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RACP Submission – Standing Committee on Government Administration B's Inquiry into the assessment and treatment of ADHD and support services

September 2024

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 30,000 physicians and trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients and the community.

We acknowledge and pay respect to the Traditional Custodians and Elders – past, present and emerging – of the lands and waters on which RACP members and staff live, learn and work. The RACP acknowledges Māori as tangata whenua and Te Tiriti o Waitangi partners in Aotearoa New Zealand.

Executive Summary

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to provide feedback to the Standing Committee on Government Administration B's Inquiry into the assessment and treatment of attention deficit hyperactivity disorder (ADHD) and support services.

ADHD affects approximately 281,200 children and adolescents (aged 0-19 years) and 533,300 adults (aged 20+ years) in Australia[1] and is one of the most frequent diagnoses managed by Australian paediatricians.[2] As a lifelong neurological disorder, ADHD can have a deep and profound impact on those who are diagnosed, their families and their loved ones.[3] The RACP emphasises the importance of diversity and inclusiveness in the support for individuals and families living with an ADHD diagnosis.

The RACP is committed to supporting enhanced services and support for children, adolescents, and adults with ADHD. In September 2022, the RACP endorsed the Australian ADHD Professionals Association's Australian evidence-based clinical practice ADHD guideline (first edition). We view the guideline as a positive and essential step towards providing people with ADHD and their families with best-practice diagnosis and evidence-based treatments in Australia.

In June 2023, the RACP provided a submission to the Senate Inquiry into assessment and support services for people with ADHD. The submission made seven key recommendations, including:

1. **Improving facilitated access to mental health services** that is appropriate to the needs of individuals diagnosed with ADHD, particularly at the time of diagnosis.
2. **Developing and implementing innovative models of care** that involve paediatricians working with, and mentoring, primary care health professionals to increase efficiency and reduce waiting times for ADHD assessments, as well as the provision of support services following diagnosis.
3. A **review of regulations for prescribing ADHD stimulant medications** should be undertaken, and for **shared care to be increased** to ensure consistency between the States and Territories in Australia.
4. **Eligibility for disability supports through the National Disability Insurance Scheme (NDIS)** should be based on the level of functional impairment experienced by the person with ADHD, rather than whether they have a particular diagnosis.
5. Further **research into a range of issues related to ADHD**, particularly epidemiology, modifiable and causative risk factors; prevention; case finding, particularly among women with risk factors; benefits of early treatment; non-pharmacological treatments; and medium to long term outcomes.
6. **Funding for development of community-based research** into the identification and diagnosis of ADHD in **First Nations families** and how to better support their needs and aspirations should be allocated. It is critical that the voices of First Nations families are heard in ADHD research.
7. **Develop a robust, fully funded strategy for implementation of the Australian Evidence-Based Clinical Practice ADHD Guideline** to ensure that all Australians

[1] The social and economic costs of ADHD in Australia Report prepared for the Australian ADHD Professionals Association July 2019 Deloitte Access Economics https://aadpa.com.au/wp-content/uploads/2019/07/Economic-Cost-of-ADHD-To-Australia.pdf

[2] RACP Position Statement: The role of paediatricians in the provision of mental health services to children and young people October 2016 RACP---the-role-of-paediatricians-in-the-provision-of-mental-health-services-to-children-and-young-people.pdf

[3] Dalsgaard S., Ostergaard S. D., Leckman J. F., Mortensen P. B., Pedersen M. G. 2015. Mortality in children, adolescents, and adults with attention deficit hyperactivity disorder: A nationwide cohort study. Lancet, 385(9983), 2190–2196. https://doi.org/10.1016/s0140-6736(14)61684-6

can receive the best evidenced diagnostic practices, regardless of their age or location, and make informed decisions about next steps.

This RACP submission provides feedback on the specific terms of reference that are relevant to the work of our RACP members. Issues relating to the diagnosis and support experiences of paediatricians treating children and young people with ADHD are key ones raised by our members.

