#### Friday, 30 August 2024

Committee Secretary
Government Administration Committee B
E: assemblygab@parliament.tas.gov.au

To the Committee Members,

RE: Inquiry into the assessment and treatment of ADHD and support services.

On behalf of the Australasian ADHD Professionals Association (AADPA), I would like to thank the Committee for the opportunity to make a submission to this inquiry.

AADPA is a national not-for-profit association representing healthcare professionals in Australia and New Zealand involved in the assessment, diagnosis, and support of ADHD. We are the second largest ADHD professional organisation in the world.

Our membership is broad and includes researchers and academics, psychiatrists, paediatricians, psychologists, general practitioners, nurses and many other allied health professionals, and ADHD Coaches.

Since 2019 AADPA Board has led the following national collaborative projects:

- Development a National ADHD Prescribing Manual (Oct 2024)
- Australian Evidence-Based Clinical Practice Guideline for ADHD (2022)
- Australian Evidence-Based Clinical Practice Guideline for ADHD: Consumer Companion Guide (2023)
- The Social and Economic Costs of ADHD (Deloitte Access Economics 2019)
- National Prescribing Manual (In development)

Based on the evidence synthesised in the ADHD Clinical Practice Guideline, our own research, and our collective experience and expertise, our submission suggests solutions that can overcome the barriers to consistent, timely, and best practice assessment and support in Tasmania. Many of the challenges in Tasmania are reflected nationally which is why we have called on the Federal Government to fund and lead a national framework.

In the attached submission we have broken down our detailed responses to the Terms of Reference with recommendations at the end of each section. We have also provided hyperlinks to the resources and projects that we have developed and launched in the past few years.

We look forward to collaborating with the Inquiry and other stakeholders to develop solutions and pathways that address the needs of individuals with ADHD and their families. All AADPA's work is geared to make a meaningful difference to people living with ADHD and to create a brighter future for our communities.

Yours sincerely

Professor David Coghill
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# Submission to the Parliament of Tasmania Government Administration Committee B

# Inquiry into the assessment and treatment of ADHD support services.

**30 August 2024** 



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#### 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 (5<sup>th</sup> Ed), more commonly referred to as the **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 resource 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 symptoms 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 (such as at home, school or work; with friends or relatives).
- 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**

### ADHD Prescribing Manual for Australian Healthcare Professionals

(To be released October 2024)

Developed by 18 Australian expert clinicians, researchers and people with Lived Experience to promote safe and responsible prescribing.

#### **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.

#### The Social and Economic Costs of ADHD in Australia

Deloitte Access Economics (2019)

Costs Australia more than \$20 billion per annum.

#### **ADHD Clinical Guideline Consumer Companion** (2023)

An easy to read and accessible guide for non-clinicians.

#### **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<sup>1</sup>.

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 Clinical Practice Guideline for ADHD, 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.

<sup>&</sup>lt;sup>1</sup> 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.

In Tasmania access to diagnosis is inadequate, it is characterised by significant barriers in both public and private sectors, affecting both children and adults.

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. Workforce Shortages and Lack of Integrated Education

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. In addition, Tasmania faces a set of unique challenges in this area as noted in the final Australian Senate report into ADHD. Child and adolescent psychiatrists are described as being on the "critically endangered list" in Tasmania, indicating a severe shortage of specialists.

Other challenges are outlined here:

**Limited Expertise:** The number of healthcare professionals qualified to diagnose ADHD in Tasmania is relatively small, primarily consisting of paediatricians, psychiatrists, and psychologists.

**Insufficient Training:** Training in ADHD assessment and management is often limited or cursory in Tasmanian healthcare provider education programs.

**Workforce Shortage:** A shortage of qualified professionals across all relevant fields, including paediatricians, psychiatrists, psychologists, general practitioners, and nurses, contributes to long wait times for ADHD assessments in Tasmania.

#### **Specific Challenges in Tasmania:**

- **Overwhelming Waitlists:** Public health services in Tasmania face extremely long waiting periods for ADHD assessments.
- Closed Practices: Many private practice paediatricians are no longer accepting new ADHD referrals in the state.
- Referrals: Reports of confusion and inefficiencies in referral and treatment processes.

- Lack of Expertise: Psychologists in Tasmania generally have limited expertise in ADHD assessment and treatment.
- Adults: No public services for adult ADHD diagnosis

#### 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 co-existing 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.

