aadpa | australian ADHD professionals association

Submission to the Senate Standing Committee on Community Affairs.

Barriers to consistent, timely and best practice assessment of Attention Deficit Hyperactivity Disorder (ADHD) and support services for people with ADHD.

9 June 2023

Contents

www.aadpa.com.au
admin@aadpa.com.au
ABN: 85 616 076 049

Introduction

What is ADHD?

ADHD is a neurodevelopmental condition that affects approximately 5-7% of children and around 2.5% of adults. The condition is defined by excessive levels of inattention and/ or hyperactivity- impulsivity that are inappropriate for developmental stage. It is widely recognised that access to accurate diagnosis and appropriate support services is critical to enable individuals with ADHD to reach their full potential.

ADHD is associated with a wide range of risks including:

- relationship problems
- family breakdown
- poor academic achievement
- increased unemployment
- teenage pregnancy
- abuse
- anxiety
- depression
- eating disorders
- substance misuse
- suicide ideation and completion
- accident and injury
- criminality and incarceration
- physical health problems
- decreased life expectancy

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (5th Ed), more commonly referred to as **DSM-5** is the primary tool used by healthcare practitioners for the assessment and diagnosis of ADHD in Australia. The World Health Organisation's International Classification of Disease (ICD-11) is another commonly used resources for diagnosis.

There are three presentations of ADHD:

The predominantly inattentive presentation

The predominantly hyperactive –impulsive presentation

The combined presentation (symptoms of both inattentive and hyperactive-impulsive subtypes)

The following are the key criteria in the DSM-5 that are considered when diagnosing ADHD:

1. A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development. (Children: must have at least 6 symptoms and adults must have at least 5 symptoms to meet criteria in the domains of inattention and/or hyperactivity-impulsivity).
2. Symptoms were present before the age of 12 years.
3. Symptoms are present in at least two settings.
4. There is evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.
5. A diagnosis is not better explained by another condition.

About AADPA

The Australian ADHD Professionals Association is committed to delivering outcomes that will improve the lives of those living with ADHD. Our membership has a diversity of voices, expertise, knowledge, and lived experience that informs our decision-making and priority-setting, and we are committed to further increasing the involvement of people with lived experience in all our activities.

We seek opportunities that will enable professionals to provide best-practice ADHD assessment, treatment and support, and promote education that assists consumers to make informed treatment decisions and foster self-determination and personal empowerment.

Since its inception in 2016, AADPA has led a broad range of initiatives and has conducted a series of important research studies in support of our vision.

Recent Projects

1. **Australian Evidence-Based Clinical Practice Guideline for ADHD** (2022) *Endorsed by all major Australian medical and allied health colleges and associations, as well as the World Federation of ADHD and ADHD New Zealand.*

2. **The Social and Economic Costs of ADHD in Australia**
   Deloitte Access Economics (2019)
   Costs Australia more than $20 billion per annum.

3. **ADHD Clinical Guideline Consumer Companion** (2023)
   An easy to read and accessible guide for non-clinicians.

4. **National Prescribing Manual** (In development)
   Will provide detailed advice about the safe and effective use of medications to treat ADHD.

5. **Talking About ADHD** (2020)
   Language Guide about the best way to talk about ADHD.

A recent piece of AADPA research that is directly relevant to this inquiry is our systematic review examining the unmet needs of consumers with ADHD, published in the prestigious Journal of Child Psychology and Psychiatry[1].

Our research showed that people with ADHD and their families reported substantial unmet needs including the need to:

- invest more time into finding and applying treatments that go beyond medication.
- improve ADHD-related education/training.
- improve access to clinical services.
- Improve carer support and financial assistance.
- increase focus on providing school-based accommodations and support.
- conduct ongoing research into improving real world treatment outcomes.

Recommendations to address these unmet needs include:

- improving access to and quality of multimodal care provision.
- incorporating recovery principles into care provision.
- fostering ADHD health literacy.
- increasing consumer participation in research, service development and ADHD-related training/education.

Based on the evidence synthesised in our ADHD Clinical Practice Guideline, our own research, and our collective experience and expertise, we would like to highlight the following issues that represent significant barriers to consistent, timely, and best practice assessment and support for ADHD in Australia.

[1] Bisset, M., Brown, L. E., Bhide, S., Patel, P., Zendarski, N., Coghill, D., Payne, L., Bellgrove, M. A., Middeldorp, C. M. & Sciberras, E. 2023. Practitioner Review: It's time to bridge the gap - understanding the unmet needs of consumers with attention-deficit/hyperactivity disorder - a systematic review and recommendations. J Child Psychol Psychiatry.

A. Adequacy of access to ADHD diagnosis:

Currently, significant challenges impede access to timely and accurate ADHD assessments in Australia. These barriers significantly increase the burden placed on people with ADHD and their families, carers and supporters, and on Australian society more generally.

This urgently needs to change.

