, as well as their families.

headspace figures show that the number of young people accessing headspace services who have been diagnosed with ADHD has increased by 45 per cent over the last three years, thus highlighting the need for adequate and appropriate supports for these young people.

In 2022, 1,858 young people accessing headspace services had a diagnosis of ADHD, recorded as either a primary or secondary diagnosis. This represents five per cent of all diagnoses recorded.^{1 2}

Of the 1,858 young people with a diagnosis of ADHD:

- 70% were aged under 18 years and 41% aged 12 to 14 years; and
- 48% were female, 46% male and 6% gender diverse.³

At headspace, our goal is to ensure young people can access the right supports, when they need them and how they want them. Consultations undertaken in developing our response to this inquiry highlight significant challenges that our headspace network is experiencing when supporting young people who access headspace services presenting with ADHD symptoms or having a confirmed diagnosis of ADHD.

Our responses below provide insight into these challenges and offer potential solutions, structured around a selection of the Terms of Reference for which we can offer our expertise and experience.

These views represent the experiences of stakeholders we consulted specifically to provide input into this response, including:

- members of the headspace Youth National Reference Group;
- members of the headspace National Family Reference Group; and
- general practitioners (GPs) and clinical professionals from across the headspace network.

¹ headspace National (2022). Unpublished service data.

² Note: 62% of young people do not have a diagnosis recorded.

³ headspace National. *ibid.*

Term of reference (a) – Adequacy of access to ADHD diagnosis.

Key takeaways

- High out-of-pocket costs and workforce shortages in clinicians are limiting access to ADHD diagnoses.
- Educators and psychologists working in schools are in important positions to recognise ADHD symptoms in young people. There are opportunities to help alleviate the challenges faced by school educators and school psychologists in supporting ADHD diagnoses.
- There are opportunities to strengthen collaboration between professionals and as young people transition between services, including establishing multidisciplinary teams, ensuring appropriate transition of care processes for paediatric patients, and involving young people with lived experience of ADHD in the design of services, policies and procedures.
- There are opportunities to build awareness of ADHD among young people, families, GPs and clinicians. Workforce upskilling should cover a broad range of areas including diagnostic and screening tools and ADHD coaching tools.
- Young people presenting to headspace services are experiencing a range of other challenges and are already experiencing difficulty accessing services.

headspace centres and service users highlight significant barriers young people are facing with access to ADHD diagnoses. These must be addressed to ensure young people are able to access the services they need to properly support their functioning and wellbeing. These barriers include:

- limited access to ADHD assessment services due to workforce shortages and high out-of-pocket costs;
- the need for increased knowledge, confidence and collaboration and transition between services;
- challenges faced by school educators and school psychologists in supporting ADHD diagnoses; and
- access challenges that exist for vulnerable young people and priority groups.

Limited access to ADHD assessment services due to workforce shortages and high out-of-pocket costs

Overwhelmingly, our headspace network stakeholders and service users reported workforce shortages and high out-of-pocket costs as major barriers to young people being able to access ADHD assessments.

GPs within the headspace network highlighted limited services in public settings and, in some cases, no guarantee a young person will be seen for an assessment, even with a referral. headspace clinicians highlighted the reluctance of government funded mental health services to assess ADHD. This results in young people experiencing wait times to access the limited numbers of clinicians (e.g., psychologists and paediatricians) who can provide assessments.

Large out of pocket fees for assessments are also cost prohibitive, with many GPs across the headspace network reporting high costs for a young person to access an initial appointment with a clinician.

“I was very surprised that neither Medicare nor our Private Health insurance covered any part of the assessment costs. I think the costs necessarily limits access for individuals and families. I was informed that my son could go on a waitlist at one of the universities to get the assessment done cheaper, but there would be a considerable time delay. We chose the private option.”

headspace National Family Reference Group member

The need for increased knowledge, confidence and collaboration between clinicians at different services and as young people transition between services

ADHD treatment is a lifelong journey and requires clinicians to conduct forward planning to ensure the transition of health services for children to adolescents, and later to adult health services, is smooth.

Transition of care processes for children in paediatric care is required to enable sharing of information that would ultimately strengthen the support provided to young people with ADHD. For example, allowing a paediatrician to provide a GP with a detailed outline of medication, dosage and other relevant information, which the GP could then use to gain permission to prescribe medication. Other clinicians would then only be required if there were issues or complications, thus easing the cost and access challenges surrounding specialist appointments.

GPs highlighted challenges with collaboration between clinicians at different services, and as young people transition between services, which are contributing to complexities of ADHD diagnoses and support. They highlighted evidence of professionals lacking cohesion and trust in working with other professionals. For example, clinicians repeating whole assessments even when an assessment had already previously been completed.

