HealthCare Consumers

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

community.affairs.sen@aph.gov.au

HCCA Submission:
Senate Inquiry into Assessment and Support Services for People with ADHD

Thank you for the opportunity to contribute to the Senate Inquiry into Assessment and Support Services for people with ADHD. The Health Care Consumers' Association is pleased to present this submission to the Inquiry. It highlights the consumer perspective on and experience of ADHD assessment and support services.

Access to timely and affordable assessment and support for ADHD is an issue for many in our community. HCCA's consultation on this subject elicited a substantial number of responses suggesting a significant unmet need within the community.

We hope that the Inquiry leads to change in the structure and provision of services to ensure that the needs of consumers with ADHD can be met safely and effectively in the future.

Yours sincerely

Kathryn Briant
Manager, Policy

14 June 2023

Health Care Consumers' Association
100 Maitland Street, HACKETT ACT 2602 Phone:02 6230 7800
ABN: 59 698 548 902   Email: adminofficer@hcca.org.au
hcca.org.au | HCCA.ACT | @HealthCanberra

HealthCare Consumers

SUBMISSION

Senate Inquiry into Assessment and Support Services for People with ADHD

June 2023

About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Not-for-profits Commission.

HCCA's approach to this submission

HCCA is a member-based organisation and we draw on the views and experiences of our membership and networks to advocate for consumers.

Consumers with ADHD can find that having a diagnosis of ADHD helps them make sense of their life and can provide an opportunity to consider treatment options. Treatment options can include medication, therapy and lifestyle changes, and often a combination of these. When there is a lack of early treatment, combined with the experience of symptoms of ADHD, this can lead to the development of other health issues, such as anxiety and depression. Treatment of these related conditions may be less effective if underlying ADHD has not been diagnosed and addressed.

> **The priority for consumers is safe, high-quality care for ADHD that is accessible in a timely way and integrates diagnosis, treatment and support.**

In preparing our response to this Inquiry we have drawn on the knowledge and experiences of our members and their feedback on access to, and experience of, services related to ADHD in the Canberra region. This feedback has been collated and contextualised to address the Inquiry's Terms of Reference below. There was significant interest in this Inquiry from consumers and we are responding to all the Terms of Reference provided.

Specific Comments addressing the Inquiry's Terms of Reference

(a) adequacy of access to ADHD diagnosis;

Access to diagnosis services for ADHD is currently inadequate. One in 20 Australians has ADHD and the real prevalence is likely higher as girls and adults are thought to be under diagnosed[1]. Children wait long periods to access specialist services in both the public and private systems and adults struggle to find appropriate specialists accepting new patients. Adults are unable to access diagnosis within the public system unless the diagnosis is obtained during treatment for another mental health condition that is provided for in the public system. Private specialist diagnosis is already prohibitively expensive for both children and adults and costs are increasing rapidly as current demand significantly outstrips supply.

Costs and delays in care

The long delays and substantial costs associated with obtaining a diagnosis place significant strain on individuals and families seeking support to manage the symptoms of ADHD which negatively impact their daily life.

> *'Even the children getting diagnosed, it is happening when they're 10/11/12. It is not happening earlier. Once they realise they need it, it is years until it actually happens.'*

---

[1] Attention deficit hyperactivity disorder - ADHD symptoms, causes and diagnosis | healthdirect

> *'You've got families who are literally having to make a decision. Well, who gets diagnosed first? Who can we afford? Who needs to prove it to the people who have to accommodate their needs most?'*

While the availability of diagnostic services varies around Australia[2] there are some significant gaps in service provision that affect everyone. There are currently no public health services providing adult diagnostic services [3]and the wait to access public services is substantial for children and young people. This is worse in some states and regions than others[4].

> *'Myself and most people I know have had to go interstate for diagnosis due to the shortage and expense of psychiatrists in the ACT.'*

While waiting lists in the private sector tend to be shorter, appointments are limited. Finding a provider who is accepting new referrals can be a challenge and consumers told us that you can expect to wait some time to receive an appointment.

There are a range of private service models providing diagnosis – including traditional private specialist practices and ADHD specific diagnostic clinics, which often provide telehealth services for interstate consumers. Consumers told us that access to these services is expensive, and often prohibitively so. Depending on service and location, consumers can expect to pay anything from $1500 to $3500 (and sometimes more) to complete the assessment process and, if appropriate, receive a formal diagnosis. This fee procures assessment and a diagnostic report, but it does not include provision of subsequent support or referrals to appropriate support services.

> *'There is no public funding for adult ADHD assessment in the ACT and I know of several people who have gone without diagnosis because they cannot afford it. This has led to significant negative outcomes like unemployment, drug and alcohol addiction and inappropriate mental health care.'*

Integration of care

Consumers told us that the lack of service options and availability often drives distressed individuals and families to seek care interstate. While this can serve to reduce the wait time for diagnosis for some consumers, it can also lead to difficulties if medications are recommended as part of treatment. HCCA looks more closely at the issues this presents under Term of Reference E on page 13. This is because States and Territories have primary responsibility for medicines regulation, and each state and territory has its own rules around prescribing of, and access to, ADHD medications.

