



Consumers Health
Forum OF Australia

SUBMISSION

Assessment and support services for people with attention deficit hyperactivity disorder

Consumers Health Forum of Australia (2023)
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for People with ADHD

P: 02 6273 5444

E: info@chf.org.au

twitter.com/CHFofAustralia

facebook.com/CHFofAustralia

Office Address

7B/17 Napier Close,
Deakin ACT 2600

Postal Address

PO Box 73
Deakin West ACT 2600

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Introduction

CHF is the peak body representing consumers of health services in Australia, regularly consulting with, and working with, consumers to develop and advocate for policies, programs and initiatives to improve practices and shape a consumer centred health system.

The Consumers Health Forum (CHF) thanks the Senate Community Affairs References Committee (the Committee) for the opportunity to lodge a submission on the barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD.

CHF recognises that the written submission process may not be easy or accessible for many people with ADHD and we tried to make our consultation process inclusive and accessible. Our submission has been informed by feedback from almost thirty consumers with lived experience of ADHD provided in a group consultation setting, individual interview, or email depending on the consumer's preferred format.

CHF would like to thank the consumers who shared their stories and experiences with us and allowed us to include some of their quotes. Consumer names have been changed to protect their privacy.

This submission focuses on proving recommendations for the Terms of Reference a) – f) as these were the areas where the consumers we spoke to tended to focus and CHF feels our contributions are valuable.

Background

ADHD is a neurodevelopmental condition characterised by differences in brain and cognitive development that affects 800,000 Australians (AADPA 2022). Symptoms include impulsivity, hyperactivity and greater difficulty focusing and sustaining attention in ways that impact several areas of a person's life. These are experienced by people of all ages, not just children, and the symptoms can be broad and difficult to diagnose when there are co-existing conditions such as anxiety, mood disorders, physical disability, autism spectrum disorder (ASD) and other learning disabilities.

People with ADHD can find it difficult to manage their time, plan, prioritise and organise tasks, and regulate their emotions (Brown et al. 2022). The consumers that we spoke to told us that their ADHD symptoms have impacted their ability to study, find long-term employment, manage responsibilities, have positive social relationships, and enjoy leisure time. Consumers report that a diagnosis provides acknowledgement that the challenges they experience are not their fault. Rather, their brains work in a different way. Without this recognition, people with ADHD can experience low self-esteem and mental health issues while having a diagnosis can provide access to tools and pathways that empower a person to understand and manage their symptoms, advocate for themselves, and seek support.

Our consultations with consumers highlighted that their lived experiences are diverse and there are many barriers to diagnosis and support for people with ADHD in Australia. Below we identify specific recommendations to address and reduce these barriers in each section.

Response to the Terms of Reference

a) Adequacy of access to ADHD diagnosis

"The high costs of seeing a psychiatrist are often not affordable, particularly to undiagnosed ADHD persons who already struggle to manage finances and holding jobs. The system seems to go against people with potential ADHD given access to a diagnosis and new scripts for medication, plus frequent reviews to find the right medication just to function better can also be taxing both emotionally and financially. It shouldn't feel like a luxury or a privilege to find out whether you have a condition that impairs every aspect of living as an adult." – Alan

"Appointments are expensive, costing upwards of \$300 or \$400. By the time I decided to seek a formal diagnosis, my mental health had long suffered due to my executive dysfunction. I was so desperate for further answers and support that I made the decision to borrow from the redraw on my mortgage to pay for my appointments." – Kerry

"I believe one factor that delayed my assessments regarding neurodivergence is the fact that my cerebral palsy and use of a wheelchair could in the minds of many explain my behaviours, such as stimming sometimes looking similar to the muscle spasms I also experience, and toe-walking and impaired coordination simply being the result of poor balance and neuromuscular issues related to my cerebral palsy. Perhaps many of my stims and self-regulatory behaviours may have been labelled correctly at a younger age if I were able-bodied." – Kerry