Interventions that increase access to ADHD assessments within public health settings are overdue, as are strategies that aim to reduce waiting times, increase the availability of affordable assessments and improve health professional expertise in diagnosing and treating ADHD.

The recommended approach to assessment for ADHD is described in detail in the ADHD Clinical Practice Guideline. There are several overlapping issues that contribute to the problems with access:

1. A lack of integrated education contributes to workforce shortages.

Clinicians conducting ADHD assessments require basic and specialist knowledge, skills and training. However, training in the assessment and management of ADHD is only integrated into Australian healthcare provider education programs in a cursory way.

Australian healthcare professionals that have undertaken significant training - in addition to their university qualifications, and developed the expertise required to diagnose people with ADHD, mostly fall within three groups: paediatricians, psychiatrists and psychologists.

There are some trained and experienced specialist nurses and general practitioners qualified to assess people for ADHD but they are in the minority.

Workforce shortages within all these professional groups currently impedes timely access to ADHD assessment. To rectify this, education on the assessment and management of ADHD needs to be routinely integrated into either basic and specialist training programs for paediatricians, psychiatrists, psychologists, general practitioners and nurses so that members of these professional groups feel adequately trained and skilled in providing assessments for ADHD.

2. Complex cases require multidisciplinary assessments.

As the AADPA ADHD Clinical Practice Guideline highlights, a best-practice, comprehensive assessment for ADHD needs to consider the common coexisting conditions, including both physical and mental health conditions. These conditions can increase complexity and often add to the impact of ADHD. As such, multidisciplinary assessment is often required which evidence indicates leads to better quality care.

3. Long waitlists in private practice and lack of multidisciplinary services.

Most of the care for ADHD in Australia is currently delivered through the private sector where clinicians often work in independent practice rather than as part of a multidisciplinary team. This increases the difficulty of getting a comprehensive assessment. People are frequently referred to multiple professionals working in different settings and are often required to wait on several different waiting lists.

4. Rising cost of ADHD assessments.

As most ADHD assessments are currently conducted within the private sector the cost of completing an assessment is considerable. This represents a significant financial barrier for many people with ADHD who, because of their ADHD, are often less well off than many of their peers.

There are also reports, in Australia and elsewhere, that increased demand for assessments against a backdrop of poor availability of services has led to some clinics increasing prices further, making access even more difficult. Unfortunately, there are also reports that the assessments being offered by some new clinics, many of which operate via telehealth, do not meet the quality standards set out in the ADHD Clinical Practice Guideline. AADPA does not support increased access that comes at a cost of reduced quality.

5. Restrictive models of care.

In Australia most ADHD assessments are conducted by paediatricians, psychiatrists and psychologists. However, in many other countries such as Canada and the United Kingdom, general practitioners and nurses make significant contributions to the assessment processes.

In these models of care, GPs and nurses work alongside psychiatrists, paediatricians and psychologists. Nurses are trained to gather information required for assessment and monitoring of treatment and work in collaboration with senior medical staff to conduct the assessments[2]. These models demonstrated increased access and reduced waiting times. They were also shown to deliver improved overall care, with nursing staff providing an important case management role that was very highly regarded by the patients and their families.

AADPA is currently involved in developing several models of care trials between specialists and GPs, particularly in regional areas, and recommends that Australia work toward expanding the professionals involved with diagnosing ADHD.

6. ADHD is under recognised.

In addition to workforce and training issues, under recognition of ADHD in Australia impedes access to care. However, we believe this is slowly changing and we are seeing greater awareness of ADHD, particularly in women and girls and more generally in adults.

This is a positive trend and is one that will continue to grow. Recent data suggests that for primary aged children, we are recognising ADHD at a reasonable rate. Although rates of treatment in youth and adults are still well below those that would be expected from epidemiological data[3]. This highlights the continuing need to focus on identifying ADHD.

However, recent media focus on the rates of medication being prescribed can be misleading if taken out of context. Our recent analysis of Australian prescribing data suggests that only around one in ten adults

[2] Coghill, David & Seth, Sarah. (2015). Effective management of attention-deficit/hyperactivity disorder (ADHD) through structured re-assessment: The Dundee ADHD Clinical Care Pathway. Child and Adolescent Psychiatry and Mental Health. 9. 10.1186/s13034-015-0083-2.

[3] Bruno C, Havard A, Gillies MB, Coghill D, Brett J, Guastella AJ, et al. Patterns of attention deficit hyperactivity disorder medicine use in the era of new non-stimulant medicines: A population-based study among Australian children and adults (2013-2020). Aust N Z J Psychiatry. 2022:48674221114782.

with ADHD are currently being treated with medication.[4]

Together, all these factors have led to long waiting times across the nation but particularly in regional and rural areas. This is leading to significant delays in diagnosis and access to intervention which results in additional negative impacts and outcomes for individuals with ADHD and their families.