Increasingly, feedback from consumers is that for diagnosis of children with ADHD, paediatricians are pulling back from taking on patients for neurodevelopmental assessment and support. This is thought to be because these cases are complex and time consuming and detract from paediatricians'' ability to provide care to the many

---

[2] Workforce shortage, soaring demand creating mental health crisis especially in rural areas, psychologists say - ABC News

[3] RACGP - New Australian ADHD guidelines released

[4] Lack of clinicians forcing parents to go interstate for ADHD diagnosis, treatment - ABC News

other children with other needs on their growing waiting lists. Access issues are likely compounded by the inappropriateness of the Medicare provisions for services of this complexity[5].

Diagnostic process

Consumers outlined for HCCA that the diagnostic process itself is very involved and includes providing reports from a range of sources including teachers, parents and doctors.

> *'for a diagnosis you need to have a full report from teachers, parents, people who support you to validate your ADHD behaviours. This is incredibly difficult when seeking a diagnosis as an adult'*
>
> *'It is hard to get the validation from parents, particularly when they don't feel like it is an issue (often due to cultural differences, or stigma attached to it)'*
>
> *'Keeping-on-top-of-things in a really prolonged process (huge wait times) is really especially challenging for people with ADHD.'*

The thorough nature of the diagnostic process is not an issue in itself (and should go some way to allaying concerns of those who may question the increasing numbers of people diagnosed with ADHD in recent years), however it can present impediments to diagnosis in adulthood. The lengthy process is likely also to contribute to the inaccessibility of diagnostic and support services – including the significant cost to consumers and the lack of available appointments with providers.

Consumers report that, as well as the diagnostic process itself, the complexity of the health system (including the rules around who can make an official diagnosis and how) is a deterrent to accessing assessment.

> *'There is a lack of information on where to start, who to talk to about your concerns and what the process will be for investigating ADHD behaviours. Most often adults going through the process will find out from their social connections on how to go about the process'.*
>
> *'There's no regulation there. Yes, you're supposed to be going through a psychiatrist but in terms of organisations that can arrange that and what can happen there, it is all over the place.'*
>
> *We're having people get doubts cast about 'is this diagnosis actually happening properly?...It then adds to the stigma.'*
>
> *[It is an] 'Extremely difficult series of hoops to jump for people with executive dysfunction - need to make appointments with GP who may or may not be willing to refer you to a psychiatrist; need to find a psychiatrist who will see adult ADHD patients (good luck with that).'*

---

[5] Paediatric waitlist 'crisis' leaves regional Victorian families desperate to access care - ABC News

Information and communication

There is a lack of high-quality information available to individuals and families considering seeking assessment for ADHD and many consumers turn to peers and social media to find the information they need to make decisions about their ADHD health care. We explore this further under Term of Reference I on page 21.

> *'I was quite lucky in that my GP took time to have an in-depth conversation about my behaviours, how it impacts my life and what I was hoping to achieve… I think quite often this whole component of conversation is missed.'*
>
> *'…we have to try to assemble support from online spaces that may be unsafe or poorly informed.'*

Consumers also report issues around communication from providers, including formal documentation of diagnoses. Standardisation of documentation may be beneficial to increase the willingness of clinicians to act on a diagnosis provided by a different provider. Some consumers have reported that they did not understand that what they were paying for was not a complete assessment/report, or that they did not know that diagnosis from a psychologist may have to be undertaken again by a psychiatrist to access medications. These issues may be reduced if clinicians provided documentation in set formats.

(b) adequacy of access to supports after an ADHD assessment;

Consumers diagnosed with ADHD have told HCCA they find it difficult to access support post-diagnosis. Feedback suggests it is common for consumers to find that diagnosis and support are not well integrated. In fact, many services that have sprung up in response to growing demand for diagnosis do not offer other ongoing support services at all[6].

This means that once consumers receive a diagnosis, they again find themselves independently trying to navigate a complex system of referrals and waiting lists.

> *'What supports? There's no system to tell people what kind of support is available or support (ha) us through the process of* ***accessing*** *supports.*
>
> *'What is really needed is clear supports and referral pathways to be able to seek some support from psychologists trained in ADHD to provide regular ongoing support to clients.'*

Consumers outlined that the same shortages of providers that affect access to diagnosis, impact on the availability of ongoing supports. Whether that support is medication or psychological services, consumers are finding that the clinical staff required to meet community need simply are not there.

---

[6] Fears children with ADHD could lose meds as paediatrician shortage sees service stop prescribing - ABC News

> *‘There are very few psychologists who are trained on ADHD, and even fewer who are trained to support adults with ADHD, so you often end up seeing someone who works with children or someone who has specialities around performance or other areas that are loosely related to ADHD.’*

> *‘There is very little support for ADHD adults in the ACT. Most are reliant on medication and if they are lucky, informal peer support. The lack of formal peer supports is particularly difficult for people diagnosed as adults as we have to try to assemble support from online spaces that may be unsafe or poorly informed.’*

Ideally, diagnosis would lead consumers directly to support to manage the symptoms and life impacts of ADHD. This is not the experience of the consumers who provided feedback to HCCA. The shortage of practitioners is so severe that consumers say they struggle to access any support at all and the restrictions around the prescribing and dispensing of Schedule 8[7] medicines in the ACT can mean that even medications are not available as a treatment for consumers, with a formal diagnosis, who may benefit.

