



Public Health Association
AUSTRALIA

Assessment and support services for people with ADHD

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Preamble

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre-eminent voice for the public's health in Australia.

The PHAA works to ensure that the public's health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people's health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.



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Introduction

PHAA welcomes the opportunity to provide input to the Committee's inquiry into Assessment and support services for people with ADHD.

ADHD is a very common neurodevelopment disorder in the population, with prevalence generally agreed to be around 4% or higher (around 800,000 Australians). There is considerable, but contested, evidence that the condition is under-diagnosed in the population, especially among females. Diagnosis is further complicated by association with other neuro-developmental disorders.

Diagnosis

The ADHD condition tends to be diagnosed in childhood, although some people do not receive a diagnosis until later in life. This makes it necessary to take a developmental approach to addressing the condition throughout life.

In recent years Australia has seen a progressive increase in diagnosis and treatment, yet given this is a significantly biologically driven disorder, the increase is more likely due to changes in assessment/diagnosis rather than an actual increase in prevalence.

While rates of diagnoses are increasing among children and teens, however, there is considerable debate as to whether ADHD is under-diagnosed or over-diagnosed, with proponents on both sides.¹ This dispute as to prevalence calls out for further research into the condition being made a national priority.

Diagnosis rates are also lower among females, with disagreement as to whether this is driven by difference in actual prevalence, differential application of diagnostic criteria, or under-diagnosis. The National Child and Adolescent Mental Health and Wellbeing Survey uses trained interviewers administering the Diagnostic Interview Schedule for Children Version IV (DISC-IV) which applies the same criteria to males and females, and it found the prevalence of ADHD was 10% in boys and 4% in girls.² This suggests that either the criteria to diagnose ADHD are incorrect, or that there is a real gender difference in ADHD prevalence for boys, as occurs in relation to females with depression and anxiety conditions.

There is also considerable variation within states and between states, suggesting there is some level of differential application of diagnostic criteria in different regions.³

Many diagnoses are made by paediatricians rather than psychiatrists, simply because the former are more available and better distributed across the country. Addressing diagnosis variation between practitioners will require clarifying diagnostic criteria, assessment procedures, and clinical guidelines, and availability of a workforce capable of diagnosing.

Treatment

While medical treatments for ADHD appear to be effective in many cases, there are arguments that our current responses to ADHD place too much reliance on medical treatments, and not enough on behavioural/psychological treatments and parenting/family supports and programs. The constraints on the latter responses are driven by the lack of availability of trained child psychologists and other allied mental health professionals.

As with most chronic conditions, it is important to have a multidisciplinary team-based approach to ADHD, yet at present the condition is largely treated by people working in private practice who work in isolation from other professionals. The Medical Benefits Schedule (MBS) should be reformed to support team-based treatment. Any relevant additions to the Pharmaceutical Benefits Scheme (PBS), including changes to prescriber authorisations, should also be considered.

Support

A key problem in our response to ADHD is a lack of non-clinical support, particularly in the classroom setting. ADHD can have major negative impacts on educational outcomes,⁴ generating in turn lifelong implications. ADHD should be addressed as a threat to children's learning and reaching their full potential, by providing more resources in the classroom and in the home for these children and adolescents. Teachers also need enhanced training in supporting children and adolescents with ADHD. Parents also need their own support.

In terms of workforce, response should look beyond the usual doctors and psychologists, and consider the role of peer workers, allied health professionals (e.g., OTs), and youth workers. Responses should address how to 'live with ADHD' so that the symptoms are not too disruptive to learning, relationships, work and social activity.

Comorbidity

There is comorbidity between ADHD and various disorders including conduct disorder, antisocial personality disorder, and substance use disorders. This places children and young adults at risk of contact with the criminal justice system, an outcome which should be prevented at all costs.