In Australia, only a pediatrician or psychiatrist can diagnose and prescribe medication for ADHD. These clinicians should seek a full developmental, medical, and mental health history, complete full clinical, psychosocial, and medical assessments, and gather input from people like teachers, parents, partners, friends and work colleagues (Brown et al. 2022). Co-occurring conditions and disabilities with symptoms that are outwardly similar to ADHD such as Autism Spectrum Disorder, mood and anxiety disorders and Borderline Personality Disorder make diagnosis more difficult to access. In a recent podcast, ABC journalist Ange Lavoipierre (2023) explores the role that social media has had in raising awareness and reducing the stigma around ADHD and finds that Australia is experiencing an 'ADHD Diagnosis Wave' because of the increased demand for these specialist services and assessments.

The consumers that CHF consulted with were all adults with lived experience of ADHD or caring for someone with an ADHD diagnosis, sometimes they were both. Their experiences of accessing a diagnosis varied but overall they described the process as slow, expensive, confusing, and exhausting. Consumers felt like they had to fight to receive a diagnosis, particularly females and those with a co-occurring condition. Those who had a positive experience attributed this to a supportive health practitioner or guidance from someone who had been through the diagnostic process, not the delivery of these services through the Australian health system.

The diagnostic process had an emotional and financial toll. Unfortunately, consumers told us that the significant impact of their symptoms was often the trigger for them seeking a

diagnosis, and starting the process at this time was extremely challenging for them and often led to further declines in their mental health. Ongoing challenges of work, study, finances, or relationships has direct effects on their ability to pay for appointments and assessments, their capacity to sort through old documentation, and their motivation to find and contact multiple psychiatry practices to get an appointment. Consumers found that there were substantial differences in service fees, upfront payments, assessment processes and practitioner attitudes towards ADHD. Navigating these with no certainty of a diagnosis added to the stress placed on consumers.

Recommendations

1. Streamlining diagnosis and prescribing

Create a consistent, accessible pathway to diagnosis by increasing the number of public sector professionals able/available to diagnose and prescribe medications for ADHD. Providing training for general practitioners and psychologists to start the diagnostic process: gather evidence and conduct assessments that can fast-track a formal diagnosis with a pediatrician or psychiatrist. In Western Australia, this model is already being trialed on a small scale (Simpkins, 2023).

2. Increasing awareness of ADHD

Provide training for GPs, psychologists and teachers working with young people to be able to recognise and provide early information about the symptoms of ADHD. This training should include information about commonly co-occurring conditions like ASD and the multitude of ways that ADHD can present.

3. Providing consumer support

Access to low-cost or free coaching or peer support that can provide guidance and strategies for people to manage their symptoms while waiting for a diagnosis.

Funding for dedicated appointments through the Better Access initiative so that people on low incomes who are seeking an ADHD diagnosis can access the Medicare rebate.

b) Adequacy of access to supports after an ADHD assessment

"At work, we've discussed reasonable adjustments and modified work arrangements, but I really don't know what helps. I have planners and diaries and calendars and a hundred to-do lists, but I can't decrease my workload, and I'm not getting supported. I have so many emails and I can't get through them. There's too much to do and nobody else can do it. My workplace is supportive, but they don't actually tell me what I can access." – Nat

"TAFE offered me a support plan, but most of it couldn't be applied to my course. I had to repeat part of the course just to graduate, despite suffering from high levels of depression and anxiety because I wasn't being supported and understood enough. I never requested a hall pass, I only wanted the right advice, the strategies, and tools I know now. Instead, I received judgement from my teachers, and in fact some very unhelpful advice to one with ADHD." – Alan

"It is an issue that ADHD is classified as a developmental disorder, fixed entirely with medication and no support via the National Disability Insurance Scheme. Some meds are not accessible on the Pharmaceutical Benefits Scheme when diagnosis occurs in adulthood. ADHD is not seen as

a lifelong disability like autism is. Adults with ADHD need additional supports in the form of occupational therapy and therapy to live impactful lives. Significant lifelong costs warrant additional supports.” – Tina