> *‘[I have been] using my GP [for prescriptions], having a transferred authorisation that is going to expire in October. He has tried to send me to another four people [to have the authorisation continued]. He has sent me to the ACT government option. They gave me a phone call and went, ‘alright, well you’ve got medication for now’ and I haven’t heard from them since.*

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

Perceptions of provider priorities

Consumers find that the attitudes of some providers can compound the challenges posed by severe practitioner shortages. Consumers shared with HCCA their perception that some providers are ‘cashing in’ on the increased demand for ADHD related services. To some degree this may be true as corporate providers advertise large salaries and benefits to recruit clinicians to work (often via telehealth) in large diagnostic clinics, while the costs passed on to consumers for diagnosis balloon well beyond CPI or other justifiable increases in fees[8].

> *‘From my own experience, some psychiatrists see ADHD as a ‘cash cow’. Most of my appointments were $300-400 for a 15 minute telehealth check up and prescription refill. If I missed the 6 month deadline, I would have to pay for an $850 initial appointment again’.*

---

[7] Schedule 8 medicines are considered to be controlled medicines or potential ‘drugs of dependence’. https://www.healthdirect.gov.au/scheduling-of-medicines-and-poisons

[8] ADHD clinics capitalise on diagnosis explosion, with some charging up to $3,000 and paying doctors up to $900,000 a year - ABC News

Some consumers also told us they feel penalised for any delay in making an appointment, which may occur due to current cost-of-living pressures making regular visits unaffordable, or ADHD-related challenges with executive function.

Stigma

Consumers are faced with a particular stigma around drug seeking behaviours as well as assumptions that many make about the increase in people seeking ADHD assessment. Some consumers shared with HCCA that they felt uncomfortable presenting to their GP to ask about an ADHD diagnosis.

> *'It is so important to stress here - not every adult seeking a diagnosis wants medication. Sometimes what is really needed is some validation of their struggle'.*

Reliance on medication

In the absence of readily available counselling-style supports, consumers felt that medication is overly relied upon to address the challenges experienced by people with ADHD.

> *'[I] would like to see a greater recognition of the need to support people particularly adults with ADHD to manage themselves outside of medication.'*
>
> *'There are very few psychiatrists with open books in the ACT, and the public waiting lists are very long.'*
>
> *'I have been told in the past that Access Mental Health does not help with ADHD diagnosis and treatment unless it comes up as part of treatment for other significant mental health issues'.*

Even medications can be difficult and expensive to access long term. Consumers reported to HCCA that treating psychiatrists can be reluctant to provide authority to their GP's to prescribe their medications, requiring them to continue with regular, expensive psychiatry appointments in order to access prescriptions to long-established medications on which they are stable. This also exacerbates the shortage of appointments available for those seeking a new psychiatry provider for diagnosis or ongoing management.

> *'[My psychiatrist] was reluctant to provide any information to my GP that would help me choose a different provider or provide them with authority to write my scripts. This is a fairly common experience.'*
>
> *'Most of these issues would have been solved if there were clearer nationally-consistent guidelines for transferring PBS authorisation to GPs and some incentive to do so for stable patients.'*

Capacity of providers

While consumers told us they have found that many practitioners decline to see adult ADHD patients, they have also discovered that those who do are over burdened and can struggle to provide consistent, high-quality care.

> *‘There is such a huge shortage of psychiatrists who’ll see adult ADHD patients that we end up with one or two trying desperately to see everyone who needs help and as a result totally overburdening themselves…’*

The level of demand for services and shortages of providers has had a negative impact on the quality of care provided and on the outcomes for people with ADHD. Consumers told us that they are finding that practitioner knowledge of, and experience in, the variety of recognised ADHD presentations and range of suitable diagnostic tools is unreliable and inconsistent. This makes it difficult for consumers to identify a practitioner who will best meet their needs before joining a waiting list. An appointment with the wrong practitioner can set a consumer’s search for help back substantially, in relation to time, treatment/support and cost.

> *‘GPs are completely hit and miss as to whether they’ll even consider/provide a referral for ADHD. Even psychologists are prone to missing anyone who isn’t the most stereotypical/obvious case ever and turning out to be a demoralising obstacle instead of a source of help.’*

Impact on quality of care and consumer rights

The imbalance between supply and demand for services can also have the effect of enabling providers to act with a certain level of impunity and provide care which is sub-standard. Consumers are reluctant to make complaints about the quality of the care they are receiving when they know the difficulties in access, and that they will need that care ongoing and that others do too.