Economic and health system impacts

The economic impact of ADHD is very significant, with an estimate in 2019 showing that the overall economic impact of ADHD was around \$20.4 billion pa. The costs, in terms of direct costs and in terms of wellbeing, are largely borne by the individuals concerned.⁵

As a condition with this prevalence, Australians should expect that our health system has developed a comprehensive response, including capabilities for diagnosing and ongoing treatment. Unfortunately, this is not yet in place.

As with many other mental health/behavioural disorder conditions, our health system should strive to address this condition without stigma or discrimination, and it should be alert to the impacts of stigma and discrimination on the availability of information to individuals with ADHD and their families, the effects on motivation of individuals with ADHD and their carers to seek treatment, and on the broader accessibility of diagnoses and care from the health system.

One key message for this inquiry is that there is a need for a stronger provision of relevant health professionals, trained and available to diagnose and address ADHD. The Commonwealth is the level of government directly responsible for providing the health systems components (policy and resourcing) to do so. This means that the appropriate MBS settings must be in place to bring about adequate supply of trained and accessible professionals, resulting in Medicare-supported care for all people affected by ADHD. It seems clear that this is not adequate at present.

There is also a need to consider the relevance of ADHD for National Disability Insurance Scheme (NDIS) assessments. This is discussed in detail below.

Summary of recommendations

The inquiry by the Committee is well positioned to play a major role on moving the debate forward on this highly prevalent health condition. We urge the Community Affairs Committee to:

- make recommendations for appropriate changes to the Medicare system, to ensure that ADHD diagnoses and ongoing treatment is adequately supported for people of all genders and ages
- in particular, focus attention to the provision of diagnoses and services for girls and women, given the strong evidence that they are under-diagnosed and under-treated
- examine any appropriate adjustments to current PBS settings that might be warranted
- ensure that NDIS settings relating to ADHD are based on accepted disability definitions of impairment and function in a diagnosis-neutral manner, with ADHD treated as are all other relevant health conditions
- make recommendations for a significant increase in research in Australia into ADHD and the services needed to diagnose and treat it.

PHAA will be happy to assist the Committee further during the course of its work.

Responses to the Inquiry Terms of Reference

1. The adequacy of access to ADHD diagnosis

There are long wait times to access health services to receive an ADHD diagnosis, often of 1-2 years.^{6, 7} The primary cause of these delays appears to be simply lack of availability of ADHD-trained psychiatrists and psychologists (see ToR 3 below).

Other precursor causes, all of which might be addressed by policy initiatives and adequate resources, include:

- lack of awareness of ADHD among parents, leading to delays in a decision to begin examination of a child's condition
- lack of awareness of ADHD among individuals with ADHD of all ages, leading to delays in seeking medical care and diagnosis
- lack of understanding of ADHD among GPs, leading to failures to refer clients to specialist assessment
- reluctance among individuals with ADHD, parents, and medical practitioners to confront stigma associated with ADHD, or stigma associated with behavioural disorders generally
- anticipation by affected individuals and families of the costs, including pharmaceutical costs, that might be associated with an ADHD diagnosis

There are also significant direct financial costs associated with health services for ADHD assessment. Full diagnoses by relevantly experienced psychiatrists and psychologists can exceed \$1,000 for a completed initial diagnosis.^{8, 9}

These costs present a significant equity problem. Those who are less able to afford an assessment may not receive the support needed.

Lack of availability of ADHD-trained psychiatrists and psychologists is one of the major causes of wait times. However, the sparse availability of such specialists also leads to physical transport and access issues for many individuals with ADHD, particularly those living in rural and remote areas, who might incur significant extra costs from the very action of travelling to see specialists at distant locations.

Aboriginal and Torres Strait Islander people experience additional barriers to accessing ADHD assessments, including due to a lack of culturally safe assessment (and treatment) approaches,¹⁰ and a lack of screening tools validated for this population. A higher prevalence of conditions often co-occurring in people with ADHD among Aboriginal and Torres Strait Islander people may add further complexity to accurate ADHD diagnosis in this population.¹¹

Culturally and linguistically diverse (CALD) populations may experience barriers to diagnosis including limited general health literacy.¹²

2. The adequacy of access to supports after an ADHD assessment

There are long wait times to access health services to receive ADHD treatments and support.