Feedback on Terms of Reference areas

Our RACP members report paediatric services in Tasmania being "overloaded", not necessarily due to children with ADHD per se, but due to the demand for timely neurodevelopmental assessments to be conducted for a cohort of children who present with neurodevelopmental or behavioural concerns that may or may not be ADHD. This means that the creation of ADHD-specific services to act as a "front door" can disadvantage other children with attentional problems for other reasons apart from ADHD (for example, hearing or vision impairment, or an anxiety disorder), and discourage critical thinking about the reasons why a child is presenting for neurodevelopmental assessment.

Assuming ADHD is the cause of an individual's developmental or behavioural issues can also lead to missed opportunities to address other underlying issues while waiting for an assessment. Similarly, our RACP members have highlighted the importance of recognising and addressing the wide range of factors which contribute to behavioural challenges, and which may or may not coincide with ADHD, such as:

- **Parenting practices:** parents can need additional support and guidance to help with managing behaviour and emotional regulation in children, however, ease of access to practical parenting and family support is challenging in the community. There must be investment in early intervention and public health strategies to promote positive parenting practices, as well as increased community support for parents.
- **Trauma, domestic/family violence and/or neglect:** there must be investment in trauma-informed services, support for people and families in violent situations, and other public health strategies to support children, parents and families in these difficult situations.
- **Lack of support in the education system:** children regularly present with unrecognised learning disorders or cognitive impairments that significantly contribute to a behavioural issue. This should be recognised early so children can be referred for a cognitive or learning assessment, rather than having to wait for a neurodevelopmental assessment and then waiting again for a neurocognitive or learning assessment. Referrals are being received with requests to medicate children. However, these primary behaviour problems cannot be improved with medication, and schools are reporting they do not have the appropriate resources to manage these children in the classroom.
- **Poor sleep related to poor health behaviours:** this can include poor lifestyle activities**,** involving diet and nutrition, inadequate physical activity or exercise, and increased screen time and sedentary behaviours. Investment in public health strategies and prevention is important for awareness and education of healthy lifestyle practices in children, parents and families.
- **Mental health:** inadequate mental health support for children and adolescents can contribute significantly to behavioural issues. The difficulties families face in accessing psychologists under mental health plans is a significant issue, as well as the availability of training for providers in managing paediatric behavioural issues. Tasmanian paediatricians report frequently managing children with primary mental health problems which are not seen by the Child and Adolescent Health Services

(CAMHS) and which the child's General Practitioner (GP) can (understandably) consider to be outside their scope of practice.

There can be a lack of easy access to formal cognitive assessments, such as the Wechsler Intelligence Scale for Children (WISC), for children in cases where it is unclear whether the source of behavioural difficulties is ADHD, intellectual disability, or both. These formal cognitive assessments are often conducted by school psychologists who our RACP members report are in high demand and short supply. Due to the long waitlists to access a paediatrician for ADHD assessment, it would be ideal for neurocognitive assessments to be conducted on children to clarify the diagnosis; however, there are not enough psychologists in schools to conduct these assessments. Our RACP paediatricians report seeing wait times of approximately two years to access school psychologist assessments in the public school system.

Access to neurobehavioural assessments by paediatricians in Tasmania is also impacted by the broad range of behavioural and mental health issues that are not ADHD or are coexistent with ADHD which might be managed by a paediatrician. Waitlists are also being extended because neurocognitive assessments cannot be conducted in schools due to resource constraints noted above, which means intellectual and learning disabilities are not identified prior to seeing a paediatrician. This in turn limits the capacity of paediatricians to provide optimal paediatric care.

Neurodevelopmental assessments have become increasingly complex over time, requiring additional time, resources and follow-up. The work is like neurodevelopmental assessments undertaken by psychiatrists however, paediatricians are unable to access a comparable Medicare Benefits Scheme (MBS) item. A review would be useful to assess whether existing Medicare items adequately reflect the medical services that are provided in the neurodevelopmental space by paediatricians today.