> *‘If you feel like you don’t have a choice, then you can’t say ‘hey, this is not up to standard’.*
>
> *‘[My] psychiatrist has been so bad at responding to any of his clients I still haven’t got a copy of the paperwork from an appointment I had with him in January last year. My hands are tied to go back and make a complaint and say that behaviour is not acceptable and not up to the standard a licenced medical practitioners should have, because I don’t have other places to go.’*
>
> *‘We’re really stuck when the other option is nobody. It really puts a whole lot of power into the hands of medical practitioners.’*

The sense from consumer feedback is that consumers would not want to risk taking action against an underperforming practitioner – even if they themselves had found an alternative - as it could have a negative impact on other consumers who also need care.

> *‘There’s nobody who is going to hold them accountable because then you leave an option that puts a massive gap [in care] for the community.’*

The current situation for consumers suggests that people are not only uncomfortable asking for their rights under the Australian Charter of Health Care Rights[9] to be upheld, but those rights are not being met by services from the outset. In particular, consumers

---

[9] My Health Care Rights Poster A4 (safetyandquality.gov.au)

highlighted the right to access healthcare services and treatments that meet their needs.

Increasing supply

Some consumers suggested to HCCA that they would like to see GPs become more involved in the diagnosis and treatment of ADHD to improve access in the short term. Consumers recognise the benefits of accessing care from a practitioner with expertise and up to date knowledge of presentations, assessment tools and treatments. However, many find that specialists currently able to diagnose and treat ADHD are not providing best practice, evidence-based care, or are over-burdened and unavailable. There is a crisis of access right now and it is likely that any measures to encourage more specialists into the field of ADHD will only result in greater availability of services in the longer term. We explore the potential for greater involvement of GPs under Term of Reference I.

(d) impact of gender bias in ADHD assessment, support services and research;

Gender bias and assessment

Evidence suggest that gender bias has a particular impact on ADHD assessment[10]. There is a stereotypical presentation of ADHD that more often occurs in males, which practitioners are primed to recognise. Appropriate assessment of other presentations, often particularly impacting females, is more varied. This means the variation in knowledge and approach of providers has a greater impact on people presenting in less stereotypical ways.

> *'Internalised presentations or 'inattentive type' (as opposed to 'hyperactive type') are not what practitioners without specific training expect, to such a degree that they won't consider the possibility – and these presentations or symptom clusters are overwhelmingly those of women. Or, more accurately, those assigned female at birth.'*
>
> *'What is really needed in the diagnostic process is a greater awareness and understanding of the nuances of the behaviours exhibited in males and females to allow for an improved diagnostic pathway.'*
>
> *'My psychologist was so dismissive of my intention to seek assessment that it very nearly made me give up – because I don't "seem ADHD". Which is a really, really common experience for women and girls with ADHD.'*

---

[10] Young, S., Adamo, N., Ásgeirsdóttir, B.B. *et al.* Females with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women. *BMC Psychiatry* **20**, 404 (2020). https://doi.org/10.1186/s12888-020-02707-9

These assumptions about how ADHD presents are also made in the education system (and by parents), where girls are less likely to be identified and provided with relevant support for ADHD related challenges in learning and behaviour[11].

Impacts of gender and cultural bias

Consumers say that missed or misdiagnosis can have long lasting impacts on their mental health and educational and professional achievements.

> *'I was raised a girl, and while my symptoms were clearly present in childhood, my schools failed to recognise the signs. As a teenager, struggling with anxiety and depression due to poorly coping with my undiagnosed condition, I was called 'hysterical' and 'attention-seeking' by teachers, doctors and other adults in my life. This discouraged me from seeking mental health assistance again until well into my 20s, further delaying diagnosis and treatment.'*

These challenges are magnified for people who are from a culturally and linguistically diverse background as diagnostic tools can be culturally biased and community may stigmatise or not recognise ADHD[12].

> *'We also need to acknowledge cultural bias in ADHD assessment, support and research. There is an underdiagnosis in some cultures largely because ADHD is often dismissed with "there isn't anything wrong with you, you're just lazy or need to try harder.'*

Transgender people face even greater barriers to appropriate assessment and care pathways due to the pathologising of transgender identity[13] and the fragmentation of care.

> *'I know of people who have been refused gender-affirming care because they have ADHD and their doctors see them as 'unstable'.'*
>
> *'I had to assure my psychiatrist that my transition was "well-managed" because he was not interested in addressing "those issues" when treating me for ADHD. This is not care that sees the whole person and may in fact cause further harm.'*

---

[11] Young S, Adamo N, Ásgeirsdóttir BB, Branney P, Beckett M, Colley W, Cubbin S, Deeley Q, Farrag E, Gudjonsson G, Hill P, Hollingdale J, Kilic O, Lloyd T, Mason P, Paliokosta E, Perecherla S, Sedgwick J, Skirrow C, Tierney K, van Rensburg K, Woodhouse E. Females with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women. BMC Psychiatry. 2020 Aug 12;20(1):404. doi: 10.1186/s12888-020-02707-9. PMID: 32787804; PMCID: PMC7422602.

[12] Miyasaka M, Kajimura S, Nomura M. Biases in Understanding Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorder in Japan. Front Psychol. 2018 Feb 28;9:244. doi: 10.3389/fpsyg.2018.00244. PMID: 29541049; PMCID: PMC5836146.