Recommendations:

- Improve training of healthcare staff, including paediatricians, psychiatrists and psychologists, general practitioners, nurses and other allied health professionals in the assessment and management of ADHD.
- Workforce planning in these disciplines needs to consider the increased recognition of ADHD and plan appropriately.
- The provision of training in the assessment and management of ADHD should be recognised as a priority by universities and the professional bodies in medicine, psychology, nursing and allied health.
- Training should start early in these professional careers and be ongoing to keep up with new evidence and approaches. We strongly believe that this is the only way that we will ever have an adequate skilled workforce.
- Redesigning services to ensure greater access and availability of ADHD assessments, and ongoing care, within primary care and public sector secondary care services. This applies equally to paediatric, youth and adult settings.
- Increase funding for public services and their ability to deliver multidisciplinary approaches to assessment and management. Currently many services regard ADHD as out of scope for publicly funded health services. We believe this is unacceptable and urge the inquiry to consider this perspective.
- Encourage public and private sectors to work together more closely to provide a comprehensive approach to assessment. The inquiry could consider whether there are ways to incentivise private practitioners to work towards this aim.
- Foster the development of models, that allow GPs and nurses an extended role in the assessment and management of ADHD. Recent inquiries at state level (such as the 2020 NSW Henry Review[5]) have indicated that it is unrealistic to think that there will ever be enough secondary care medical practitioners to adequately manage the demand for ADHD assessment and ongoing management.
- Change the way that funding for ADHD assessment and management are allocated, and effect changes in prescribing regulations that facilitate the prescribing of ADHD medications in primary care settings.
- Increase awareness training for health professionals as well as those in education, justice, welfare and employment sectors.

[4] Bruno C, loc. cit.
[5] https://www.health.nsw.gov.au/kidsfamilies/paediatric/Pages/henry-review.aspx

B. Adequacy of access to support after receiving an ADHD assessment:

Access to care continues to be an issue for Australians with ADHD even after they have received a diagnosis. The ADHD Clinical Practice Guideline makes very clear recommendations that people with ADHD should receive multimodal treatment. Please note that our guideline uses the term 'should' to denote the strongest type of recommendation which is underpinned by high-quality evidence and feasibility of implementation.

In practice what this means is that people with ADHD should have access to a combination of high-quality psychoeducation (process of providing education and information), alongside medication and non-medication approaches. This includes evidence-based parent training (for children) and cognitive behavioural therapy. These approaches are seen as complementary with different strengths that together can provide a holistic approach to supporting people with ADHD. The rationale for this is:

1. Psychoeducation forms the platform from which those with ADHD can be properly engaged in collaborating with health professionals in making key treatment decisions and choices.
2. Medication treatments are the most effective approach to reducing core ADHD symptoms. It can help people reach a state of mind whereby they are more able to benefit from education, psychological therapies, vocational support etc.
3. Non-pharmacological approaches are also important. While medication treatments can also lead to improved functioning and a better quality of life they are, on their own, unlikely to improve all aspects of someone's life. For younger children, parent training approaches can help improve parent child relationships and improve positive aspects of parenting as well as reduce oppositional behaviours. Cognitive behavioural approaches can help older children, youth and adults with ADHD manage and organise their lives and address many of the negative feelings and beliefs that are present for many people with ADHD.

Professional workforce shortages also impact delivery of treatments and interventions these are outlined here:

1. The lack of training for core health professionals who manage ADHD limits the quality of psychoeducation that is delivered, and the funding protocols, both in the private and public sectors, do not support the delivery of high-quality psychoeducation.

2. The lack of research evidence regarding the active ingredients of high-quality psychoeducation. Clinical experience has highlighted that current approaches are highly variable in both content and quality. We are proposing to conduct further research in this area as a collaboration between lived experience and healthcare professionals.

3. The lack of skilled practitioners trained to deliver ADHD-specific parent training programs, particularly in the public sector. In many countries, these programs are delivered in the community free of charge to the consumer by community health services or not for profit consumer led organisations. They can be delivered one-to-one or in groups, depending on the setting. A few groups in Australia do this, including our colleagues at the ADHD Foundation and ADHD WA. But a paucity of funding means they often need to charge a small fee.

4. A similar lack of skilled practitioners trained and willing to deliver ADHD- specific cognitive behavioural approaches, particularly for youth and adults. This is due both to there being too small a workforce, who are already over stretched and struggling to cope with demand from more general mental health difficulties, and a lack of training in ADHD and ADHD-specific approaches. These programs exist and have been shown to be effective but they require training that is currently not available. As with all other aspects of ADHD, these problems are found in both the private and public sectors but are most acutely felt within the public sector where ADHD treatment is notably under-resourced, particularly for adults.

5. There are currently restrictions about who can prescribe ADHD medications and these differ across the states and territories. This makes it very difficult to define national care pathways for the initiation and continuing prescribing of ADHD medications across the country. This area is a major focus for AADPA as previously mentioned we are developing a national manual but this requires investment.

