

CoMHWA



Consumers of Mental Health WA (Inc)

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**Feedback to the  
ADHD Inquiry**

**9<sup>th</sup> June 2023**

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Consumers of Mental Health WA

Street Address: 12/275 Belmont Ave, Cloverdale 6105

P: (08) 9258 8911 W: [www.comhwa.org.au](http://www.comhwa.org.au) E: [admin@comhwa.org.au](mailto:admin@comhwa.org.au)

# 1. Preliminaries

## **About the Respondents**

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues, psychological or emotional distress). We are a not-for-profit, systemic advocacy organisation independent from mental health services that exists to listen to, understand and act upon the voices of consumers. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

## **Request for Feedback**

CoMHWA works to uphold the dignity and human rights of consumers, through providing advocacy in leading change with and for consumers. We appreciate notification of the outcomes of our submission to this consultation in order to understand and communicate the difference made through our work.

Please provide feedback via the contact details on this submission's cover page.

## **Language**

CoMHWA uses the term mental health 'consumer' throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services. Other ways people may choose to describe themselves include "peer", "survivor", "person with a lived experience" and "expert by experience".

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify. As individuals we choose different ways to name and describe our experiences that may confirm or trouble ideas about 'mental illness'.

## **About the Consultation: ‘ADHD Inquiry’**

### ***Reproduced from Website***

On 28 March 2023, the Senate referred an inquiry into the Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD to the Senate Community Affairs References Committee for inquiry and report by 27 September 2023.

The terms of reference for this inquiry include barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD, with particular reference to:

- a) adequacy of access to ADHD diagnosis;
- b) adequacy of access to supports after an ADHD assessment;
- c) the availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services;
- d) impact of gender bias in ADHD assessment, support services and research;
- e) access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications;
- 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;
- g) the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages;
- h) the adequacy of Commonwealth funding allocated to ADHD research;
- i) the social and economic cost of failing to provide adequate and appropriate ADHD services;
- j) the viability of recommendations from the Australian ADHD Professionals Association’s Australian evidence-based clinical practice guideline for ADHD;
- k) international best practice for ADHD diagnosis, support services, practitioner education and cost; and
- l) any other related matters.

**Close Date:** 9<sup>th</sup> June 2023

**Submissions to:**

community.affairs.sen@aph.gov.au

## 2. Introduction

CoMHWA welcomes the opportunity to make a submission to the Committee's Inquiry into the barriers to supports for people with ADHD. The intersections of neurodiversity and mental health challenges are profound and well-documented among consumers. Many consumers described their experience of living with ADHD and the challenges they faced in obtaining diagnosis and treatment. Responses we received reiterated some key themes:

- The majority of responses we received emphasised the difficulty consumers face in finding available doctors to pursue diagnosis, and managing the cost of pharmaceuticals and ongoing treatment.
- There was a consensus from consumers that the NDIS should be reformed to offer support for ADHD as a primary disability.
- Additionally, while many consumers highlighted the potent relief they have experienced from ADHD diagnosis and treatment, a common theme emerged about the enduring stigmas surrounding ADHD in both a clinical and social context.

Accordingly, CoMHWA has developed thirteen recommendations for the inquiry that address consumers' concerns in relation to key questions from the terms of reference. These recommendations are followed by the rationale CoMHWA believes support the recommendations, which include, where possible, direct quotations drawn from the participation of our consultation.

We base our submission on:

- A survey sent out to all CoMHWA members which was open for responses between 17<sup>th</sup> April and 15 May 2023.
- Ongoing data collection and input from CoMHWA's Individual Advocacy and Peer Pathways (service navigation) programs.
- Ongoing consultation with consumers in Western Australia on joint priorities for an improved mental health system
- Consumer representation in relevant settings, including but not limited to: Primary Health networks (WAPHA), WA regional equivalents of the Local Health Networks (regional mental health services under the WA Health Board structure), the Mental Health Commission and the health complaints agency, Health and Disability Services Complaints Office (HaDSCO)

## Discussion and Recommendations

### ***Access to diagnosis (Term of Reference ‘a’)***

**Recommendation 1: The government should develop ways to ensure that there are a greater number of psychiatrists who can pursue potential ADHD diagnosis at an affordable cost.**

Rationale: The consumers surveyed by CoMHWA were passionate about describing the challenges they faced (or continue to face) in obtaining an ADHD diagnosis. When outlining barriers to their care, 32 out of 46 respondents (69.6%) agreed that ‘Waitlists are too long’. There were dozens of comments that ADHD diagnosis involved:

*‘Long wait times and was extremely expensive to get a diagnosis.’*

The cost of diagnosis was another prominent issue identified by consumers, 39 of 46 respondents (84.78%) agreeing that ‘supports are too expensive.’ The challenges of being able to financially pursue diagnosis and treatment in the context of the public healthcare system were also a topic of concern to some consumers:

*‘You need to have money to be diagnosed. If it is missed in public school and public hospital, and you have no finance, then it’s bad luck—just cope with it.’*

The difficulty in being assessed by the public system was contrasted with the extremely high cost involved in private practice clinics that specialise in ADHD diagnosis. Accordingly, efforts to increase the availability of psychiatrists able to diagnose and treat ADHD should not be limited to the encouragement of private clinics, and should include a robust investment in the capacity of the public health system to support low-income consumers. Developing steps towards increasing psychiatric capacity for ADHD should also include a focus on ensuring greater numbers of paediatric psychiatrists, where wait times are even longer.

**Recommendation 2: Consumers who have been previously diagnosed with mental health concerns should have the ability to pursue ADHD diagnosis without pre-judgement or stigma.**

Rationale: An issue that was raised in our consultation with consumers was the unique difficulty consumers face seeking a potential ADHD diagnosis when they have been previously diagnosed with other mental health challenges. As one consumer put it:

*'I would like practitioners to be aware of the consequences of making diagnoses to individuals who may, at that stage or a later stage, require access to stimulant medications...There are ways of managing medication side effects and co-occurring social/psychological crises with the consent of the person that do not involve irresolvable stigma and therapeutic blacklisting'*

The potential for an earlier diagnosis to hinder seeking treatment for ADHD is a complex issue, given that certain conditions can 'mimic' ADHD. There are also established and important concerns about the interaction of medications for conditions such as bipolar disorder and the medications sometimes used to manage ADHD. However, our recommendation is to ensure that psychiatrists receive training in negotiating between extant diagnoses to investigate the potential for such a consumer also having ADHD, importantly conducted without stigmatising assumptions about potential consumer motivations and in good faith.

### ***Access to support after diagnosis (Term of Reference 'b')***

When asked about obtaining support after a diagnosis, the responses from consumers tended to focus on three primary concerns, namely the cost/accessibility of follow-up appointments for treatment, the cost of engaging with 'ADHD coaches' or ADHD support groups, and the absence of non-clinical/pathologising peer worker support groups.

***Recommendation 3: The government should enact measures to ensure the ongoing support of consumers who struggle to meet the financial demands of the appointments required for continuing ADHD treatment and prescriptions.***

Rationale: The effect of managing the cost of ongoing appointments and treatment for ADHD was a key issue for consumers discussing supports. What became clear in these responses is that obtaining diagnosis was only the first challenge, and that managing finances to attend psychiatrist appointments and afford medicine posed great difficulties for some consumers.

*'Accessing these medications requires a script that can ONLY be provided from my psychiatrist which requires an appointment. As you can imagine a psychiatrist's time is quite expensive and so each time I require a script, currently bi-yearly, I am paying the private fee associated with roughly 15 minutes of their time.'*

Alongside the cost of repeated appointments that are needed, other consumers described the difficulties that emerge when a psychiatrist retires or moves to a different location.

*'I have faced difficulty as my treating psychiatrist retired due to sudden health issues and it has taken me 6 months to find a new one, their books aren't free for another 6 months, so I have been taking my medication every 2nd to 3rd day to make it last.'*

The issue of access to a psychiatrist to treat consumers is accordingly not merely limited to the process of diagnosis, and also involves the continued engagement for medication prescription and monitoring. These disruptions that occur post-diagnosis are often from common life events, such as consumers moving or psychiatrists retiring/changing location. The lack of availability turns such routine events into stressful experiences for consumers who struggle to find available practitioners to continue their treatment.

Without a system for ensuring that required follow-up appointments are subsidised and that there are enough psychiatrists to support people who have already been diagnosed, disadvantaged consumers will be unable to pursue post-diagnosis treatment easily or reliably. Some consumers recommended amending the status of ADHD medication as a controlled substance in their responses, with the goal of allowing for General Practitioners to re-prescribe scripts to consumers with an established diagnosis.

**Recommendation 4: Ensure that peak bodies supporting consumers with ADHD are appropriately funded.**

Rationale: There were a number of responses from consumers that described the challenge of even affording access to a support network to help them to manage the symptoms of their ADHD. For example, 'ADHD Support Australia' offers consumers useful monthly online meetings and speakers discussing ADHD, but must charge fifteen dollars per event to cover their costs. The 'ADHD WA' group also charge annual membership fees to attend support groups, and specific costs for additional services. Consumers who could not afford to attend these support groups reported that they, and others, have turned instead to online influencers. Providing funding for ADHD peak bodies would thus offer consumers a space for non-clinical support, as well as indirectly helping to promulgate better community education about ADHD from reliable sources, rather than from the unregulated influencers on social media.