[13] "Pathologization – Being lesbian, gay, bisexual and/or trans is not an illness" For International Day against Homophobia, Transphobia and Biphobia - Tuesday 17 May 2016 | OHCHR

The prevalence of ADHD in transgender and non-binary people is higher than in other groups[14] and suitable diagnostic and treatment pathways should be available.

Adequacy of funding

While consumers who provided feedback to HCCA were not aware of the adequacy (or otherwise) of current research funding and activity around ADHD and gender, it was noted that:

> *'Whether there's a genetic or hormonal difference or a socialisation thing or a combination thereof is not sufficiently researched, but the end result is that it's an extra obstacle.'*

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

Many medications often prescribed for consumers to help manage the symptoms of ADHD are in the category of Schedule 8 (Controlled) medicines. In the ACT, prescribers must obtain ACT Chief Health Officer approval before prescribing a controlled medicine to a person[15]. Computer generated scripts also require confirmatory handwriting in the ACT, meaning scripts cannot be emailed/texted.

For consumers this creates a barrier to accessing telehealth or interstate services if medication is needed.

> *'… when people move interstate, and the prescribing doctor agrees to continue care via telehealth - there is an issue with the new state chemist accepting a prescription from an out of state clinician'.*

Moving to a new area can also become a problem for consumers who obtain care from a new local provider. This is because providers often require new patients to undergo diagnosis again before they will continue prescribing even long-established treatments. This is expensive and time consuming for consumers, and can delay ongoing access to settled and effective medications.

> *'In order to continue your medication you have to find someone who is taking someone on…and a lot of them won't prescribe to you unless they confirm your diagnosis by doing it again.'*

One alternative that can provide a stop gap for consumers is for their GP to apply for authorisation to prescribe ADHD medications. Not all are willing to do this because of the time it takes to step through the process. Consumers expressed concern that this

---

[14] Teddy G. Goetz & Noah Adams (2022) The transgender and gender diverse and attention deficit hyperactivity disorder nexus: A systematic review, Journal of Gay & Lesbian Mental Health, DOI: 10.1080/19359705.2022.2109119

[15] FAQ - Controlled Medicines Prescribing Standards (act.gov.au)

can mean that the overall costs in time can outweigh the benefits for the GP. Some had experienced their psychiatrist's reticence to provide authorisation, for example:

> *'…there may be a lot of reluctance on the part of the psychiatrist to transition the patient to a GP'*

Schedule 8 prescriptions are only valid for 6 months, meaning that patients need to see their provider twice a year to continue accessing their medications, even when they are well established. This can be prohibitively expensive if a specialist provider elects not to provide authorisation for a GP to prescribe.

> *'Once diagnosed, I have found it relatively easy to afford my ADHD medications. However, the ongoing cost of returning to a psychiatrist for script renewals became such a barrier that I have had to ration my medication to put off appointments until I could afford them'.*
>
> *'Personally the cost of meds isn't prohibitive for me – but the cost of psychiatrist appointments is so high that the cost of medication pales in comparison. Like if you've afforded the several hundred dollars for a first appointment (and still many but not quite* ***as*** *many hundreds of dollars for ongoing appointments – which are important for medication management, at least initially), then the cost of meds is probably survivable.'*

Some consumers have found that there is pressure to take a particular type of drug because providers make recommendations based on assumptions about potential misuse of *dexamphetamine and methylphenidate*. Even when consumers find these short acting medications effective and preferable, there can be pressure to change to long acting alternatives to avoid the perception of potential for misuse.

> *'Myself and others that I know have experienced pressure from doctors or pharmacists to move to long-acting forms of medication when we are stable and happy with the shorter acting forms. This is because there is an assumption that the short acting forms of dexamphetamine and methylphenidate will be abused.'*

The potential for misuse of ADHD medications drives a lot of the challenges people with ADHD encounter in accessing their medications. The inconsistencies between state and territory-based regulations may compound these issues.

HCCA suggests it would be worth exploring the potential of real time prescription monitoring, which exists nationally, to engender confidence in safer inter-jurisdictional access to Schedule 8 prescriptions. Real time monitoring of prescribing and dispensing, wherever in Australia it is used, might encourage state and territory governments to consider and implement consistent regulation at a national level. Currently, regulatory inconsistencies between the jurisdictions' implementation of the real time prescription monitoring system impede the use of the system to create a truly national medication monitoring (and by extension, prescribing and dispensing) environment. National regulation (either by the Commonwealth or by the agreement of the states and territories) mandating its use should be possible, and could ensure that potential misuse of Schedule 8 medicines can be identified regardless of the state or territory where it occurs. This could provide confidence in the safety of cross-border prescribing and dispensing and enhance equity of access.

This additional layer of oversight may allow for GPs to more easily take on the prescribing for consumers who are well established on their ADHD medications. It would also mean greater accessibility of prescriptions for consumers accessing assessment interstate and via telehealth.

(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;

Although consumers noted that they would like to see greater provision of support to those diagnosed with ADHD, consumers also told us that they hold concerns over the appropriateness of the NDIS as the vehicle for that support. Consumers say that it would be rare for ADHD to meet any primary disability threshold set to access supports via NDIS.