Ongoing ADHD coaching is an important support providing behavioural strategies for children and adults with ADHD. Currently, there are a lack of ADHD specialist coaches, some have closed their books and wait times can be several months.

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

The severe delays in meeting demand indicate there is a serious lack of ADHD-trained psychiatrists and psychologists in Australia.

Some general practitioners, who will typically have a key role in referring patients to specialists, may have insufficient ADHD literacy, including with regard to stigma and myths about ADHD, especially in adults.

4. The impact of ADHD gender bias in ADHD assessment, support services and research

ADHD is expressed differently in boys and men compared to girls and women. The perception exists that ADHD is a condition associated more strongly with boys, in particular with behavioural disorders that are less frequently diagnosed in girls and women. As a result, girls and women are often undiagnosed or misdiagnosed.

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

Two key pharmaceutical treatments currently available are Ritalin (methylphenidate) and Adderall (amphetamine-dextroamphetamine). Adderall is a slow-acting release treatment appropriate for many patients, but present costs can exceed \$30/day for prescribed usage.

The cost of ADHD medication is high, especially for adults with ADHD. Some medications are not covered under the PBS if patients have not had a diagnosis as a child, resulting in significantly increased costs for patients diagnosed as an adult.

Patients' out-of-pocket ADHD medication costs in Australia in 2019 have been estimated at \$26.6m (noting that this estimate is limited to medications listed on the PBS).¹³ Given that ADHD is a lifelong diagnosis and that core ADHD medication costs tend to increase with age,¹⁴ PBS subsidy settings should be reconsidered with a view to ensuring that appropriate medications are supported for appropriate prescriptions at all stages of life.

6. 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

Terminology and Conceptualization of Disability

The World Health Organization's (WHO) *International Classification of Functioning, Disability and Health* (ICF) conceptualizes disability as the result of "interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others",^{15, 16} it is diagnosis-neutral, and centres the individual's functional capacity. Disability and health exists on a continuum of function with no single defined cut-off point between the two.¹⁷

The relationship between neurodevelopmental disorders and disability is complex, and use of the term 'disability' is itself subject to strong views, particularly among individuals with such conditions. It is not correct to say that all such disorders necessarily cause disability, as functional impacts may be experienced

across a spectrum from mild to severe. Nor should such conditions be generally described as a 'disability', or such individuals as having a disability; some individuals may consider their condition as an attribute or positive part of their identity.¹⁸

PHAA acknowledges that people with neurodevelopmental conditions including ADHD often have very strong preferences for either identity-first or person-first language and the need to respect and affirm each individual person's choice of language they use about themselves.¹⁹ The PHAA remains committed to inclusive language. The PHAA recognises the predominant use of person-first language when referring to people with disability on the basis that people's impairment should not be unnecessarily focussed on,²⁰ however we do not mean to exclude or disrespect those who prefer identity-first language. We wish to highlight the key need to take care in the use of language, to minimize or eliminate stigma to ensure that people are not subject to discrimination, not least because of the direct impacts of stigma and discrimination on the motivation to seek health care and on the provision of appropriate care.

PHAA policies regarding disability

PHAA's general policies relating to [Disability and Health](#) are available through our standing policy position statements.

The National Disability Insurance Scheme and the National Disability Strategy (NDIS) increased the focus on disability services, but the health of people with disability has not been fully addressed.²¹ Disability is most often viewed as an outcome to be prevented, and disability is conflated with poor health. However, the poor health of people with disability is not always caused by their disability but by obstacles to accessing healthcare, discrimination and social determinants of health.

The social determinants of health are key drivers of health inequities for people with disability.²² People with disability are often excluded from employment and from education through direct and indirect discrimination,²³ and are disadvantaged with respect to almost all social determinants but particularly education, income, and employment.²⁴

NDIS' role in supporting a healthy and equitable Australia

The NDIS was established to improve the lives of Australians with significant disability. However, the very definition of 'disability', at least for the purposes of eligibility for NDIS support, is subject to definitional debates.