“I was told after my medication options were running out to do “ADHD coaching”, but I wasn't told what that is, what it costs or where to find it. I was told to google it, which I keep putting off, and my psychiatrist has not followed it up... I've learned most strategies from my peers, or social media.” – Nat

“By the time the school put in places appropriate supports it was after the diagnosis came it was far too late and that was despite them knowing we were on a journey of assessments and seeking answers because of the challenges that my 15 year old son was having. What is confronting for me is that we are a family with the financial and emotional resources to get the help we need yet the waiting lists were so long that despite seriously declining mental health issues we couldn't access the services we needed. How do less educated people and families who are less financially able or less stable cope in these situations?” – Jane

The AADPA (2022) states that medication should be one part of person's ADHD treatment plan, but will rarely decrease all their ADHD-related difficulties or work effectively across the whole day. The consumers that CHF consulted with told us that they need more support in their homes, educational institutions, and workplaces to participate and thrive. While some clinicians tell people about ADHD coaches or occupational therapists, most consumers we spoke to had not been able to access funding through the National Disability Insurance Scheme (NDIS) unless they have a co-occurring condition like ASD and so cost remains a barrier, even after diagnosis.

Consumers tell us that there is a gap between the support available to them and how it is implemented. Educational institutions and workplaces generally have policies around reasonable adjustments, but the onus is often on the person with ADHD to understand how the policies can meet their needs. For example, a survey conducted by ADHD Australia (2021) found that the majority of teachers feel they have some knowledge of ADHD and can recognise a student with ADHD in their classroom but are not confident in supporting them and do not have adequate learning support or resources. In a survey of parents conducted by the Parents for ADHD Advocacy Australia (2019), one third (36%) of respondents reported that no adjustments in teaching, classroom tasks or assessment processes had been made. CHF spoke to some parents whose children were diagnosed late in high school and felt that there was not enough urgency in providing reasonable adjustments before key assessments such as Year 12 exams. Other consumers said that their support plans could not be applied to their TAFE course or that the process of applying for reasonable adjustments at university was inaccessible to them. There is clearly a gap between the intention to support people with ADHD and the skills, knowledge and resources to do so.

People who have recently been diagnosed may not have the experience to ask for or advocate for their support plans to be implemented, especially children. Some adults may worry that their education or employment will be compromised if they disclose their diagnosis or fight for reasonable adjustments. This review needs to consider how we can make inclusive spaces and practices the norm for workplaces and educational institutions. How can we make it so that the neurodiverse population and their needs are considered alongside Culturally and Linguistically Diverse or LGBTIQ+ people? Clear information about the adjustments available and how these can be implemented effectively should be provided to the person with ADHD and the employer, manager or teacher.

Recommendations

4. *Supports and adjustments in education and work*

There needs to be an established pathway or process in place to support people seeking 'reasonable adjustments'. Educational institutions should receive funding to have an ADHD officer or an access and inclusion officer so that students and their families have a single point of contact while implementing reasonable adjustments.

Develop authoritative, current and accessible information and professional learning seminars or webinars that empower teachers to teach and support students with ADHD more effectively. This aligns with the policy priorities of the Australia's Disability Strategy 2021–2031 to build capability in the delivery of inclusive education.

Provide information to organisations about how they can cater to neurodivergent people by normalizing supports across their workplaces. Practices include offering flexible schedules, providing access to quiet/private spaces, installing different lighting options, and making it easy for employees to opt-in for supports without needing to disclose their diagnosis.

5. *Support at home*

Develop psychoeducation for people with ADHD and their friends and family following a diagnosis. This should include helping people to understand their diagnosis, symptoms, and the adjustments that might support them.

c) The availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services

"While the clinical psychologist who gave me my initial ADHD diagnosis was wonderfully knowledgeable and respectful, getting the diagnosis confirmed by a psychiatrist in order to allow access to medication was painful and drawn out. The psychiatrist was insistent that my symptoms could all be explained by my existing mental health diagnoses and trauma, as though someone "merely being traumatised" is acceptable and does not require further investigation or support. Practitioners need to be more understanding and respectful of the intersection of various conditions." - Kerry