6. Many psychiatrists currently do not feel skilled or confident in prescribing for ADHD and many currently do not see it as part of their remit, which over time has become more focussed on managing so called 'severe mental illness'.

7. Shared care between primary and secondary care is the norm in many other countries but is currently challenging in Australia. While shared care is possible in some circumstances it is complex to arrange and varies greatly across the country. General practitioners are very skilled and experienced in chronic disease management. The barriers to GPs becoming more involved in the ongoing care of people with ADHD include access to training and support, the restrictions on prescribing stimulant medications which, as highlighted above, vary across the different states and territories, and funding models.

   The recent Federal Budget allocated funding for "Voluntary Patient Enrolment" for patients with chronic conditions. People with ADHD should qualify for this group and this would make it easier for GPs to work with this group.

8. ADHD Coaches are an important resource for supporting people with ADHD. While Australia is leading the way for ADHD coaches, there is still a long way to go. We need to develop the professionalisation and accreditation pathways for coaches. We also need to develop an evidence base to properly determine their effectiveness and how best to integrate their work into that of other health care professionals.

9. Another key issue is the need to integrate support and treatment services into treatment pathways and packages of care so that those with ADHD can receive the multimodal care recommended by the Guideline. While there are some examples of good practice, much of the care currently provided is delivered in relative isolation and without any real coordination or integration.

   The Guideline recommends that every person with ADHD should have someone to coordinate their care. This is currently not the case for most Australians. It is also important to recognise that support

for people with ADHD needs to come from multiple sources. This includes not only health professionals and coaches but also from those delivering education at primary secondary and tertiary levels, and those working in the justice, welfare, drug and alcohol, disability and employment sectors.

AADPA believes that the issues currently limiting access to treatment for those with ADHD can be addressed. However, this will require funding and support from governments, both Federal and State, the medical, psychology and nursing colleges, allied health peak bodies and universities who provide education to our current and future health professionals, and for professionals to work closely with people with lived experience to develop and implement services that work together across traditional boundaries.

There are models of care in other countries that, whilst not perfect, can provide inspiration for the development of new service models for the Australian context. In Australia there is a large body of talent and skill that can take this work forward. Through our work over the past six years AADPA has brought these groups and individuals together and we would hope that we can, with the support of the inquiry, fully implement the Guideline's Recommendations:

Recommendations

- More research into identifying high-quality evidence-based psychoeducation between lived experience and healthcare professionals.
- Develop initiatives to increase the number of skilled practitioners trained to deliver ADHD-specific parent training programs and cognitive behavioural approaches.
- Education and training programs to upskill psychiatrists to confidently prescribe medication for ADHD.
- Fund a coordinated approach to shared care models in Australia.
- Extend the "Voluntary Patient Enrolment" program to people with ADHD.
- Develop professionalisation and accreditation pathways for ADHD coaches.
- Integrate support and treatment services into treatment pathways and packages of care so that those with ADHD can receive the multimodal care recommended by the Guideline.

C. Availability, training, and attitudes of treating practitioners:

As highlighted earlier, the availability of health professionals with expertise in ADHD, particularly in regional and rural areas, and particularly within publicly funded services, is limited. This has resulted in significant variations in quality and quantity of care, access to assessment and support services, and long wait times.

There is a need for deep examination of workforce development options. Key to this will be a focus on improving training and education opportunities and facilitating access to these for professionals at all stages of their careers. This will facilitate an increase in the number of health professionals who are competent in assessing and managing ADHD.

As already outlined, one aspect of this is the need to investigate the opportunities to increase capacity for ADHD assessment and management in the public sector and primary care.

ADHD is a chronic condition that for many people has a lifelong presence. GPs are very experienced in the management of complex chronic health conditions and therefore bring skills to the table that have not always been recognised or appreciated.

They are also very experienced working with nurses and other health professionals and are used to being the central pillar around which care is managed. This makes them an exciting potential resource for ADHD care.

However, increased involvement of primary care and other professions in the assessment and management of ADHD will require not only improved training opportunities but will also need the funding mechanisms by which these professionals can allocate the time required for a comprehensive and accurate assessment to be addressed.

It is accepted that a good quality assessment for ADHD takes time, roughly estimated at around 3 hours. In addition, there is more time spent gathering and reviewing data and reports that may have already been conducted. Unfortunately, this is currently not possible within many healthcare settings, particularly general practice.

Another issue that is not always acknowledged, is that while many professionals now understand the importance of high-quality clinical services for ADHD, there are those who still hold some prejudices and misconceptions about ADHD. We must address negative attitudes and misconceptions about ADHD among these health professionals to ensure that individuals with ADHD receive appropriate and evidence-based care.

For these issues to be addressed, funding will be required to conduct high quality implementation work and research. AADPA was created to provide a platform for this purpose. We believe we have made significant progress in this area. Our recent work on the Guideline showcased our organisation's unique ability to unite stakeholders to achieve credible and impactful outcomes and we strongly believe that we have a major role to play in pushing the field forward.