> *'Whilst it would be beneficial for those who need significant support to be eligible for the NDIS, many people with ADHD may not need significant enough supports to qualify for the NDIS. This means that relying on the NDIS to support people with ADHD is going to miss a huge number with unmet needs. There is a need for tier 2 funding to provide community based supports, like peer support.'*

Instead, HCCA believes it is likely more consumers may benefit from access to better targeted financial support via Medicare. Regardless of the mechanism for financial support, people with ADHD would benefit greatly from better access to the care they need.

> *'I would love to see NDIS covering some of the costs of seeing psychiatrists. And/or decent coverage by Medicare'*
>
> *'[We need] some kind of subsidisation because you have multiple family members who need access to care. At the moment, it is like 'what can we afford to get done'? Who needs help the most? You should be able to get all your kids life-saving support.'*

Access to financial support is particularly pressing when access to public care options are so inadequate and disconnect between supply and demand is putting upward pressure on private service costs.

(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;

Many consumers who provided feedback noted that the inconsistencies around regulation of providers prescribing and dispensing medications was an impediment to continuity of care and equitable access.

People who want to continue their ADHD medications find moving states problematic as they are unable to continue with their current prescriber as their prescriptions may be unable to be filled in their new location and finding a new provider is difficult. The disconnect between individual providers is also an issue as they often decline to honour a previous diagnosis and require repetition of the process in order to prescribe medications already well established.

> *‘It is incredibly difficult to have a new psychiatrist prescribe medication for ADHD without needing to go through the diagnostic process again’.*

Consumers also suggested that consistency of prescribing requirements nationally would mean they have greater choice in provider and would go some way to equalising access geographically.

The lack of recognition of ADHD as a disability and lack of integration of ADHD into extant disability support structures at all levels of Government - including the NDIS and educational systems - means help for people with ADHD is, at best, ad hoc. It tends to be entirely consumer driven.

> *‘There is no provision of financial support or acknowledgement of ADHD as being a chronic condition that requires long-term and frequent visits with mental health professional to manage ADHD - to access medicare rebates, patients need to continuously see a GP to renew a mental health plan - there needs to be a more streamlined process’.*
>
> *‘There is no funding for support for students with ADHD in the same way there is for Autism or other neurodevelopmental conditions.’*
>
> *‘My son ‘only’ has ADHD so he can’t access extra support at school.*

Consumers told us they feel unsure if national standardisation would enable help or hinder. Standardisation of diagnostic processes, for example, may serve to exclude a range of consumers with a-typical presentations of ADHD (and potentially further entrench the gender divide). Less regulation or standardisation of diagnostic processes and tools allows for greater innovation and recognition of individual presentations and experiences and consumers value the potential of this more individualistic approach.

> *‘People are always sending me new questionnaires, new diagnosis tools, various things that different psychiatrists are using in order to produce an ADHD diagnosis.’*

> *'… you would go through all of these different processes and depending on who you end up with to try and get an ADHD diagnosis… you might get diagnosed with one person, but you might not with another depending on how your presentation is.'*

Consumers can also see some potential benefits of regulation and standardisation. Some reflected on the greater certainty it might give people seeking a diagnosis - that the provider they manage to get in to see will assess them in the same way as any other.

> *'We need to deal with the variability of presentation, but we also need people not to be at the complete mercy of whatever provider they're so lucky to get in to see.'*

(h) the adequacy of Commonwealth funding allocated to ADHD research;

Consumers see that our evolving understanding of ADHD and other neurodevelopmental conditions has uncovered gaps in our knowledge.

> *'There are so many things that need so much more research when it comes to ADHD. How sex and gender differences … play into it is in dire need of more understanding. Genetics too. Comorbidities – anecdotally, there seem to be a lot of comorbidities for ADHD (e.g. Ehlers-Danlos Syndrome, gut issues, Positional Orthostatic Tachycardia Syndrome, other neurodivergence and/or mental health issues) but no understanding as to how/why and nothing like routine screening for other issues if one is detected.'*

The growing awareness of the role of genetics and common co-morbidities, means we have a new field of study available looking at ADHD through a more wholistic lens – seeing it as one feature of whole-body system differences[16] and recognising the impact of environment. The different experiences of people with ADHD through the COVID-19 pandemic – in terms of their experiences of lockdowns[17], but also their susceptibility to severe disease[18] and Long-COVID-19 (in part due to being more susceptible to poor mental health[19]).

> *'Things like the pandemic and corresponding lockdown… there have been a lot of people who have recognised and sought diagnosis because they have*

---

[16] Pan, PY., Bölte, S. The association between ADHD and physical health: a co-twin control study. *Sci Rep* **10**, 22388 (2020). https://doi.org/10.1038/s41598-020-78627-1

[17] Pandemic triggers rise in ADHD referrals | Monash Health

[18] Merzon E, Weiss MD, Cortese S, Rotem A, Schneider T, Craig SG, Vinker S, Golan Cohen A, Green I, Ashkenazi S, Weizman A, Manor I. The Association between ADHD and the Severity of COVID-19 Infection. J Atten Disord. 2022 Feb;26(4):491-501. doi: 10.1177/10870547211003659. Epub 2021 Apr 2. PMID: 33797281.