We also appreciate that the emergence of very great financial demands on the NDIS, leading to inevitable pressure on government to control outlays. We appreciate that government decisions regarding the NDIS are at risk of being driven by the need to minimize the scope of categories of eligibility, or deny proposals for new eligibility – such as ADHD. However, as with many other aspects of population health, expenditure on prevention or early management of health conditions often proves to result in lower costs to government finances, economic vitality and social wellbeing over the longer term. Modelling in 2021 estimated that for each dollar invested in the NDIS, over two dollars is returned to the economy.²⁵

PHAA believes that the application of NDIS eligibility criteria should always be evidence-based, give priority to prevention to minimize life-long health impacts, and focus on equity across our society, rather than driven by near-term outlay hesitancy which is actually counter-productive to longer-term public financial interests.

NDIS eligibility and ADHD

Aligned with the ICF, the NDIS Act 2013 does not specify conditions that meet early intervention or disability requirements. Rather, disability requirements relate to the presence of impairment(s), the permanence of the impairment, and the impact of impairment on individual's function including on social

or economic participation. To be eligible to access the scheme, an individual must have substantially reduced function in one or more of the following domains: communication, social interaction, learning, mobility, self-care or self-management.²⁶ Discussions on recognition of ADHD as a primary condition should therefore focus on these requirements, and acknowledge that lists which identify categories of conditions (eg: Lists A, B and D) should serve only to guide - not to narrow - eligibility as intended by the Act.²⁷

Consequently, it need not be argued that ADHD in isolation be regarded as a condition creating a general eligibility for NDIS support. Nonetheless, it will also be true that some individuals who meet NDIS disability or early intervention requirements will be people with ADHD, and that ADHD will contribute to their overall function. Any individual applying to access NDIS should be assessed in line with the functional domains as listed above; the impact of ADHD on function should be considered as any other condition. Taking an ADHD diagnosis and treatment course into account should be normalized as a part of dealing with any individual's overall NDIS support issues.

Both the *NDIS (Becoming a Participant) Rules 2016* (under the NDIS Act 2013) and the Productivity Commission's 2011 Inquiry Report 'Disability Care and Support' recommend that the ICF framework underpin assessment of function.^{28, 29} Within this conceptual framework, assessment tools should be specifically tailored to particular disabilities, and facilitate the identification of reasonable and necessary supports.³⁰

Finally, it should be understood that evidence-based recognition of ADHD as a relevant condition for NDIS purposes will not result in the NDIS assuming any excessive degree of responsibility for people with ADHD generally. Adequately funded services with clear referral and access pathways in the mainstream health system will continue to be a major source of ADHD diagnoses and treatment.

Equity considerations

Discussions regarding NDIS eligibility for individuals whose circumstances include ADHD should give consideration to specific populations who are currently under-represented among NDIS participants and/or experience disadvantage with respect to disability service access or utilisation. These include:

- Aboriginal and Torres Strait Islander people ^{31, 32}
- women and girls ³³
- LGBTIQ+ people ³⁴
- people from culturally and linguistically diverse backgrounds ^{35, 36}
- people living in rural and remote areas ³⁷
- people who are incarcerated ^{38, 39}
- people experiencing homelessness
- (see [PHAA Disability and Health Background Paper](#) for further details)

Given that some of these populations have higher rates,⁴⁰ or recognised under-diagnosis⁴¹ of ADHD, targeted strategies to promote equity of benefit from any changes to NDIS eligibility is paramount to avoid compounding disadvantage.

7. The adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages

As a clearly recognized health condition, the primary responsibility for diagnosis and treatment lies with services provided by the GP and specialist health professions, funded by the resources of the Medicare system, and is thus a Commonwealth-level responsibility.