AADPA members and meetings by our Board with members of the Government have highlighted the following acute problems in Tasmania:

- Public service waitlists can be years long
- Private psychology waitlists for children up to 2 years
- Adult assessments can have over 2-year wait times

Additionally, in Tasmania there are the following factors:

- No public service for adult ADHD diagnosis
- Limited willingness or capacity of GPs to apply for prescriber authority
- Recent increase in GP willingness to get prescriber authorities, but still a slow process.

#### 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.

Only paediatricians and child and adolescent psychiatrists can assess and initiate treatment for ADHD in Tasmania.

There are also reports from our members in Tasmania, as well as in other states, 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. Full ADHD assessments can cost between \$500 to \$3000 which is common in other states as well.

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 the 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 the information required for assessment and monitoring of treatment and work in collaboration with senior medical staff to conduct the assessments<sup>2</sup>. 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 impedes access to care. There is an ecdotal evidence of limited awareness and support in schools, although there is an ongoing discussion about developing online professional development for teachers.

AADPA recognises there is 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<sup>3</sup>. 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 with ADHD are currently being treated with medication.<sup>4</sup>

#### **Recommendations:**

 Improve training of healthcare professionals, including paediatricians, psychiatrists and psychologists, general practitioners, nurses and other allied health professionals in the assessment and management of ADHD.

<sup>&</sup>lt;sup>2</sup> 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.

<sup>&</sup>lt;sup>3</sup>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.

<sup>&</sup>lt;sup>4</sup> Bruno C, loc. cit.

- 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 care 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<sup>5</sup>) 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 training about ADHD awareness for health professionals as well as those in education, justice, welfare and employment sectors.

 $<sup>^{5}\</sup> https://www.health.nsw.gov.au/kidsfamilies/paediatric/Pages/henry-review.aspx$ 

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

In Tasmania, even after receiving an ADHD diagnosis, many Australians encounter difficulties in accessing comprehensive treatment. The ADHD Clinical Practice Guideline stresses the importance of a multimodal approach, which combines psychoeducation, medication, and non-medication interventions to ensure well-rounded care.

Professional workforce shortages in Tasmania also impact the delivery of treatments and interventions for ADHD. These challenges are outlined as follows:

#### 1. Lack of Training for Health Professionals:

The insufficient training for health professionals in Tasmania who manage ADHD limits the quality of psychoeducation provided. Additionally, funding protocols in both the private and public sectors do not adequately support the delivery of high-quality psychoeducation.

#### 2. Insufficient Research on Psychoeducation:

There is a lack of research evidence regarding the key components of effective psychoeducation for ADHD in Tasmania. Clinical experience has shown that current approaches are highly variable in content and quality. We propose further research in this area through collaboration between those with lived experience and healthcare professionals.

#### 3. Shortage of Skilled Practitioners for Parent Training:

There is a shortage of skilled practitioners in Tasmania trained to deliver ADHD-specific parent training programmes, particularly within the public sector. In many countries, these programmes are offered free of charge by community health services or not-for-profit organisations. While some groups in Australia, such as the ADHD Foundation and ADHD WA, provide these services, limited funding means they often require a small fee.

#### 4. Limited Practitioners for Cognitive Behavioural Approaches:

A similar shortage exists for practitioners trained and willing to deliver ADHD-specific cognitive-behavioural therapy (CBT), particularly for youth and adults. The workforce is too small, overstretched, and often lacks ADHD-specific training. These programmes are effective but require training currently unavailable in Tasmania. The public sector, in particular, faces significant under-resourcing in ADHD treatment, especially for adults.

#### 5. Restrictions on ADHD Medication Prescribing:

There are restrictions on who can prescribe ADHD medications in Tasmania, as in other states and territories. This variation complicates the definition of national care pathways for the initiation and continued prescribing of ADHD medications across Australia. Addressing this issue has been a major focus for AADPA, and we are about to launch our ADHD National Prescribing Manual.

Recent data about the prevalence and prescribing rates from the Federal Government gives a snapshot of Tasmanian rates vs national averages.

	Prevalence of ADHD %	Prevalence of ADHD Prescribing Australia (%)	Prevalence of ADHD Prescribing Tasmania (%)	Highest Prescribing States (%)
Under 6 years	N/A	0.4	0.55	Tasmania 0.5
6 to 12 years	8.2	6.9	8.7	Tasmania 8.0
13 to 18 years	6.3	5.1	5.8	ACT 6.9
Over 18 years	2.5	1.1	0.87	WA 1.8

#### 6. Psychiatrists' Confidence in Prescribing ADHD Medication:

There are psychiatrists in Tasmania who do not feel skilled or confident in prescribing ADHD medication and do not see it as part of their remit, which has increasingly focused on managing severe mental illness.