(a) Adequacy of access to ADHD diagnosis

It is important to recognise that some individuals with ADHD, who have good coping mechanisms and fewer comorbidities, may face stigma for coming forward for assessment, with the implication that these people are following a 'trend', rather than genuinely struggling with day-to-day functioning because of ADHD. A culture of support and openness to these individuals is important, as well as ensuring that assessment tools can fairly evaluate a cohort of people who have developed coping strategies to manage their ADHD in their lives.

Wait times and financial barriers
Accessing timely ADHD assessments is challenging for many families across Australia, but particularly in Tasmania. Despite an increase in the number of paediatricians working in the public sector in Tasmania, our RACP members report seeing extended waitlists of up to two years before a child can be assessed for the possibility of an ADHD diagnosis. This is despite increases in number of paediatricians, including in the North West region. In instances where services have no capacity, children can even be turned away entirely. Children and families face long waitlists for publicly funded neurodevelopmental assessment by a paediatrician or psychiatrist.

There are also significant wait times to access private services. One RACP member reported that the retirement of even a couple of paediatricians has significantly impacted wait times in Tasmania. Cost of living pressures can also place these assessments beyond the reach of many families, especially for families facing poverty, disadvantage, or

living in low socioeconomic conditions. Families who live in rural areas must also factor in the costs of travelling to access specialist care.[4]

The challenges of accessing ADHD assessments and treating ADHD should also be analysed in its broader context. ADHD is a common diagnosis with other psychiatric disorders including depression, anxiety, trauma, and bipolar affective disorder.[5] ADHD is often associated with, or substantially shares symptoms with trauma, Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder.[6] [7] ADHD has also been associated with substance use disorder, obesity, asthma, diabetes, epilepsy, and sleep disorders.[8] Insufficient understanding of these comorbidities and contributing factors can lead to poor quality assessments, relevant assessments not being undertaken, no assessment of learning ability, or alternative issues not being considered in referrals. These matters contribute to a high case load for paediatric services and potential delays in assessment, correct diagnosis, and appropriate treatment or therapy.

Cultural accessibility
The cultural accessibility of services is an important consideration to ensure that families from culturally and linguistically diverse communities and First Nations Communities have access to appropriate supports. The Australian Evidence-Based Clinical Practice ADHD Guideline notes that careful consideration of the validity of standard ADHD screening and assessment tools is necessary for First Nations people, and that simple adaptations of current tools may not be sufficient.[9] Specific cultural assessment for ADHD for First Nations people could be developed to adopt a holistic lens and consider physical, mental, emotional, social, cultural, family and Country connections.[10]

(b) Adequacy of access to supports after an ADHD assessment

Our RACP members have previously noted complex cases of ADHD often have several contributing factors and require multimodal care with allied health input. This can be difficult to access in the public sector and involves additional expenses to patients and their families to access privately. Once ADHD is diagnosed, whilst a key treatment is often medication, however there are often minimal supports and/or programs available to provide additional assistance. Medicare provides a limited number of allied health therapy sessions, which is generally insufficient and can involve a substantial gap payment. ADHD coaches are also not supported by Medicare, despite offering strategies to help people with ADHD to function more efficiently. Increasing demand for occupational therapists and speech pathologists is also extending allied health waitlists and becoming another barrier to accessing support after diagnosis.[11]