However, patients presenting with ADHD symptoms will also interact with state health services, state services in other domains, and local government services on a regular basis. As with any mental health condition, there can be a variety of impacts on the daily lives of individuals with ADHD, including with governmental services. Such impacts will be aggravated if conditions are undiagnosed, or untreated.

8. The adequacy of Commonwealth funding allocated to ADHD research

A 2019 study *The social and economic costs of ADHD in Australia* concluded that from 2000 to 2015 total NHMRC-sourced –

“...expenditure associated with research for ADHD ... [was] \$15.7 million [in 2019 dollars]. Taking an average across the periods, the equivalent annual funding allocated to ADHD research in 2019 was estimated to be \$820,000.”⁴²

ADHD is a very significant condition in the population, manifesting in around 4% of people. At this scale it is clearly a health condition deserving of significantly greater research investment than has been occurring, including investment through the Commonwealth MRFF and NHMRC funding streams.

Most of the research to date has focused on children, specifically boys. There is thus a critical need for more research into ADHD in girls and women, and adults generally.

More research funding is needed to reduce the impacts on health systems and improve the health and wellbeing of people with ADHD across the life course and reduce the social and economic cost of ADHD in Australia described below.

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

Without adequate and appropriate ADHD services there is an increased risk of the following for people with ADHD:

- Mental health issues and conditions, and poor wellbeing
- Poor educational outcomes
- Reduced capacity to participate in the workforce
- Substance abuse and addiction
- Premature mortality

According to *The social and economic costs of ADHD in Australia* report (2019) –

“Productivity costs make up 79% of total financial costs, which is followed by deadweight losses (11%), health system costs (6%), and other costs including educational and crime and justice costs (3%). Employers were estimated to bear the largest share of financial costs (39%) followed by governments (30%), individuals and their families (20%) and society and other payers (11%). In addition to the substantial financial costs associated with ADHD, 40,890 DALYs were lost due to ADHD in 2019, which, using the VSLY, is a cost of \$7.6 billion. The total financial costs associated with ADHD were estimated to be \$12.8 billion in 2019, which equates to \$15,747 per person with ADHD.”⁴³

Inadequate management of ADHD also has clear equity impacts. A very recent Australian study has concluded that “a social gradient exists in both healthcare service use and children's [health-related quality of life] among those with ADHD”.⁴⁴

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

We defer to the expertise of others on this ToR.

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

The following programs could be considered for application to Australian conditions:

- **Access To Work** is a UK government program that grants up to £62,900 per annum to support people with a physical or mental health condition or disability to take up or stay at work.⁴⁵
- **Able Futures** is a UK (and UK-wide) government program for those in work (or individuals otherwise eligible for the Access to Work program) whose circumstances or mental health may affect their well-being or work performance.⁴⁶ It provides access to around 9 months of mental health support, generally made up of monthly support sessions. The support is for wider mental health and, although not ADHD-specific, can be very useful in managing ADHD.
- The **EY (Ernst and Young) Neuro-Diverse Centre of Excellence** approach, operating in the UK, Canada, and the US. This service is designed to create a supportive working environment for individuals with cognitive differences – such as autism, dyslexia and ADHD – that will help them to apply their strengths and meet clients' business needs in emerging technologies.

Conclusion

PHAA appreciates the opportunity to make this submission. We urge the Community Affairs Committee to:

- make recommendations for appropriate changes to the Medicare system, to ensure that ADHD diagnoses and ongoing treatment is adequately supported for people of all genders and ages
- in particular, focus attention to the provision of diagnoses and services for girls and women, given the strong evidence that they are under-diagnosed and under-treated
- examine any appropriate adjustments to current PBS settings that might be warranted
- ensure that NDIS settings relating to ADHD are based on accepted disability definitions of impairment and function in a diagnosis-neutral manner, with ADHD treated as are all other conditions
- make recommendations for a significant increase in research in Australia into ADHD and the services needed to diagnose and treat it.

Please do not hesitate to contact us should you require additional information.



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