[19] Wang S, Quan L, Chavarro JE, et al. Associations of Depression, Anxiety, Worry, Perceived Stress, and Loneliness Prior to Infection With Risk of Post–COVID-19 Conditions. *JAMA Psychiatry.* 2022;79(11):1081–1091. doi:10.1001/jamapsychiatry.2022.2640

> *encountered how well they cope working from home (if that was their experience), or exactly how well they don't cope working from home.'*

> *'Getting some more research into environmental factors would be something that I think would help a lot of people because there are a lot, anecdotally, of people finding themselves aware of their ADHD through recent circumstances'.*

New research into ADHD has the potential to enable more a more proactive approach to identifying and managing co-morbid conditions as well as improving treatment pathways for people with ADHD more generally.

(i) the social and economic cost of failing to provide adequate and appropriate ADHD services;

Consumers who have been diagnosed and provided appropriate treatment and support are keenly aware of lost opportunities – personally and professionally.

> *'I, and people I know, frequently say "who knows what I could have achieved had I known this a lot earlier".'*

Consumers are also aware of the potentially life limiting problems that can occur with untreated ADHD. People with ADHD are more likely to engage in risk taking behaviours[20]. They are also more likely to experience poor mental health[21].

> *'Not addressing the needs of people with ADHD very often leads to a lot of other problems like anxiety, drug and alcohol abuse, underachieving/underperforming in work/study.'*

> *'I know that myself and people with undiagnosed ADHD have developed substance abuse issues as a coping strategy for their ADHD. This has financial costs but also major flow on costs to the health system and our communities.'*

The costs of undiagnosed or untreated ADHD born by the individual are significant.

> *'[They are] serious costs – scary costs, to be honest. The impact of not having diagnosis or treatment (of not having any explanation other than "well I guess I'm just a no-good person") is frankly dangerous to individual safety.'*

> *'People with ADHD are more likely to be susceptible to things like substance abuse, they're more likely to 'self-medicate', they're more likely to seek other means of trying to get by in life.'*

The costs to consumers with undiagnosed or untreated ADHD are both personal (in terms of mental and physical health and safety) and financial. Consumers report the

---

[20] Shoham R, Sonuga-Barke EJ, Aloni H, Yaniv I, Pollak Y. ADHD-associated risk taking is linked to exaggerated views of the benefits of positive outcomes. Sci Rep. 2016 Oct 11;6:34833. doi: 10.1038/srep34833. PMID: 27725684; PMCID: PMC5057118.

[21] ADHD more strongly linked to anxiety and depression compared to autism – new research (theconversation.com)

challenges of poor executive function can result in financial hardship – due to mismanagement of money and impulsive spending.

> *‘Undiagnosed ADHD can manifest itself in several ways that have significant personal financial costs – e.g. forgetting bills due to poor executive function, missing medical appointments and therefore paying cancellation fees, impulsive spending.’*
>
> *‘People can be completely incapacitated by unmanaged ADHD – all the economic stuff about not being able to work, but it can also prevent basic personal care, socialising, living life in general.’*

Poorly managed ADHD can pose significant challenges to employment due to executive dysfunction, lack of employer adjustments and the resulting burn-out.

> *‘Personally, I have experienced significant burn-out, employment set-backs and poorer health outcomes due to being undiagnosed for 26 years of my life. I have burned out of previous jobs because I did not have strategies to manage ADHD nor the language to ask my employer for adjustments.’*

The personal costs of misdiagnosis are also significant.

> *‘Due to misdiagnosis, I was on medications from ages 13-26 which included side effects such as weight gain, brain fog and fatigue. These side effects exacerbated both my arthritis and my brain condition, which has lead to significant reduction in my ability to work and major costs to access further health care. Once diagnosed, I was able to stop those medications and manage my health significantly better. I can now work more and have been able to reduce a number of other medications, however, the long term effects on my health such as exacerbated arthritis, and mental health issues are permanent.’*
>
> *‘In the absence of ADHD diagnosis people are ineffectually treated for years/decades for depression and anxiety without seeing the actual cause of their struggles or any real improvement.’*

The Deloitte Access Economics report *The Social and Economic Costs of ADHD in Australia*[22] assesses the impact at $12.8 billion in financial costs and $7.6 billion in wellbeing costs. With more appropriate access to high-quality assessment and treatment as well as improved recognition and acceptance of useful accommodations in the workplace and school system, HCCA believes these costs could be significantly reduced.

---

[22] The social and economic costs of ADHD in Australia | Deloitte Australia | Deloitte Access Economics, Healthcare, Economics

(j) the viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD;

Consumers generally commented favourably on the Australian ADHD Professionals Association's clinical practice guideline for ADHD. However, the experience of consumers seeking diagnosis and treatment still does not reflect the guideline and its impact has been limited in terms of making a difference to outcomes for consumers.