This is exacerbated by a lack of knowledge and understanding of ADHD among young people and their families. For example, some young people and families source information on ADHD through social media forums and are increasingly presenting to GPs with self-referrals and self-diagnoses. Consequently, this can place significant pressure on GPs to refer these young people to clinicians for ADHD assessments and to access stimulant medications to treat ADHD, for which a formal diagnosis is required. On the other hand, a lack of information leads to families, at times, questioning the legitimacy of ADHD diagnoses.

Capacity building among clinicians was also identified by GPs and clinical leads as a significant need to ensure they are aware of ADHD symptoms and the process for undertaking an assessment. This would ensure they consider a young person’s history, including identification of other medical and neurodevelopmental conditions which often co-occur with ADHD, as outlined in the *Australian ADHD Professionals Association’s Australian evidence-based clinical practice guideline for ADHD*.

“Despite seeing many professionals over the years, the possibility of an ADHD diagnosis only ever came up once. I did my own research and suggested it to a psychologist...My symptoms were misinterpreted as anxiety or autism...I strongly believe this is due to stereotypes, particularly as I am a woman, am naturally reserved/quiet, and I am a high achiever.”

headspace National Youth Reference Group member

“I still vividly remember my GP telling me that “most people with ADHD will never reach their full potential” when she first referred me for diagnosis”.

headspace National Youth Reference Group member

In addition, school professionals play a critical role in the early identification and support for young people with ADHD, which is further elaborated on below.

Challenges faced by school educators and school psychologists in supporting ADHD diagnoses

School educators and psychologists working in schools are in important positions to recognise ADHD symptoms in young people. These professionals in schools are identifying young people who are displaying symptoms of ADHD, however, are limited in the action they can take due to capacity constraints. They are often managing multiple and varied priorities and face complex systems challenges, such as lack of clear pathways to which they can refer young people for assessment and ongoing treatment and support.

Our headspace network stakeholders highlighted that school responses to – and support provided for – students with ADHD, vary considerably at the local level. For example, development of individual learning plans and individualised support provided to students to assist with their completion of assessment tasks, such as exams, vary depending on how actively engaged teachers and wellbeing teams are in supporting students with ADHD.

“One of the things that surprised me was nobody during my son’s schooling had ever recommended [ADHD assessment], maybe because he was not hyperactive/disruptive and was quite smart. His main symptoms (disorganisation and lack of focus) are common in teenage boys. We (his parents) believed it was due to distraction by technology and lack of interest in schooling. His psychologist had mentioned the testing at one other point, but it was just after he changed schools, so we felt his distraction was from anxiety.

headspace National Family Reference Group member

Importantly, ADHD needs to be diagnosed as early as possible so that supports can be put in place. This highlights the role of schools and families in awareness of indicator signs and pathways to assessments. It is recognised that the diagnoses of ADHD in young girls are often delayed, partially because they may show symptoms in different ways to young boys and this may not come to the attention of teachers. In addition, young girls may be diagnosed with other mental health illnesses instead and have their ADHD condition go unrecognised for long periods of time.

headspace network stakeholders recognised that a strength in schools is often the development of individual learning plans to support students. However, they noted the reluctance of some students to self-identify their ADHD diagnosis for fear of potential stigma associated with requiring additional support.

Access challenges that exist for vulnerable young people and priority groups

Many young people presenting to headspace services are psychosocially vulnerable, including experiencing challenges relating to accessing affordable housing, disengagement from education or employment and rising cost of living pressures. Many are affected by trauma, substance use, relational issues or interaction with the criminal justice system.

Many young people accessing headspace services are First Nations young people, LGBTQIA+ young people and young people from refugee and migrant backgrounds. The intersectionality of one or more of these factors exacerbates the already complex environment surrounding assessment of ADHD and support for young people following a diagnosis.

For example, pre-requisite blood testing and drug screens, and attending appointments can all present challenges for vulnerable young people, making it difficult for them to receive the support they require. In addition, culturally unsafe environments, which includes mainstream medical models in which ADHD diagnoses are undertaken, adds to the challenges faced by First Nations young people and those from refugee and migrant backgrounds.

Overcoming the challenges highlighted above

Without immediate action to build and ensure a sustainable youth mental health workforce, young people presenting with ADHD symptoms will continue to experience limited access to, and high out-of-pocket costs for, specialists. In building the workforce, there is a need for specialists in youth and positions made available in services that specifically focus on young people.