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[4] RACP Position Statement: The role of paediatricians in the provision of mental health services to children and young people October 2016 RACP---the-role-of-paediatricians-in-the-provision-of-mental-health-services-to-children-and-young-people.pdf
[5] Faraone SV et al. The World Federation of ADHD International Consensus Statement: 208 Evidence-based conclusions about the disorder. Neuroscience & Biobehavioral Reviews. 2021;128: 89-818.
[6] Benjamin R, Haliburn J & King S. Humanising Mental Health Care in Australia: A Guide to Trauma-informed Approaches. 2019.
[7] Van Hulzen KJE et al. Genetic Overlap Between Attention-Deficit/Hyperactivity Disorder and Bipolar Disorder: Evidence From Genome-wide Association Study Meta-analysis. Biol Psychiatry. 2017 Nov;82(9):634-641.
[8] The Royal Australian and New Zealand College of Psychiatrists (RANZCP) Position Statement: ADHD Across the Lifespan https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/attention-deficit-hyperactivity-disorder-in-childhood-and-adolescence
[9] ADHD in Aboriginal and Torres Strait Islander peoples - Australian ADHD Clinical Practice Guideline https://adhdguideline.aadpa.com.au/subgroups/aboriginal-and-torres-strait-islanders/
[10] Dudgeon P, Walker R, Scrine C, Shepherd CCJ, Calma T & Ring I 2014. Effective strategies to strengthen the mental health and wellbeing of Aboriginal and Torres Strait Islander people. Issues paper no. 12. Australian Institute of Family Studies. https://www.aihw.gov.au/getmedia/6d50a4d2-d4da-4c53-8aeb-9ec22b856dc5/ctgc-ip12-4nov2014.pdf.aspx?inline=true
[11] Marozzi, M. (2022). Speech pathologist and OT demand soars with waitlists blowing out, job ads going unanswered. ABC News. https://www.abc.net.au/news/2022-05-11/job-ads-go-unanswered-as-demand-for-speech-pathologists-ots-soar/101041504

One RACP member reported that many early development support groups, which provided support for families of children with ADHD, have ceased operating. In many cases, this leaves the NDIS as the key mechanism for families of children with ADHD to access support. However, the NDIS faces long waitlists – for assessment processes and services – and not all children and families can access NDIS support, even if the child's functional impact is severe. This leaves some children and families falling through the cracks, with some also facing concurrent challenges in accessing mental health supports in Tasmania as well.

Mental health and developmental comorbidities are common across the lifespan, with about half of those with ADHD also meeting the criteria for at least one other condition.[12] RACP members have provided feedback that there is a strong need for improved access to psychological support for people diagnosed with ADHD. There is a well-recognised shortage of mental health professionals in rural areas across Australia.[13] This is especially the case in Tasmania, which in 2021 had 5 psychiatrists per 100,000 people in regional parts of Tasmania, compared to the national average of 15 psychiatrists per 100,000 people; and 44 psychologists per 100,000 people in Tasmania's north-west, compared to 122 per 100,000 people across Australia.[14]

Our RACP members report that Tasmanian GPs are using telehealth to access psychiatrists on the mainland due to limited numbers of psychiatrists in Tasmania. While many children and families don't need to be seen by a psychologist on a life-long basis, they may need psychotherapy at the time of diagnosis and for additional behavioural management, as well as for management of co-morbid anxiety, depression, or trauma. Additionally, when a patient previously prescribed stimulants for ADHD by a paediatrician reaches adulthood, the stimulants then need to be prescribed by a psychiatrist. Increasing access to psychiatrists in Tasmania is important to ensure continuity of care and ongoing access to medication for patients with ADHD. The RACP recommends improving facilitated access to mental health services that is appropriate to the needs of individuals diagnosed with ADHD. One RACP member suggested a psychiatric appointment may not be necessary in circumstances where a child reaches adulthood with a long-established diagnosis of ADHD and on stable, effective treatment; these young adults could potentially be transitioned to ongoing GP care or shared GP care.

On a broader scale, the National Children's Mental Health and Wellbeing Strategy[15] was developed in response to the limited capacity of mental health services across Australia. The Strategy is designed to implement a preventive, integrated, whole-of-community approach to maintain and support the mental health and wellbeing of children and their families. Ensuring that this Strategy is fully funded and implemented will substantially expand mental health support for children, young people and their families and carers in Tasmania and all of Australia.[16]

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[12] Capusan A. J., Bendtsen P., Marteinsdottir I., Larsson H. (2019). Comorbidity of adult ADHD and its subtypes with substance use disorder in a large population-based epidemiological study. *Journal of Attention Disorders*, 23(12), 1416–1426. https://doi.org/10.1177/1087054715626511