Shared models of care in Australia & the need for cooperation.

In Australia, ad-hoc agreements between specialists, general practitioners, and other health professionals to share the care of patients with ADHD, have been in place for at least two decades. They have largely been informal arrangements and vary depending on the regulatory requirements in each state or territory.

With the health sector in the grip of critical workforce shortages and increasing numbers of people seeking assessment, diagnosis and treatment for ADHD, the need for effective shared models of care has escalated, especially for people seeking assistance in rural and regional areas.

There are several trials, pilots and professional education resources being developed in NSW, QLD and WA. The NSW Government has invested $7.7m to trial new models of care in regional areas for children with ADHD aged 5-12. AADPA has been involved in developing a number of these projects.

However, the risk of piecemeal and siloed models of care developing is high if stakeholders are unable to co-operate effectively. There is no mechanism for collecting evidence and data from these projects to evaluate their efficacy or sustainability. With investment, AADPA could assist stakeholders to measure and evaluate their trials and enable information sharing to ensure optimal care.

Recommendations:

- Address clinician misconceptions and negative attitudes with better education and training informed by appropriate research.
- Investigate the opportunities to increase capacity for ADHD assessment and management in the public sector and primary care.
- Improve training and education opportunities and facilitate access to these for professionals at all stages of their careers.
- Invest in AADPA to coordinate and help evaluate and review the various shared models of care being developed around the country prioritising those that could assist chronic workforce shortages in regional and rural areas.
- Examine funding mechanisms by which these professionals can allocate the time required for a comprehensive and accurate assessment to be addressed.

D. Impact of gender bias in ADHD assessment, support services, and research:

There is evidence to suggest that ADHD is currently underdiagnosed in females compared to males and that females with ADHD are not only less likely to receive a diagnosis of ADHD but also more likely to be misdiagnosed with another mental health condition. This is in part due to the diagnostic criteria skewed toward males.

There is evidence that this trend is starting to change.

Our recent study identified that the biggest increases in medication use for ADHD in Australia are seen in females, particularly youth and young adults[6]. We need for more research into how ADHD presents in women and girls, how it responds to treatment and how it develops over time.

This should include a focus on the impact of puberty, pregnancy and the menopause. We already have some evidence that females with ADHD often present with different symptom profiles and patterns compared to males, and that is likely to contribute to the gender biases seen in assessment and support services.

In addition to a better understanding from a science perspective, there is also a need for increased awareness and education among health professionals about the presentation of ADHD in females, as well as the impact of gender bias in our assessment, support services, and research into ADHD. This includes addressing gender biases in research funding, diagnostic criteria, and treatment guidelines.

There is also increasing anecdotal evidence that people in the LGBTIQA+ community may also have higher rates of ADHD and experience gender biases in terms of recognition and access to services.

Recommendations

- Funded research of how ADHD presents in women and girls across the lifespan.
- Funded research into the rates of ADHD in the LGBTIQA+ community and differing presentations.

[6] Bruno C, loc. cit.

E. Access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications:

Access to ADHD medication is crucial for people with ADHD to manage their symptoms and lead productive lives. However, the cost of medication and access to these drugs can be a significant barrier for many individuals, particularly those from low-income backgrounds. The Pharmaceutical Benefits Scheme (PBS) provides subsidised access to medication for eligible Australians, including those with ADHD. However, the cost of some medications can still be prohibitively high for some individuals and not all medications are covered by the PBS, particularly in adults with a late diagnosis.

We recommend that the government increases funding to the PBS to expand access to ADHD medications and reduce the out-of-pocket expenses for individuals. In addition, the government should introduce targeted subsidies for low-income individuals with ADHD to ensure that they can access the medication they need to manage their symptoms.

Regulation of medications in Australia is also an important barrier to access.

Each state and territory have different regulations for prescribing simulants. Most jurisdictions restrict the initiation of medication to paediatricians and psychiatrists, except for Queensland, where GPs can initiate stimulant treatment for patients under 18. AADPA currently maintains the only comprehensive digital resource that details regulations across the country here.

Paediatricians and psychiatrists can continue to prescribe and, in some cases and in some states, GPs can prescribe stimulants. GP prescribing is generally as a part of a shared care arrangement with a specialist. Many GPs require special approval to perform this role (as is the case in NSW).

The requirement for the involvement of a specialist, which again differs in different regions, can become a real issue for patients. For a highly mobile workforce these arrangements can pose problems for those who need to access medication.

We recommend that a national regulatory code be introduced for all jurisdictions.

A lack of clinician training and education in ADHD is another key factor that impacts on access to medications for ADHD in Australia.

While the Guideline describes best practice with regards to ADHD medication, we need to build on these recommendations with a more detailed discussion around good prescribing practice. Having identified a gap in this area, AADPA is developing a National Prescribing Manual to complement the Guideline. This resource will provide templates for prescribing and monitoring ADHD medications. It is required because there is strong international evidence of a clear gap between the potential benefits of medication and real-world clinical outcomes.