"ADHD is so complex and it affects everyone differently. So understanding how and when to apply certain tools is a challenge that requires a lot of training I believe... I was handed medications and left to figure it out. No mention of side effects, long term effects or even when to consider other medications as an option. No guidance towards support services, no advice on how to manage symptoms." – Alan

"There aren't enough practitioners who understand or have the skills to support people with ADHD, particularly in mental health settings. – Nat

"I have been seen as lazy, disinterested, non-compliant, rude, a liar, and all sorts of disrespectful things because people don't understand what I'm going through, and that has messed up my self-esteem. It's not seen as a result of disability, it's seen as a personal fault of me as a human." – Nat

Consumers report diverse experiences with practitioners, which has influenced their diagnosis and access to treatment. The biggest challenge seems to be finding a medical practitioner who is supportive of ADHD and has availability for the ongoing prescriptions and treatment required. As discussed previously, ADHD friendly medical practitioners who can diagnose and prescribe ADHD medications are incredibly busy, have long waitlists and spend a lot of time doing things like repeat prescriptions.

Consumers tell us that they have found it difficult to get follow up appointments with medical practitioners even after diagnosis. This is a pivotal time for them, and the consumers we spoke to thought there should have been more opportunities to ask questions about the dosage, timing, side effects, and alternative options of medications, discuss strategies for their symptoms, and find ongoing support such as peer groups.

Recommendations

6. Include neurodiversity in undergraduate medical degrees

Build a greater awareness of neurodiversity in health practitioners by including it in undergraduate medical degrees. This should include the different presentations of ADHD, the possibility that people have developed compensation strategies (otherwise known as masking) for their symptoms, and common co-morbidities during their training and also as part of ongoing professional development.

7. Invest in telehealth

Expand and incentivise the creation of more telehealth services to address long wait times and ensure people in rural, remote, and regional areas have adequate access to services.

8. Integrated models of care

Prioritise the creation of integrated models of care in primary health care settings so that GPs and specialists are working together to provide continuous care to people with ADHD. Through integrated models, GPs have the potential to help consumers with diagnostic processes, repeat prescriptions in certain circumstances, and primary health care interventions for physical and mental health issues that commonly occur alongside ADHD. In Victoria, GPs can already seek permits to prescribe ADHD medications in cases where there is evidence of a specialist diagnosis (Victorian Government, 2023) and in Western Australia GPs are trialling a collaborative diagnostic model (Simpkins, 2023).

d) Impact of gender bias in ADHD assessment, support services and research

"I one hundred per cent experienced the gender bias... I think that was to do with the psychiatrist's training and professional development. It felt like he hadn't done that learning that has happened in the last five or ten years about the different way that symptoms present in women to boys and young men." – Maggie

"Lack of understanding as to what ADHD is - particularly for assigned female at birth people, it gets misdiagnosed as mood/anxiety disorders, personality disorders, etc." – Nat

"Gender bias also affects the provision of appropriate support services, as girls with ADHD may not receive the same level of support as boys. I am a non-binary person assigned female

at birth, and feel a lot of my inattentive symptoms were chalked up in my childhood to me being “ditzzy” or a “daydreamer”, terms I don’t recall hearing used to describe boys and men” – Kerry

ADHD is still understood to be more prevalent in males and the symptoms that they exhibit. This was a common view in the 1990s and early 2000s and, while there has been a shift towards recognising ADHD traits in females, the view that males more commonly have ADHD is still present in school settings and with medical practitioners. The flow on effect is that females are more often diagnosed with conditions that outwardly present as anxiety and/or depression. While these conditions may also be present, ADHD as an underlying cause or contributing factor may go untreated. This gap in the education and awareness of medical practitioners and people working with young people needs to be addressed, in particular around the different ways that ADHD can present.

The female or assigned female at birth (AFAB) consumers that we heard from felt that their gender was a factor that impeded their access to a timely ADHD diagnosis and supports specific to their symptoms. As the understanding of ADHD grows, there needs to be accompanying research, funding and services to support this, and it needs to be a national priority to ensure that what is learned filters down to services and individual medical practitioners.