**Recommendation 5: Take steps to develop and support networks that incorporate peer-workers and that promote a holistic, non-clinical perspective about managing with ADHD.**

Rationale: Several consumers expressed frustration with the lack of available community support groups that involved peer-workers, or people with lived experience of ADHD.

*'I find it hard to find authentic psychosocial and peer support, compared with the number of 'influencers' who seem to be taking advantage of a more common occurrence of diagnosis in society right now.'*

Establishing a well-regarded peer-worker support group would provide a space for education and day-to-day support for consumers, some of whom are dissatisfied with the inconsistent and sensationalised groups of influencers who currently serve as the dominant locus for free-of-charge community support.

Another benefit of developing support networks around peer-workers will be to offer a less clinically-orientated perspective on how to cope with the everyday challenges facing consumers with ADHD. As one consumer wrote:

*‘Often the support available is very medical-model and pathologising...They aren’t holistic at all and subscribe to the idea that you have a brain problem.’*

Many consumers find the language of biomedical disorders to be dehumanising and reductive, focused on trying to explain the mechanism of ADHD rather than concretely helping by providing strategies relevant to the lived experience of people who have ADHD. Peer-worker support networks offer consumers a sense of hope and belonging in a space that does not over-emphasise the clinical perspective, while also providing consumers with valuable expertise and advice from their peers for coping with ADHD.

## ***Training and attitudes of treating practitioners (Term of Reference ‘c’)***

**Recommendation 6: Ensure that the education of medical professionals is updated regularly and incorporates a broader range of symptoms and behaviours that can frequently be displayed by those with ADHD.**

Rationale: The above recommendation was developed from a number of consumers’ responses, which highlighted a frustration with their experience of psychiatrists who held narrow views about the potential symptoms of ADHD, especially in relation to the variety of different ways ADHD can present in women and minorities. Broadly, CoMHWAA received several comments that were critical of how psychiatrists had investigated the possible symptoms of ADHD that consumers experienced.

*‘...in my experience a majority of diagnosing (ADHD specific) Psychiatrists do not have a wealth of knowledge on what ADHD is and how it presents outside of the context of the DSM-5.’*

Extending current psychiatric education to include more granularity about behaviours and symptoms that may be clinically relevant would help to address this concern held by



consumers. Additionally, it could also help to educate the public more broadly—by making psychiatrists aware of current prevalent trends in classifying particular behaviours as ADHD symptoms. This knowledge would position psychiatrists to better acknowledge and understand these different presentations of symptoms, as well to potentially question misinformed or overly generalised claims consumers may learn from unreliable sources such as social media influencers.

**Recommendation 7: Develop social education programs and awareness to help reduce both the clinical and public stigmas associated with ADHD diagnosis and treatment.**

Rationale: A number of consumers reported that they experience enduring stigmas about ADHD diagnosis and treatment from both medical professionals and the broader public. In terms of a public stigma, one consumer made the following observation:

*‘There is a lot of stigmas around ADHD. Some of my friends were really unhelpful. The media is pushing this idea that ADHD is either not a ‘real’ problem or over diagnosed.’*

For people already struggling to manage their circumstances with the symptoms of ADHD, the view that such concerns are either ‘not real’ on the one hand, or ubiquitous and easily surmountable on the other, makes it harder to seek out treatment. Of particular concern for some consumers was the dismissive stigma they experienced from their psychiatrists and doctors in relation to considering an ADHD diagnosis. For example, one consumer notes that:

*‘My first psychiatrist...ended up telling me not to ‘get excited’, because ‘you’re not getting any stimulants’*

The above description of a psychiatrist’s hasty dismissal, and their characterisation of our consumer hoping for relief through treatment as an ‘excitement’ for ‘stimulants’ highlights the enduring stigmatisation consumers can face in the medical system when asking for an ADHD assessment. Notably, this consumer explained that they were eventually diagnosed and treated for ADHD by a different psychiatric professional. While the public stigmas around ADHD can cause consumers distress, the stigmas held by medical professionals can severely impact and limit the ability for consumers to autonomously seek out ADHD diagnosis and treatment.