Education, training and capacity building are critical to building knowledge and awareness and empowering those who are supporting young people presenting with ADHD symptoms. Education and awareness building activities and programs must be tailored for and delivered to a range of audiences including families, teachers, GPs and the broader public. They should support greater awareness and knowledge of: ADHD symptoms; underlying factors to investigate prior to considering ADHD; what is involved in properly assessing a young person for ADHD; comorbidity; and available avenues of support.

Clinical leads in headspace centres highlighted that the workforce seeks additional training on ADHD to improve confidence in providing psychological intervention. Training and development for GPs and clinicians would help to equip them to support young people who are waiting for assessment.

Education on assessments should include:

- information about conducting multiple psychometric tools; and
- collating childhood information, school reports and investigations.

headspace is actively seeking to upskill the workforce around ADHD and improve experiences for young people by:

- providing access to, and increasing familiarity with, resources including diagnostic clues, screening tools, ADHD coaching tools, to assist in identifying when a young person needs to refer to a clinician for assessment;
- upskilling through undertaking training run for PHNs and extended skills posts for GP registrars; and
- keeping abreast of expert updates from the Australian ADHD Professional Association, including research and updates from Professor David Coghill.

GPs across our headspace network indicated strongly the need for all relevant peak bodies across general practice, allied health and specialist mental health to collaborate and strengthen respectful relationships, considering skills of all relevant disciplines.

The use of multidisciplinary teams and clinics is a key avenue for exploration. These teams could:

- engage GPs and allied health professionals with specialised skills who would work with mental health specialists to provide ADHD assessment and support to young people following diagnoses; and
- involve teachers and wellbeing professionals at the young person's school. They should be equipped with the knowledge and confidence to enable them to identify and support students who may require ADHD assessments. Clear options for referral pathways would assist them to guide young people and families appropriately in accessing ADHD assessments and supports.

The headspace Youth National Reference Group members highlighted the importance of involving young people with lived experience of ADHD and their families in decision making and the design of services, policies and supports. headspace National Family Reference Group members emphasised

the need to involve families in the provision of support for young people and provide support and information for families.

Term of reference (b) – Adequacy of access to supports after an ADHD assessment.

Key takeaways

- High out-of-pocket costs are limiting young people from receiving appropriate and ongoing care from qualified clinicians. The cost of medication is also prohibitive, particularly for young people diagnosed after 18 years old.
- Absence of bulk-billed mental health services significantly impacts at-risk young people, causing them to go without assessment or care due to lack of access and/or cost.
- Legislation regulating the prescription of stimulant medications is complex and inconsistent across different Australian jurisdictions, making it difficult to achieve a cohesive and consistent approach to supporting young people with ADHD.

The increasing presentations of ADHD highlight the need to ensure adequate supports for young people. Key challenges that our headspace network stakeholders highlighted in relation to accessing support after a diagnosis include:

- high out-of-pocket costs for ADHD supports and medication;
- limited access to ongoing ADHD supports; and
- the complexity and inconsistency in prescribing medication.

High out-of-pocket costs for ADHD supports and medication

Similar to issues outlined in Term of Reference (a) above, our headspace network stakeholders and reference group members reported high out-of-pocket costs as a major barrier to young people being supported following an ADHD diagnosis.

The cost of medication, including the need for ongoing GP visits, is also prohibitive particularly for young people diagnosed after 18 years old.

“Access to medication was stressful, as I had to access my GP every time I needed a new script and he was frequently booked out. At these times I had to ration out my medication, only taking it at times I felt like I really needed it.”

headspace Youth National Reference Group member

Transitions in care from paediatric to adult services were cited by our headspace network stakeholders as a challenge, despite having confirmed diagnoses, due to limited access to suitable and affordable clinicians.

Without measures in place to reduce out-of-pocket costs, access to support will become unattainable for young people and will have a significant detrimental impact on their wellbeing and executive function.

Limited access to ongoing ADHD supports

Absence of bulk-billed mental health services significantly impacts at-risk young people, causing them to go without assessment or care due to lack of access and/or cost. This in turn risks worsening conditions, with a 2021 study finding “people with ADHD are at increased risk of low-quality life, substance use disorders, accidental injuries, educational underachievement, unemployment, gambling, teenage pregnancy, difficulties socialising, delinquency, suicide and premature death”.⁴

Access to headspace services covered under the Medicare Benefits Schedule (MBS) is diminishing. headspace data show substantial reductions in bulk billed services – the proportion of young people receiving MBS services at headspace centres have nearly halved over the past five years, falling from 41 per cent in 2018 to 23 per cent in 2022, and with steeper declines for new clients, from 31 per cent in 2018 to 12 per cent in 2022. Nationally, there has been a 44 per cent reduction in Occasions of Service assigned to MBS funding over the past five years across all services, from 42 per cent in 2018 to 24 per cent in 2022.⁵