[13] RACP Position Statement: The role of paediatricians in the provision of mental health services to children and young people October 2016 https://www.racp.edu.au/docs/default-source/advocacy-library/racp---the-role-of-paediatricians-in-the-provision-of-mental-health-services-to-children-and-young-people.pdf

[14] Australian Institute of Health and Welfare. (2024). Mental Health Workforce https://www.aihw.gov.au/mental-health/topic-areas/workforce cited in Blackwood, F. (2023). Tony taking up the mental health fight for those in regional Tasmania needing services. ABC News https://www.abc.net.au/news/2023-08-20/lack-of-mental-health-service-access-in-tasmania-regional-areas/102745856

[15] National Children's Mental health and Wellbeing Strategy (2021) National Mental Health Commission Australian Government https://www.mentalhealthcommission.gov.au/projects/childrens-strategy

[16] RACP Kids Catch Up Campaign https://kidscatchup.org.au/wp-content/uploads/2022/08/KCCU-website-additional-info-formatted-into-web-2022-Ask-3.pdf

Our RACP members emphasise the need for a greater focus on supporting students with ADHD in primary and secondary school and tertiary education settings. In school settings, symptoms of ADHD can result in unsupported or untreated students falling behind academically in comparison to their peers and experiencing adverse social treatment by both peers and teachers.[17] Teachers play an important role in adjusting the school environment to support learning for children and young people with ADHD.

More funding is urgently required to support paediatricians, specialty nurses, psychologists and other mental health services, and services in schools to assist neurodiverse children and children with behavioural issues. Increasing the ease of referral to multidisciplinary services would also help reduce barriers to referral (including the administrative burden of paperwork and frequency of rejected referrals).

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

The RACP strongly supports integrated, cross-profession, team-based approaches to care, albeit with varying roles in relation to screening, diagnosis, co-management, and prescribing. Our RACP members advise that paediatric ADHD is complex and often requires specialised knowledge and formal training to assess the presence of ADHD, while accounting for other contributing factors, as well as managing medications which could have the capacity to harm a child's development if improperly prescribed. Assessment and diagnosis of ADHD should remain the role primarily of paediatricians (and other specialists such as psychiatrists), supported by models of care that are appropriately set up and supported to facilitate the kinds of assessments that are needed.

The RACP acknowledges that children and their families are currently experiencing extended wait times for ADHD assessments and there are insufficient medical physician specialists to meet the need for assessment and diagnosis of ADHD. The RACP has been liaising with the Federal Government and advocating to increase the number of training positions across the country, which has a longer-term impact. In the 2023 Federal budget, the Government announced it would boost incentives to expand multidisciplinary team care in primary care settings. This needs to be continued and expanded, and the RACP strongly recommends that physician specialist care, including paediatric care, is included in these reforms so that patients, including children, young people and their families, can access the services they need.

GPs are often the first point of contact for health care for patients of all ages, genders, and cultures across all disease categories through all stages of life. Our RACP members agree that this holistic, patient-centred approach places GPs in an excellent position to aid in the diagnosis and management of patients with ADHD and connect patients and their families with other specialists and support as necessary. In Tasmania, GPs are able to prescribe stimulants following diagnosis under the supervision of a paediatrician,[18] which reduces the time paediatricians spend on review and scripts and increases the time paediatricians can spend on assessments. Additionally, as summarised in the Royal Australian College of General Practitioners (RACGP) feedback on the Australian Evidence-Based Clinical Practice ADHD Guideline, "shared care arrangements should be supported, in the form of clinical protocols and funding systems, so GPs can access

[17] Jangmo A, Stålhandske A, Chang Z, Chen Q, Almqvist C, Feldman I, Bulik CM, Lichtenstein P, D'Onofrio B, Kuja-Halkola R, Larsson H. Attention-Deficit/Hyperactivity Disorder, School Performance, and Effect of Medication. J Am Acad Child Adolesc Psychiatry. 2019 Apr;58(4):423-432. doi: 10.1016/j.jaac.2018.11.014. Epub 2019 Feb 2. PMID: 30768391; PMCID: PMC6541488.