***Impact of gender bias (Term of Reference ‘d’)***

**Recommendation 8: Develop education programs for treatment providers to help them identify particular differences that can exist in the presentation of ADHD symptoms**

**from different genders and minorities, as well as the specific challenges these consumers may face in pursuing treatment.**

Rationale: This recommendation is based on multiple concerns relayed by consumers about their diagnosis or treatment for ADHD that centred on how gender can impact this process. One issue that was repeated was the dissatisfaction with how medical professionals standardised symptomatic ADHD behaviours, without considering how symptoms might differ between genders and minority cultures. As one consumer wrote:

*'Most specialists lack education in recognising ADHD in females, people of colour, LGBTQIA+, or those with comorbid conditions such as autism.'*

In addition to the lack of awareness of alternative indicating behaviours, a consumer who has transitioned to a different gender than the one they were assigned at birth encountered difficulty in having an earlier diagnosis made available to their doctor:

*'After I changed my gender legally, I found it really impossible to access my old diagnosis. My psych couldn't retrieve it without ID I no longer had access to.'*

Promoting professional awareness of the potential gender-based challenges consumers may face in seeking treatment for ADHD may help to secure more equitable consideration in the clinical setting. In particular, given the high cost of arranging appointments, it is crucial that any impediments to accessibility are removed where possible.

### ***Cost and access to medication (Term of Reference 'e')***

The responses provided by consumers regarding ADHD medication were focused on the incredible benefit many consumers felt after receiving pharmacological treatment, the high cost of this treatment, and the stigmas that they experienced when using ADHD medications.

**Recommendation 9: Ensure that medication for consumers with ADHD is made more affordable, and end the disparity in cost between childhood and adult diagnosis for some ADHD medications.**

Rationale: The rationale for the recommendation to make ADHD medication more affordable was drawn from the overwhelming number of responses that specified cost as one of the key difficulties faced in pursuing treatment. The available pharmacological treatments for ADHD were cited by a significant number of consumers in their responses to the term of reference about medication. The following response is an example of the many consumers who had positive experiences with using approved medications to manage their ADHD:

*'Yes, I have found the medication has changed my life substantially, once my psychiatrist had diagnosed me ... getting my medication was easy and he has been a massive help in adjusting it to my needs.'*

For many of consumers, medication provided them with the means to cope with everyday life more successfully, with less instances of distress and feeling overwhelmed. However, there were many comments outlining how they struggled to manage the cost of their treatment, of which the following is an example:

*'ADHD medication is very, very costly. I have at times had to go without when my low-income health care card has not been valid.'*

There were multiple responses that spoke about rationing their medication or periodically going without treatment due to the cost. Additionally, some consumers noted that, because they were not diagnosed with ADHD as children, they could not obtain their medication at a discounted cost through the Pharmaceutical Benefits Scheme (PBS). While lisdexamfetamine (Vyvanse) was included in an amended PBS listing in 2021 to be available for consumers diagnosed with ADHD as adults, other ADHD medications such as methylphenidate (Concerta and Ritalin LA) and atomoxetine (Strattera) remain at full cost for adults not diagnosed as children. Given the individualised nature of which pharmaceutical will be most effective for a consumer, our recommendation is that a key part of addressing medication cost should be to standardise the PBS to include all relevant medications for adult ADHD.

**Recommendation 10: Promote education about ADHD and treatments to help dispel prevalent stigmas around medication.**

**Rationale:** This recommendation is a result of consumers providing CoMHWA with feedback discussing their experience of stigma stemming from using ADHD medication. This stigma extended from the clinical setting, through assumptions made by doctors and pharmacists, to the prejudices held by the public at large. One consumer summarised this position as follows:

*'You basically feel like a criminal. I wish that ADHD medication wasn't a drug that is restricted and abused by some people because you feel judged, and like your psychiatrist and the pharmacy are constantly monitoring you like a criminal. I also found there is a lot of stigma in the community from people who don't understand ADHD and the medication. For example, people saying ADHD medication is basically 'meth'.'*

The feeling of a broad social stigma was a frequent theme in the responses about medication, in particular the prejudice that ADHD medication is for ‘recreation’ rather than to alleviate symptoms. One consumer phrased their concerns as follows:

*‘Sometimes I get embarrassed if people see them in my bag, I don’t want to be known as a drug seeker. I think there is a stigma attached with the meds. It’s not something I tell people and only a very few people know.’*

It is not appropriate for consumers suffering from a recognised disorder to be subjected to suspicion and judgement while pursuing treatment. In light of the concerns held by consumers, it is CoMHWA’s position that this disturbing trend should be countered by a robust effort to promote public education about medication used to treat ADHD, underscoring the important therapeutic help it offers people living with ADHD.