Recommendations

9. Fund Research Grants

Fund research to deepen the understanding around the diverse presentations of and effective treatments and strategies for ADHD, particularly in females and AFAB people. This group has only been recognised recently and needs to be prioritised to ensure females and AFAB people are not disadvantaged by the treatment that they receive because of their gender assigned at birth.

e) Access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications

“My psychiatrist is available 3 months in advance... So, if I can't make it to an appointment, usually for a new medication script, I'm out of meds for 3 months unless I'm lucky and he has a cancellation. That means 3 months without these incredibly helpful medications.” – Alan

“Some medications are PBS, but I'm never told the cost before I'm given the script to put through, or whether or not they are subsidised. One medication cost me ~\$80 a month, others have cost me \$5. Information on what the different options are, how much they cost, and any side effects would be amazing to be able to make an informed decision.” – Nat

“I didn't have any tests before being medicated to see if I would be able to safely take them

(other than the drug test). It was known that I had tachycardia, yet I was prescribed Ritalin, and when I mentioned that my heart felt a little funky while on them, it wasn't acknowledged. It wasn't until I went to a different psychiatrist that I was told that heart conditions are a contraindication to prescribing stimulant medications. I often wonder if being on stimulants messed up my heart further. He doesn't want me on stimulants, and none of the other options have done anything."

– Nat

According to an analysis by the Drug Utilisation Sub-Committee (2021) information on the Pharmaceutical Benefits Scheme (PBS) website, psychostimulants are the first line pharmacological treatment for ADHD. People generally start on a low dose of the immediate release stimulant. If they tolerate it, the dose is gradually increased until effective and then they have the option of transitioning to a long-acting form. Where stimulants are not suitable or tolerated then non-stimulant options are available. ADHD is a lifelong neurodevelopmental condition, however ADHD medication is not easily or equally provided across a person's life in Australia.

The PBS subsidises ADHD medication but has limitations based on age and dosage. People who are diagnosed with ADHD as adults do not have the same access to some PBS discounts as those who were diagnosed before they turned 18. Prior to 2021, there was no long-acting medication listed for people diagnosed as adults and some stimulants are still only discounted for certain age groups (AADPA 2023). The PBS also has restrictions based on upper doses, but these limits vary for medications and some states and territories also have their own limits. As described above, it is common to trial a few medications and doses before finding the optimal treatment and so it is important that consumers can base their decision on how they respond to a medication rather than the cost. These guidelines are discriminatory, and it is important to remove them to ensure all Australians with ADHD have equal access to treatments.

The states and territories all have different laws around stimulant prescribing. Doctors need clear national guidelines so that they can provide treatment more efficiently, for example a doctor providing telepsychiatry and prescribing medicine to a consumer in a different state needs to know how to report that they are starting a new prescription to the relevant authority, what is required to co-prescribe with a GP in that state, what the age and maximum dosage limitations are, and whether that state requires a drug test (AADPA, 2023).

Co-prescribing mechanisms exist in every state and have the potential to alleviate high demand and long waitlists for specialist appointments. Few consumers that CHF spoke to during our consultations were aware that their GP can co-prescribe their ADHD medication and in some states this option does depend on the specialist. There is a lot of variation between the jurisdictions, for example in New South Wales a consumer needs to have a review with their specialist each year to continue their prescription while in South Australia a review is only required every five years (AADPA, 2023). For consumers who are stable, a longer break between reviews may be beneficial and two years seems to be the average across states and territories.

Recommendations

10. Remove age restrictions

Remove the age restrictions that limit PBS access to some ADHD medications so that adults who receive a diagnosis have the same access as people who are diagnosed as children.

11. Review maximum dosage limits

Review and work with the states and territories to make the upper dosage limits consistent in line with manufacturer guidelines.

12. Work towards national uniformity

Develop national guidelines for stimulant prescribing that consider routine and non-routine situations such as high dose, substance abuse, co-morbidities, common medication interactions, etc. These guidelines should include clear information about each of the state and territory requirements around initiating and co-prescribing ADHD medications.