[18] Australasian ADHD Professionals Association. (2024). ADHD Stimulant Prescribing Regulations & Authorities in Australia & NZ. ADHD Stimulant Prescribing Regulations & Authorities in Australia & New Zealand - AADPA

timely assistance from paediatricians and psychiatrists to support diagnosis and management and mitigate risk of both over and under treatment".[19]

One RACP member previously provided an example of a pilot model for integrated care to address the shortage of ADHD assessments within the public sector, as outlined in the RACP submission to the Senate Inquiry into assessment and support services for people with ADHD. At the Lifespan Community ADHD Clinic at Cranebrook Community Health Centre[20] in Nepean Blue Mountains Local Health District (LHD) in NSW, GPs train with experienced clinicians in ADHD identification and are given the same prescribing rights as psychiatrists and paediatricians. These GPs have privileged access to the ADHD Clinic for more complex patients, peer support and ongoing education. Suitable clinic patients are referred back to an increasingly experienced cohort of GPs, who can provide continuity of care into adulthood. This can be regulated to maintain the requisite rigour needed for ADHD identification and management, and to expedite the process of individuals receiving the support they need.

The RACP welcomes the development and implementation of appropriate innovative models of care that involve paediatricians working with, and mentoring, primary care health professionals to increase efficiency and reduce waiting times for ADHD assessments, as well as the provision of support services following ADHD diagnosis.

(d) 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

States and Territories have different laws about stimulant prescribing which poses a problem for patients moving between jurisdictions and for medical professionals engaging in telehealth across jurisdictions. In addition, some States/Territories do not honour prescriptions from other jurisdictions.[21] Our RACP members believe there should be greater uniformity and consistency in stimulant prescribing between jurisdictions.

Generally, only medical specialists are authorised to prescribe stimulant medications. To receive regular medication, people diagnosed with ADHD must see a medical specialist on an ongoing basis; GPs are only authorised to prescribe medication in limited circumstances. The prescription of stimulants must continue to be regulated, given the potential for substance abuse. Options to make the care provided to individuals with ADHD more efficient should be explored, for example, one of our RACP members suggested that paediatricians could be given the ability to prescribe two months' supply of medication as an initial trial while waiting PSB authority could potentially remove additional appointments and delays to treatment.

Additionally, our RACP members have provided feedback about the need for better integration between prescribing software, TasScript and the Pharmaceutical Benefits Scheme (PBS) to streamline the process of prescribing and to reduce the chance of errors. One of our RACP members emphasised the importance of transparency in PBS decisions about collection requirements for patients and carers, and of publicly available data to demonstrate that the current system of restricted availability provides safety at the individual or community level.

[19] RACGP Submission to the Australian ADHD Professionals Association RACGP-submission-to-AADPA-ADHD-guidelines-7-April-2022.pdf.aspx
[20] Lifespan Community ADHD Clinic at Cranebrook Community Health Centre https://www.nsw.gov.au/health/nbmlhd/locations/adhd-clinic-nepean
[21] Australasian ADHD Professionals Association. (2024). ADHD Stimulant Prescribing Regulations & Authorities in Australia & NZ. ADHD Stimulant Prescribing Regulations & Authorities in Australia & New Zealand (aadpa.com.au)

In terms of access to ADHD medications more broadly, concerns about the PBS limitations on ADHD medication subsidies based on age and dosage are outlined in the RACP submission to the Senate Inquiry into assessment and support services for people with ADHD. The RACP would like to see a review of regulations for prescribing ADHD stimulant medications, and for shared care to ensure consistency between the States and Territories in Australia. These regulations should reflect scientific evidence and best practice, and not restrict the availability of medication or treatment.

Conclusion

The RACP and our members would welcome the opportunity to discuss the information in this submission further with the Committee, and believe that engagement with our experts, such as our paediatrician members, would be of significant benefit. Please contact Policy and Advocacy via policy@racp.edu.au for further engagement.