### **NDIS support for ADHD (Term of Reference ‘f’)**

**Recommendation 11: The NDIS should be reformed to accept ADHD as a ‘Primary Disability’ in order to alleviate the prohibitive cost of ADHD treatments and provide better support to disadvantaged consumers.**

Rationale: The response from consumers regarding the NDIS were frequent and univocally in support of changing the NDIS so that it recognises ADHD as a primary disability. There were a number of consumers who expressed considerable frustration that the high cost of receiving treatment for ADHD could not be ameliorated through the NDIS. The key theme in support of changing the NDIS was to promote accessibility—specifically the cost of repeated specialist appointments and ongoing medication costs. One consumer phrased this desire as follows:

*‘...the things I know would help me, including increased access to my psychologist appointments and seeing an ADHD coach, are not financially viable. It would be great to get some support to increase access to this via NDIS’*

Reconfiguring the NDIS to accept ADHD as a primary disability would be a comparatively straightforward step towards addressing one of the key difficulties faced by consumers and other consumers struggling with the costs of managing their ADHD.

### **The economic and social cost of failing to provide adequate support for ADHD (Terms of Reference ‘g’ and ‘i’)**

**Recommendation 12: Making ADHD diagnosis and treatment more accessible and affordable will help curtail both economic and social disadvantages faced by consumers.**

Rationale: One common response from consumers was the identification of a difficult and vicious cycle that can emerge in managing ADHD, wherein losing access to medication or other support in managing ADHD symptoms impacts their ability to focus and take the steps to regain this support. In other words, the better supported consumers are, the more able they will be to manage their commitments at work and home. One consumer captured this idea, presented in relation to expanding the NDIS, as follows:

*‘Please let us onto the NDIS. Even if it is on a case-by-case basis and in a separate entry stream, having access to funding and supports will help so many people, which in turn will help the economy by adding functional, capable workers.’*

The economic benefit outlined in the above response was echoed by other consumers who also emphasised the challenge ADHD presents in maintaining friendships and other social connections. Increasing the accessibility of diagnosis and treatment for ADHD would, in CoMHWAs view, allow people living with ADHD to participate more fully and meaningfully in their lives, and would also support the development of more financially secure and socially engaged consumers.

**Recommendation 13: The government should develop strategies for educating employers about ADHD and other neurodivergence, in order to facilitate the inclusion of neurodivergent people into the workforce. Additionally, the government should ensure that neurodivergence is accommodated when accessing government support services.**

Rationale: An important theme raised by consumers in relation to providing support for consumers with ADHD was the challenge involved in pursuing work and navigating government support services while experiencing the symptoms of ADHD. These comments spoke towards a need to develop consideration within existing systems and institutions rather than for new services. However, the theme of expanding the NDIS was frequently paired with this discussion, as the comment below demonstrates:

*‘ADHD should be part of the NDIS. It does impact people and make some aspects of life far more challenging...Government needs to look at neurodivergence inclusion strategies for workforce and also consider the presence of neurodivergence when working with people needing government support.’*

The majority of comments calling for further government action to support consumers with ADHD spoke towards the hope that this change could help to facilitate more successful engagement with both workplaces and friends/family. The impact of ADHD symptoms made these regions of life more difficult to successfully navigate, and there was thus considerable frustration at the barriers for obtaining treatment experienced by consumers. In their view, accessing ADHD treatments would be an important step in regaining autonomy and coping with the demands in their lives.

## ***Concluding remarks***

The key themes—drawn from consultation and survey with consumers—that informed CoMHWA’s recommendations to the inquiry can be summarised as follows:

- The lack of availability of psychiatrists to pursue an ADHD diagnosis.
- The (often prohibitively) high cost of accessing and continuing to receive support from psychiatrists.
- The (often prohibitively) high cost of medication that might be required to provide treatment for ADHD.
- The enduring social and medical stigmas that impact consumers living with ADHD.
- The need for more education for psychiatrists and doctors to heighten awareness of atypical presentations of ADHD symptoms, especially for women and minorities.
- Establishing a system or set of protocols to ensure that consumers, previously diagnosed with other mental health issues, can access psychiatric investigations into a possible ADHD diagnosis that are conducted in good faith without pre-judgement.
- The desire to have access to support networks that utilise peer-workers, and that avoid the clinical language of biomedical dysfunction in favour of providing everyday advice grounded in a shared, lived experience.

It is CoMHWA’s belief that this inquiry has the possibility of helping tens of thousands of Australians who are struggling to manage their experience of ADHD. Our sincere hope is that the recommendations we have outlined above may, if incorporated into future planning, serve to help build a more caring, just and productive society for consumers, and for Australian mental health consumers more broadly.