> *'The recommendations acknowledge that there needs to be ongoing non-pharmacological supports provided to people with ADHD - this is not communicated well with patients and when it is, it is difficult to access the supports.'*
>
> *'The recommendations while sound aren't really viable until there are more trained practitioners and a reduction in the cost and logistical burden on seeking support.'*

Some consumers remain concerned that the guidelines are not sufficiently evidence based – reflecting the limits of up-to-date research around ADHD.

> *'The feedback on those recommendations is essentially that not enough is evidence based.'*
>
> *'Like a lot of this stuff there isn't an evidence base because we haven't, you know, looked at it yet.'*

Consumers would like to see greater evidentiary rigour behind future evolutions of the guideline.

> *'We should be doing research on the various diagnostic tools that have been used. What tools are resulting in who getting a diagnosis? What tools are resulting in people with varied presentations achieving a diagnosis.'*

Despite their noted concerns about the evidence base behind the guideline, consumers are appreciative of having Australian based resources for diagnosis and support – which remain rare – and would like to see more recognition of cultural and environmental factors.

> *'A lot of the resources that are online, a lot of things available for people to use, a lot of the diagnostic criteria are America or UK based. You know there's not things that look at the impact of our culture and the way we do things.'*

(k) international best practice for ADHD diagnosis, support services, practitioner education and cost;

Consumers expressed in their feedback to HCCA that 'best practice' is not collectively understood by practitioners. There remains great variation in the diagnostic process and treatment pathways as well as in recognition of ADHD traits in both adults and children.

The current system is not always consumer-centred[23] and tends to be procedural in nature rather than focussed on the particular needs and goals of the individual seeking care.

> *‘There is almost nothing in the diagnostic process that asks about the impact your ADHD symptoms have on you - this needs to be acknowledged in the diagnostic and management process because ultimately, the way a person perceives their own strengths and weaknesses impacts how they are able to function in the community.’*

The process of diagnosis itself can be damaging to a consumer’s mental health being based on a deficits model with an external focus.

> *‘The questions asked in the DSM and the diagnostic process is all about the negative impact ADHD symptoms has on other people.’*

The accepted diagnosis process is also heavily weighted towards the perceptions of others of the observable behaviours associated with ADHD.

> *‘Other people's perceptions impact whether you even get assessed let alone a diagnosis - e.g. teachers don’t recognise the intelligent, gets bored easily and very chatty students as having ADHD symptoms.’*

Consumers would like to see a move to a greater focus on the experience of the individual seeking diagnosis and care and on strengths focussed treatment and management.

(l) any other related matters.

With a fragmented system of care – inaccessible and not well integrated or well understood by providers or consumers – reliable and accessible information for consumers is essential. Currently many turn to the advice of their peers and to the internet, in particular to social media[24], for information about both ADHD and the health system.

> *‘I provide people with information. I love doing that, but I hate the fact that there are people that need me to do that because there should be better sources.’*
>
> *‘Why are people getting their information from social media? It's not accurate. A lot of the time it's not accurate. But where else do people have to go? You know, what other options do they have?’*
>
> *‘I would much rather that they could get their information from somebody in the medical profession or in the health care field. And the problem is they can’t. So*

---

[23] HCCA Consumer-Centred Care Position Statement https://www.hcca.org.au/wp-content/uploads/2022/06/20211208-Final-Consumer-Centred-Care-Position-Statement.pdf

[24] ‘Changed my life’: how social media is aiding adult ADHD diagnoses (smh.com.au)

> *they go to places like TikTok, they are going to places like Facebook. A lot of information there is great... [but] A lot of it is not.'*

While changes to the health system are vital to improve the accessibility and experience of care for people with ADHD, it is also important that people have easy access to high quality information to guide their health decisions and provide support where it is not currently offered by the system.

Although consumers have expressed that they believe that specialist assessment and support is optimal, they take the view that care must be available to those who need it when they need it. Current circumstances mean the specialist model of care is likely to inaccessible to many for the foreseeable future and we feel that consideration should be given to alternative models of care including hybrid care, which relies more strongly on General Practitioners.

Despite their already onerous workload, GPs are well placed to provide carefully considered elements of ADHD related care with the right guidelines and training[25].

> *'There were a few bits of feedback about, you know, GPs not being a long-term solution but we are not necessarily saying they are a long term solution. But what are we doing in the meantime? Are we just going to leave people by themselves?'*

Consumers see GPs as suitable providers due to their continuity of care and longitudinal view of patients – the ability to form a more wholistic view of the individual and their challenges over time and to provide ongoing, readily accessible support.

> *'GPs will have a better idea of the person in front of them.'*
>
> *'If they are their regular GP they will understand that person far better than a specialist they see once every six months.'*
>
> *'I would rather somebody that knows the patient, somebody that has that amount of history and somebody that has some level of education available to them for support.'*

The priority for consumers is safe, high-quality care that is accessible when it is needed and integrates diagnosis, treatment and support. Upskilling GPs to take a greater role as a member of a multidisciplinary care team, either in terms of diagnosis or treatment, may mean easier and more affordable access and care.

---

[25] RACGP - New Australian ADHD guidelines released