Workforce pressures are a significant constraint in accessing MBS-funded services. The number of providers delivering MBS services for headspace fell from 1,110 in 2018 to 650 in 2022. The decline has been particularly sharp for psychologists – a drop of 40 per cent since 2020 (compared with 12 per cent for GPs and 16 per cent for other professions). One in six headspace services registered no MBS activity in 2022 and headspace centres are providing services in these centres through other sources of funding.

headspace network stakeholders also noted the challenge of limited access to allied health professionals with specific skills in coaching and supporting young people with ADHD. Access to suitably qualified professionals can improve awareness and understanding of practical support strategies for young people experiencing ADHD.

“After diagnosis, I mostly relied on internet resources to understand and work through the supports required.”

headspace National Youth Reference Group member

Clinical leads within the headspace network also highlighted contrasting views and practices among specialists, with some focussing on medication, while others on non-pharmacological supports. Adherence to evidence-based practice guidelines is essential for clinicians, including their awareness of and training in these.

“I’ve considered occupational therapy to improve in time management/ social skills but haven’t been able to access it yet. I have tried to seek career counselling to improve on my job interview skills (and related skills) but the advice given is unspecific to ADHD and not helpful. The majority of the information/skills I’ve learned since diagnosis has been through my own research.”

headspace National Youth Reference Group member

“I think the process of finding the right services is difficult for a young adult, because they are expected to follow this process on their own. When some of the worst parts of

⁴ Faraone, S. V. et al (2021). “The World Federation of ADHD International Consensus Statement: 208 evidence-based conclusions about the disorder”. *Neuroscience & Biobehavioral Reviews*. 128, 789–818. <https://doi.org/10.1016/j.neubiorev..01.022>

⁵ headspace National (2022a). Unpublished service data.

ADHD include lack of organisation and faulty executive function, most ADHD young people will feel this is rubbing salt into the wounds.”

headspace Family Reference Group member

The complexity and inconsistency in prescribing medication

Legislation across Australian jurisdictions which regulates the list of professionals who can prescribe stimulant medications is complex and inconsistent across different Australian jurisdictions. This can make it difficult to achieve a cohesive and consistent approach to supporting young people with ADHD. This is particularly challenging for headspace services which services young people across the paediatric, adolescent, and adult age ranges, and with services spanning all states and territories.

For example, regulation varies across states and territories with respect to professionals who are permitted to prescribe medication following an ADHD diagnosis. The [Stimulant Prescribing Matrix](#) published on the Australian ADHD Professional Association summarises these differing regulations.

Age-based prescribing restrictions are also an issue, particularly for those people whose diagnosis was missed earlier in life. For example, PBS restrictions on prescribing long-acting methylphenidate only for adults who have been diagnosed in childhood needs to be reconsidered.

Adding to these complexities, there are varying degrees of interest among GPs for prescribing/applying for prescription rights in order to continue medication for young people, even once treatment is established and stable. This highlights the need for additional education and training, as covered in Term of Reference (a).

“Initially medication access was a challenge (having to see my GP to get my scripts refilled every month) ...I have not been given the option to change my medication to long-release despite the convenience with my busy schedule.”

headspace Youth National Reference Group member

Overcoming the challenges highlighted above

As per Term of Reference (a), education was highlighted by headspace network stakeholders and members from the headspace Youth National Reference Group and headspace National Family Reference Group as a critical component to appropriately supporting young people who have a confirmed ADHD diagnosis. Some potential supports include:

- resources and workshops for parents, teachers and wellbeing teams in schools, with a focus on practical strategies to support young people and scaffold their learning to ensure they are encouraged to achieve to their full potential; and
- capacity building for GP specialist services and clinicians that goes beyond seminars and workshops to more robust training and development programs. This would be best supported by expanded training positions for the broad clinical workforce in ADHD in headspace services, including for more GP Registrars and completing training posts in headspace services. These positions should include a focus on ADHD and other developmental disorders and focus on a holistic model of care that incorporates both medication and non-pharmacological interventions.

“Trauma-informed training [is needed] so professionals can understand the inherent trauma of growing up in a society that prioritises those [who are] neurotypical”.

headspace Youth National Reference Group member

In relation to reducing barriers to prescribing medication, there are a number of measures that could be taken, including:

- Australian governments working towards making these regulations uniform across Australia, including establishing nationally consistent rules and a permit system to enable GPs to prescribe medication after an ADHD diagnosis; and
- the Commonwealth Government reviewing the pharmaceutical benefits scheme (PBS) regularly, including age-based prescribing restrictions, and ensure any changes made are evidence based.