#### 7. Challenges in Shared Care:

Shared care between primary and secondary care is common in other countries but remains challenging in Australia, including Tasmania. While possible in some cases, shared care is complex and varies greatly across the country. General Practitioners (GPs) are skilled in chronic disease management, but barriers to their involvement in ADHD care include access to training, support, prescribing restrictions on stimulant medications, and funding models. The Federal Budget allocated funding for "Voluntary Patient Enrolment" for patients with chronic conditions, which should include people with ADHD to facilitate GPs' involvement.

#### 8. Development of ADHD Coaching:

ADHD coaches are a valuable resource for supporting individuals with ADHD. While Australia is leading in this area, Tasmania still needs to develop professionalisation and accreditation pathways for coaches. Furthermore, an evidence base is needed to assess their effectiveness and integrate their work with other healthcare professionals.

#### 9. Integration of Support and Treatment Services:

A significant issue in Tasmania is the integration of support and treatment services into cohesive care pathways. While some examples of good practice exist, much of the care provided is delivered in isolation without coordination or integration. The ADHD Clinical Practice Guideline recommends that every person with ADHD have someone to coordinate their care, which is currently not the case for most Tasmanians. Support for people with ADHD needs to come from various sources, including health professionals, coaches, educators, and those working in 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 both the Federal and Tasmanian governments, 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 in Tasmania 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.
- 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. The availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services.

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.

The availability, training, and attitudes of treating practitioners for ADHD assessment and support services in Tasmania are currently limited, particularly in regional and rural areas. This has resulted in significant variations in care quality, access to services, and long wait times.

#### **Current Situation**

There is a shortage of health professionals with expertise in ADHD, especially in publicly funded services. Some practitioners still hold misconceptions and prejudices about ADHD, which can impact the quality of care provided.

The time required for comprehensive ADHD assessments (approximately 3 hours) is often not feasible within current healthcare settings, particularly in general practice.

#### **Challenges:**

- Limited availability of expert clinicians outside of Launceston and Hobart.
- Time constraints for thorough assessments within current healthcare settings.
- Persistent misconceptions about ADHD among some health professionals.
- Funding limitations for comprehensive assessments and service provision.

#### **Workforce Development Options**

To increase access to ADHD assessment and support services in Tasmania, several workforce development options could be considered:

#### 1. Improved Training and Education:

- Enhance training opportunities for health professionals, especially GPs at all career stages.
- Focus on improving competency in ADHD assessment and management.

#### 2. Increased Public Sector Capacity:

 Investigate opportunities to expand ADHD assessment and management capabilities in the public sector and primary care.

#### 3. Leveraging General Practitioners:

- Recognize and utilize GPs' expertise in managing complex chronic conditions.
- Explore ways to involve GPs more centrally in ADHD care.

#### 4. Multidisciplinary Approach:

 Encourage collaboration between GPs, nurses, and other health professionals in ADHD care management.

#### 5. Addressing Funding Mechanisms:

 Review and adjust funding models to allow professionals to allocate sufficient time for comprehensive ADHD assessments.

#### 6. Attitude Shift:

• Implement programs to address negative attitudes and misconceptions about ADHD among health professionals.

#### 7. Research and Implementation:

• Allocate funding for high-quality implementation work and research to improve ADHD 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 assist the development and evaluation of a trial of a GP shared care model. AADPA is already assisting NSW Health in their trial and could replicate this in Tasmania.
- Examine funding mechanisms by which these professionals can allocate the time required for a comprehensive and accurate assessment to be addressed.

#### 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.

D. The regulations regarding access to ADHD medications, including the Tasmanian Poisons Act 1971 and related regulations, and administration by the Pharmaceutical Services Branch (PSB), including options to improve access to ADHD medications

The Tasmanian Poisons Act 1971 requires medical practitioners to obtain authority from the Secretary of the Department of Health before prescribing Schedule 8 psychostimulants, including ADHD medications like dexamphetamine, methylphenidate, and lisdexamfetamine.<sup>6</sup> This authority is issued under Section 59E of the Act and may include conditions or be refused.<sup>7</sup>

- Authorities are required for treatments lasting longer than two months.
- Applications are assessed to ensure patient safety and address public health concerns.
- Medical practitioners must be present and practicing in Tasmania to be authorized to prescribe Schedule 8 psychostimulants.<sup>8</sup>
- Diagnosis and treatment recommendations should come from appropriately qualified specialist medical practitioners, such as psychiatrists, paediatricians, sleep physicians, or neurologists.