Promote existing co-prescribing mechanisms and work with states and territories to make these nationally consistent where possible. Consumers want more support from medical practitioners when starting ADHD medications and this arrangements mean that GPs can provide assistance if required.

f) The role of the National Disability Insurance Scheme in supporting people with ADHD, with particular emphasis on the scheme's responsibility to recognise ADHD as a primary disability

"Being able to put ADHD as a diagnosis on my application would have helped massively in terms of accessing the NDIS and understanding my health as a constellation of issues that coexist in my body and affect my life adversely. It's not just one thing" – Maggie

"I am a wheelchair user due to cerebral palsy, I am mentally ill and autistic and I can still say that, even with all the difficulties those conditions present I can still say confidently I feel ADHD is my most 'disabling' condition. The issues presented by my physical disability are largely obvious and can be 'bridged' with fairly straightforward solutions, e.g., support workers and home modifications. But the battle I am fighting against my own mind is more entangled and more complex, and, because I function very well in many areas, is often downplayed." - Kerry

"Access to things like cleaning, financial planning and allowances in the workplace would be so helpful. These are things that have brought me shame, and before my diagnosis, I thought there was some degree of personal choice in not being able to do things that other people find easy" – Maggie

"If the neurotypical world could adapt and let us learn, build and function in whatever way works for us, then we would be creating the most amazing things. But instead we are addicted to illicit drugs, on Centrelink and in jail. It's so stupid. The world is changing. I know that but I still feel so damn frustrated." – Theresa, on behalf of a family member

Although ADHD is a lifelong neurological condition, it is not currently recognised as a primary disability for NDIS funding. While there are medications that effectively address the symptoms for some people, ADHD can have significant impacts in many areas of a person's life; commonly education, employment, financial and social. People with ADHD are more likely to experience mental health issues, addiction, die by suicide (NHMRC, 2012), and are overrepresented in the criminal justice system (Freckelton, 2020) than the neurotypical population. This inquiry needs to address the lack of supports currently available to the ADHD

population and identify ways to enable and empower them to flourish in line with the goals of Australia's Disability Strategy 2021–2031 (Australian Government, 2022).

Recommendations

13. Make NDIS funding available to people with ADHD

The NDIS should recognise ADHD as a primary disability in cases where it results in significant functional impairment. As with ASD, there are a range of levels with some people experiencing much greater functional impairment. Individuals should be assessed based on their need for extra support, not just on having a certain diagnosis.

Conclusion

As understanding of neurodiversity and ADHD presentations, symptoms and treatments develops, so must the Australian systems, policies, and level of awareness in education and workplace settings. The recommendations of CHF's submission are to extend and connect the mechanisms that are already in place to ensure this group is included and supported to flourish. We have made a number of recommendations for the Terms of Reference a) – f) but these can be summarised by the following:

Simplify the Processes

- Processes need to be simpler, more consistent and more affordable to increase access for people with ADHD. This starts when a person seeks a diagnosis and needs to continue for them to access medication, follow up appointments, support and funding.
- Developing national guidelines for medical practitioners to navigate the differences between state and territory laws in regard to reporting and prescribing ADHD medication.

Increase Funding

- ADHD needs to be a priority in the public sector. This means involving GPs with the diagnosis, prescribing and ongoing management of ADHD and any co-occurring conditions.
- Expanding funding available to people seeking a diagnosis or managing ADHD through Medicare items, telehealth incentives, the Better Access Initiative, the PBS, and the NDIS.

Raise Awareness

- Equipping medical practitioners, parents, carers, teachers, and employers with the knowledge and skills to identify, understand and support people with ADHD.
- Fund research to expand our understanding of ADHD, particularly in groups that have been overlooked in the past.

People with ADHD are best placed to decide which models of health care recognise, support and meet their needs as a diverse group. The key to success will be prioritising the lived experience of consumers in these discussions and empowering them to lead and evaluate the changes at all levels. Creating a more inclusive health system with services that acknowledge and cater for all neurodiverse people is a positive outcome for health care consumers.

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