AADPA has brought together an expert advisory for this project but the manual requires investment to enable its delivery and implementation of the manual into routine practice. We are looking forward to working alongside government, medical colleges, allied health associations and other stakeholders,

including those with lived experience, to ensure that recommendations are converted into routine clinical care.

The challenges associated with ongoing prescribing – a case study from Victoria.

In Victoria, the regulations do not allow the Specialist and the GP to both have permits to prescribe at the same time. But regulations will allow *co-managing*. This means that the permit to prescribe is transferred from the Specialist to the GP, and the GP can keep prescribing stimulants (after the permit has been approved) for up to 2 years. A Specialist review is required after two years to allow this model of care to continue.

This can work well if the Specialist is willing to make the commitment to review the patient every two years. However, patients have reported that at the two-year review, they discover their original Specialist has discharged them, closed their books and will not conduct the review.

Patients are forced to find a new Specialist for review; a challenge because of a lack of qualified clinicians accepting new patients. Even if a patient can engage a new Specialist they will often be required to undertake and pay for a new assessment because the new specialist does not have access to the previous records.

This can place the patient at risk of not being able to continue their treatment putting their current well-being and functionality at risk.

Recommendations

- Expand PBS access to ADHD medications and reduce the out-of-pocket expenses.
- Introduce targeted subsidies for low-income individuals with ADHD to ensure that they can access the medication they need to manage their symptoms.
- Introduction of a national regulatory code for all jurisdictions.
- Investment in the delivery and implementation of AADPA's National Prescribing Manual.

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:

Currently many individuals with ADHD as their primary diagnosis are excluded from the National Disability Insurance Scheme (NDIS). Unlike autism, ADHD is not included in the list of recognised conditions and is only rarely recognised as a primary disability within the NDIS. We recommend that the NDIA and AADPA work together to develop clearer evidence-based guidelines on how ADHD impacts an individual's ability to function in everyday life and how they might best be supported within the scheme.

The Guideline recommends that ADHD be part of the NDIS. However, AADPA believes that inclusion should not be based solely on a diagnosis but on how ADHD impacts the ability of a person to function and thrive.

Considering the substantial impact of ADHD on productivity, costing Australia over $12 billion a year, AADPA is perfectly placed to develop specific supports to improve employment pathways for individuals with ADHD. The goal is to improve opportunities for gaining meaningful employment for people with ADHD and then support them to succeed.

It will also be important to facilitate education about ADHD for NDIA assessors to ensure that they are aware of how to identify ADHD early in a person's journey through the system and what the potential pathways for support are for those with ADHD.

Recommendations

- NDIA and AADPA work together to develop clearer evidence-based guidelines on how ADHD impacts an individual's ability to function in everyday life.
- Include ADHD in the NDIS based on need and functionality.
- Education for NDIA assessors to properly identify ADHD in participants.

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:

There is little consistency or coordination between Commonwealth, state, and local government services in supporting individuals with ADHD. This can lead to confusion and frustration for individuals and their families, as well as gaps in service provision which means that those with ADHD often feel as if they are falling between the gaps between services.

The impact of ADHD is broad and touches many aspects of society. So, the responsibility for providing access to adequate support for people with ADHD does not just rest with one or two government departments.

We strongly support the need for policy makers at all levels of government to work together to support those with ADHD. This will mean active cooperation between the departments responsible for health, disability, education, justice, welfare and employment to develop funding plans to optimally support those with ADHD to thrive and contribute to the wellbeing of the country.

We believe that the most effective way to deliver an integrated and effective approach to ADHD is through the development of a National ADHD Strategy that generates a clear set of priorities and actions for improving support and services for individuals with ADHD. This would require close communication and cooperation between the Commonwealth, state and local government services to ensure that services are delivered effectively and efficiently to stop people with ADHD from falling through the gaps.

We believe the recommendations in AADPA's Clinical Practice Guideline provides a blueprint to develop a strategy that is relevant and deliverable. With the support and engagement of many of our colleagues in the colleges and associations around the country we have already started this work by beginning to tackle legislative and policy barriers such workforce capacity, education resources and national prescribing standards but this work requires investment to be fully realised.

Recommendation:

- Development of a National ADHD Strategy that complements and builds on current initiatives and frameworks Such as the National Disability Strategy, the National Child Mental Health and Wellbeing Strategy and Vision 2030.

H. The adequacy of Commonwealth funding allocated to ADHD research:

Research is critical for advancing our basic understanding of ADHD, and the development of improved ADHD treatments, support and services. Australia is home to some of the top ADHD researchers worldwide. AADPA has brought this group together over the past four years during which time they have produced a series of highly impactful projects that have generated a wealth of new knowledge and pushed the field forward. There has also been a strong focus on developing the next generation of ADHD researchers. We would be keen to present to the inquiry examples of what we have achieved so far.