#### Recent changes and options for improving access:

The Tasmanian Government has recently taken steps to improve access to ADHD medications which AADPA supports. As of July 2024, specialists and GPs with Special Interests in ADHD and appropriate training can be authorized to prescribe medications for up to three years, increased from the previous two years. Plans are underway to deliver a new GP specialist service for children with ADHD, aiming to improve access to GPs with special interests.

- **1. Consistent National Approach:** Tasmania supports a consistent, evidence-informed approach to regulating Schedule 8 ADHD medications across jurisdictions. This could help address issues faced by patients moving between states and doctors engaging in tele-psychiatry across jurisdictions.
- **2. Enhanced GP Involvement:** Expanding the role of GPs in prescribing ADHD medications could improve access, especially in areas with limited specialist availability. The recent changes allowing certain GPs to prescribe for longer periods is a step in this direction.
- **3. Streamlined Authorization Process:** Implementing a more efficient system for obtaining prescribing authority could reduce delays in treatment initiation and continuation.
- **4. Improved Information Access:** Providing clearer guidelines and readily accessible information about the prescribing process could help both healthcare providers and patients navigate the system more effectively.

 $<sup>^{6} \ \</sup>text{https://www.aph.gov.au/DocumentStore.ashx?id=f5b2b96f-3ae3-413a-b1d8-ec792be42069}$ 

<sup>&</sup>lt;sup>7</sup> https://www.health.tas.gov.au/health-topics/medicines-and-poisons-regulation/information-patients-and-general-public-about-medicines-and-poisons/applications-issue-authority-prescribe-certain-medicines

<sup>&</sup>lt;sup>8</sup> https://aadpa.com.au/adhd-stimulant-prescribing-regulations-in-australia-new-zealand/

 $<sup>^{9}</sup>$  https://www.premier.tas.gov.au/latest-news/2024/july/delivering-our-commitment-on-adhd-medication-access

- 5. Increased Funding and Subsidies: As suggested in the provided text, increasing funding to the Pharmaceutical Benefits Scheme (PBS) and introducing targeted subsidies for low-income individuals could help reduce financial barriers to accessing ADHD medications.
- **6. Enhanced Clinician Training:** Developing and implementing comprehensive training programs for healthcare providers on ADHD diagnosis and treatment could improve the quality and availability of 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.

#### **Recommendations:**

- Lobby the Federal Government to expand PBS access to ADHD medications and reduce the out-ofpocket 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.

## E. The adequacy of, and interaction between the State Government and Commonwealth 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.

When it comes to 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:**

- Development of a National ADHD Strategy that complements and builds on current initiatives and framework such as the National Disability Strategy, the National Child Mental Health and Wellbeing Strategy and Vision 2030.
- 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 the symptoms of ADHD in participants.

#### F. 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<sup>10</sup>. 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.

<sup>&</sup>lt;sup>10</sup> 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.

#### G. 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<sup>11</sup> including spiritual, environment, country, community, cultural, political, social emotional and physical health<sup>12</sup>.

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<sup>13</sup> and a large study in 2018 found that 1 in 3 students received no school-based interventions or benefited from classroom management strategies<sup>14</sup>.

<sup>11</sup> 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.

<sup>&</sup>lt;sup>12</sup> 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.

<sup>&</sup>lt;sup>13</sup> 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.

<sup>&</sup>lt;sup>14</sup> 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.

A 2019 Australian national survey<sup>15</sup> of over 1200 people by Parents for ADHD Advocacy found:

- 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 have been highly variable. AADPA recommends bringing stakeholders together to redesign national standards to achieve better outcomes for educators and students.

#### 3. The adequacy of 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.

# 4. The Australian ADHD Professionals Association's Australian Evidence-Based Clinical Practice Guideline for ADHD

The Guideline 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 and that the Tasmania Government can draw upon.

 $<sup>^{15}\,\</sup>text{https://parentsforadhdadvocacy.com.au/adhd-in-australian-schools-critical-gaps-report-released/}$ 

Building on the well-respected NICE ADHD Guidelines (2018)<sup>16</sup> 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 of 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. There is scope for State Governments to invest in the development of specific services as required.

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<sup>&</sup>lt;sup>16</sup> https://www.nice.org.uk/guidance/ng87

#### 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)

ADHD in Australian Schools: 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 <u>here</u>