However, this work has been conducted on a shoestring budget and funding and support for ADHD research in Australia is very limited. If not addressed this will hinder the further development of new clinical approaches and the implementation of the ADHD Guideline. AADPA has identified several areas of research that should be funded and this brief has also been submitted to the Committee.

Recommendation:

- Support the development of a stream of targeted funding (both public and philanthropic) for ADHD research in Australia.

I. The social and economic cost of failing to provide adequate and appropriate ADHD services:

In 2019 we partnered with Deloitte to study the social and economic cost of ADHD. The subsequent Report found that the cost of ADHD to the economy is estimated at over $20 billion a year[7]. It highlights the very real costs we will continue to accrue if we fail to provide adequate and appropriate support and services for individuals with ADHD.

These costs arise because individuals with ADHD are at increased risk of academic failure, social isolation, and unemployment, all of which can have lifelong knock-on effects on mental health and wellbeing. For those of us on the Board involved in the economic analysis, the biggest shock and the biggest lesson, was that lost productivity accounted for 81% of the total financial costs.

There were also significant costs associated with health, education, justice, and wellbeing, but they were outstripped by the impact on the nation's productivity. This brings into sharp focus the issues around identifying and treating adults with ADHD, how we support the parents of children with ADHD, and the need to take a systemic approach when we develop our strategies for addressing ADHD.

While we believe that the methodology used to generate our economic analysis of ADHD was strong, it was dependent on indirect cost measures. AADPA strongly believes that an economic evaluation with a direct measurement of costs should be done as soon as possible. The goal is to provide the government with the necessary evidence to document the economic impacts of investment in improving services and outcomes for ADHD.

[7] Sciberras, E., Streatfeild, J., Ceccato, T., Pezzullo, L., Scott, J. G., Middeldorp, C. M., Hutchins, P., Paterson, R., Bellgrove, M. A. & Coghill, D. 2022b. Social and Economic Costs of Attention-Deficit/Hyperactivity Disorder Across the Lifespan. J Atten Disord, 26, 72-87.

J. The viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD:

The Australian ADHD Professionals Association's Australian Evidence-Based Clinical Practice Guideline for ADHD provides an evidence-based framework for the diagnosis and management of ADHD in Australia.

It is a roadmap for policy makers to improve the assessment, care and support for people with ADHD.

Building on the well-respected NICE ADHD Guidelines (2018)[8] developed in the UK it represents the most up to date evidence-based guideline for ADHD internationally.

The Guideline was developed with funding received by AADPA from Australian Government Department of Health in 2018. The Guideline Development Group (GDG) followed the National Health Medical Research Council (NHMRC) Principles for Guidelines, adhered to a strict approach to avoid conflicts of interest and included representatives from a broad range of professional organisations, consumers, and First Nations peoples.

Following development of the draft guideline there was a public consultation and peer review with 51 submissions accepted, containing 755 items of feedback. These were addressed by the GDG and the final Guideline was launched by Minister Butler in October 2022.

The process of developing recommendations includes an explicit consideration of how feasible it is to implement a recommendation within the Australian context with priority given to the following:

1. Upskilling the existing clinical workforce.
2. Optimising Care Pathways.
3. Reducing Policy and regulatory barriers.
4. Prioritising and increasing Research Opportunities (Women & Girls, First Nations presentations).
5. Giving a meaningful voice to Lived Experience.
6. Better understanding how ADHD impacts Indigenous and CALD communities.
7. Providing better resources for indigenous and CALD communities that align with the Guideline.

Implementation of clinical guidelines takes time to effectively execute. Although AADPA was required to submit an implementation plan to the NHMRC for their endorsement, the Guideline's full implementation was not funded in the development grant.

Recommendation:

- Invest in AADPA to enable the organisation to fully implement the ADHD Guideline.

[8] https://www.nice.org.uk/guidance/ng87

K. International best practice for ADHD diagnosis, support services, practitioner education and cost.

International best practice for ADHD diagnosis, support services, practitioner education, and cost is constantly evolving based on research, clinical experience, and cultural considerations.

These practices often involve a multi-modal approach that includes comprehensive assessment, evidence-based interventions (including psychological therapies and approaches, educational, and pharmacological approaches). This requires a multidisciplinary team approach involving healthcare providers, educators, and families. Best practices also emphasise the importance of ongoing professional development for practitioners and the need for accessible and affordable ADHD services.

While specific practices may vary across countries, collaboration and knowledge-sharing among professionals globally can help identify and implement the most effective strategies for ADHD diagnosis, support, practitioner education, and cost optimization.

One such approach is the highly influential Dundee ADHD Clinical Care Pathway (DACCP)[9] developed in the UK by AADPA President, Professor Coghill.

This model of care has nurse practitioners and GPs providing much of the front-end clinical care. While the original DACCP was designed for doctors and nurses, it is not specific to any one profession, thus enabling translation into different settings and health systems at both primary and secondary care levels.

The DACCP also pioneered the development of measurement-based care approaches in mental health and in ADHD particularly. This is where the clinician routinely measures outcomes during a clinical encounter and uses the results to make changes in treatment with the aim of optimising care. While measurement-based care is routine practice in somatic medicine (e.g., measuring blood glucose and HbA1c in diabetes, blood pressure when treating hypertension or weight when managing obesity), it is less commonly used in mental health settings.

The use of measurement-based care in this context resulted in a dramatic improvement in clinical outcomes. DACCP is now being taken up by clinics across the world and this model of care has been used as the basis for the development of clinical pathways for ADHD in New South Wales.

[9] Coghill, David, loc. cit.

L. Any other related matters.

1. A key aspect not highlighted in the Terms of Reference is the presentation, assessment and treatment options of ADHD for First Nations people and for those in CALD communities.

Very little is known about the understanding and meaning of ADHD in First Nations people or whether different approaches to identification, assessment and support are needed for them and for those in CALD communities.

For Aboriginal and Torres Strait Islander peoples, mental health interconnects with numerous domains[10] including spiritual, environment, country, community, cultural, political, social emotional and physical health[11].

Indigenous communities and other CALD communities can view the symptoms of mental health conditions differently. For example, there could be misidentification of symptoms that are otherwise considered as culturally appropriate.

We need more information to effectively deliver culturally appropriate and competent care; especially when working with Aboriginal and Torres Strait Islander peoples, clinicians need more support to know how to frame mental illness and how treatment (clinical and cultural) can be articulated, building on the already existing strengths, beliefs and practices held within Aboriginal and Torres Strait Islander cultures. **These key areas have been identified by AADPA as a research priority.**

2. Another key area where there are worrying levels of misinformation and poor pedagogy regarding ADHD is in the education sector.

This is an issue across all stages from early childhood through to tertiary. The lack of understanding amongst educators about what ADHD is and how to develop strategies for various learning environments is woefully inadequate and is leading to poor learning and mental health outcomes for people with ADHD.

Research in US over the past decade has pointed to alarming dropout rates (around 32%) in high school students with combined type ADHD[12] and a large study in 2018 found that 1 in 3 students received no school-based interventions or benefited from classroom management strategies[13].

A 2019 Australian national survey[14] of over 1200 people by Parents for ADHD Advocacy found:

[10] Dudgeon P, Milroy H and Walker R. Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice 2nd Edition. ACT: Commonwealth of Australia, 2014.
[11] Loh P-R, Hayden G, Vicary D, et al. Attention Deficit Hyperactivity Disorder: an Aboriginal perspective on diagnosis and intervention. Journal of Tropical Psychology 2017; 7.
[12] Breslau, Joshua et al. (March 2011). Childhood and adolescent onset psychiatric disorders, substance use, and failure to graduate high school on time. *Journal of Psychiatric Research* 45(3):295–301.
[13] George J. DuPaul, Andrea Chronis-Tuscano, Melissa L. Danielson, Susanna N. Visser. Predictors of Receipt of School Services in a National Sample of Youth With ADHD. *Journal of Attention Disorders*, 2018.
[14] https://parentsforadhdadvocacy.com.au/adhd-in-australian-schools-critical-gaps-report-released/

- Poor ADHD-specific knowledge among school staff and educators with many students missing out on appropriate resources and adjustments to help them learn.
- High rates of detentions, exclusions and suspensions among their children with ADHD resulting in reduced time in education and a negative impact on mental health.

- High levels of bullying and social isolation experienced by their children, which was often not adequately addressed by schools and caused distress for children and their families.

- An absence of ADHD-specific funding for learning support resulted in parents being pressed by some schools to gain alternative or escalated diagnosis for their children and/ or give their children medication or adjust their medication dose.

- A lack of procedural fairness and a limited capacity for parents to redress their child's access to education, with suspension and appeal policies not well understood and a perception that their child's ADHD was not adequately considered when schools applied punitive measures.

With responsibility for education residing with State Governments attempts to address these gaps has been highly variable**. AADPA recommends bringing stakeholders together to redesign national standards to achieve better outcomes for educators and student.**

www.aadpa.com.au
admin@aadpa.com.au
ABN: 85 616 076 049

List of extra resources

AADPA Evidence-Based Clinical Practice Guideline for ADHD click here

AADPA Consumer Companion for the ADHD Guideline click here

Federal Health Minister, Mark Butler launches ADHD Guideline click here

Deloitte Access Economic report into The Social and Economic Costs of ADHD in Australia

Talking about ADHD Language Guide click here

ADHD stimulant Prescribing Regulation &Authorities in Australia & New Zealand click here

Dundee ADHD Clinical Care Pathway (DACCP) click here

World Health Organisation's International Classification of Disease (ICD-11)

American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (5th Ed)

ADHD in Australian School: Critical Gaps (2019) click here

The NICE Guideline for the diagnosis and management of ADHD (2018) click here

The Henry Review (2020) - Review of health services for children, young people and families within the NSW Health system click here