

# ADHD Foundation Australia

"where everyone deserves a chance to shine"

Submission to the Senate into Inquiry into Assessment and Support Services for People with ADHD



ADHD



Foundation

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## Introduction

The ADHD Foundation welcomes the opportunity to participate in the Senate Assessment and Support Services for people with ADHD Inquiry (the Inquiry).

Outlined in this submission are three (3) key recommendations and seventeen (17) sub-recommendations, related to the Inquiry's Terms of Reference which the ADHD Foundation would like to further explore with the committee.

The ADHD Foundation's comments and recommendations are supported by defensible and extensive validated research and anecdotal evidence gleaned from its extensive Helpline operations, education programme participants and research. This includes case studies which can be made available to the Senate Inquiry Committee upon request. In addition, all ADHD Foundation recommendations have incorporated extensive local and international research data resulting in what we believe to be a best practice approach to rectifying current Australian health system issues as they relate to ADHD identification, treatment and management. Source data used to derive these recommendations, including case studies, will be made available to the Senate Inquiry Committee upon request.

The ADHD Foundation recognises ADHD as the most common neurodevelopmental disorder present in our community affecting an estimated 1.5 million Australians. This position is supported by the 2019 Deloitte Access Economics report which estimated the cost of ADHD to the Australian economy to be \$ 20.4 billion. This figure accounted for the impacts on the Australian healthcare, judicial and education systems as well as the negative impacts on national productivity. It is our belief based upon the increase in demand for ADHD Foundation services, that this figure has significantly increased.

The ADHD Foundation is advocating for swift government action, including ensuring accurate public healthcare ADHD diagnosis and treatment supported by a national education program and dedicated telephone and online helpline service.



## About the ADHD Foundation

The ADHD Foundation is a national for purpose, registered not for profit consumer-based organisation, providing support services to people with ADHD and their support networks. The organisation is run entirely by volunteers and is fully self-funded. Founded in 2017 the ADHD Foundation has grown to include a nationally expanding membership base of 12,650 people and processes thousands of inquiries per year.

The ADHD Foundation is structured to provide three levels of support;

### 1) ADHD FOUNDATION HELPLINE

The ADHD Foundation Helpline is our flagship service providing critical community support Australia-wide to those in need. The National Helpline is manned by well-trained volunteer councillors with lived ADHD and neurodiverse experience.

The helpline deals with a wide audience including people in crisis, such as those contemplating suicide, people with ADHD desperate to obtain diagnosis and treatment, people who have lost their jobs, families and/or homes due to their condition, and are now seeking support, people seeking clinical provider recommendations, people who have been exploited by healthcare providers, stakeholders wishing to source accurate information concerning ADHD and other neurodiverse conditions.

Since its inception, the ADHD Foundation National Helpline estimates it has processed over one hundred thousand enquiries and based upon the current rate of community demand, we are projecting annual enquiries will exceed 70,000 over the next twelve months.

The ADHD Foundation Helpline is an invaluable Australian community service that partially alleviates the burden placed on current government and privately funded helplines, many of which are ill-equipped to support ADHD. With the demand for support increasing weekly, the need for a dedicated and better-funded ADHD helpline has never been greater.

### 2. EDUCATION AND TRAINING

The ADHD Foundation provides regular free online webinars, newsletters, and blogs designed to disperse accurate information and useful practical strategies for the effective management of ADHD. The ADHD Foundation also provides fee-for-service programs for organisations to assist in the management of staff with ADHD.

### 3. ONLINE RESOURCES, RESEARCH, AND ASSESSMENTS

The ADHD Foundation website, provides valuable resources, advice and support for people with ADHD and their carers. The ADHD Foundation library of reference materials is vast, current, and accurate and benefits thousands who seek relevant content. The ADHD Foundation has driven and contributed to many local and international peer-reviewed research programmes and papers covering ADHD and other forms of neurodiversity.

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## Summary of Recommendations

The ADHD Foundation wishes to highlight three key recommendations and seventeen (17) sub-recommendations for consideration by the Committee, all of which were derived via extensive research, case studies and consultation.

### Key Recommendation 1:

#### Recognise and manage ADHD in the public healthcare systems as a primary mental health condition

**Recommendation:** The public health system to recognise ADHD as a primary and lifelong condition.

**Recommendation:** ADHD to be included within the Mental Health Public Policy Framework.

**Recommendation:** The public health system to include ADHD diagnosis and treatment for all age groups as part of their services using the Australian Evidence Based Guidelines for ADHD.

**Recommendation:** Include ADHD as a disability under the National Disability Insurance Scheme (NDIS) to allow people with functional impairments due to ADHD to access the Scheme.

**Recommendation:** Include ADHD medication in the Pharmaceutical Benefits Scheme (PBS) and develop national harmonised standards for prescribing.

**Recommendation:** Support the Australian Evidence-Based Guidelines for ADHD recommendations, namely allowing ongoing condition management by GPs following successful condition stabilisation by psychiatrists. This will include enabling GPs to prescribe medication and support ongoing treatment. Ongoing non-medicating support should also be expanded to include appropriately qualified psychologists.

**Recommendation:** Regulate private clinic diagnosis and treatment costs.

**Recommendation:** Fully fund the ADHD Foundation Helpline to provide evidenced-based access to information, advice, and support.



## Key Recommendation 2:

### Improve and broaden ADHD education and training and education for mental healthcare professionals

**Recommendation:** The Royal Australian and New Zealand College of Psychiatrists (RANZCP) to mandate ADHD education and training as part of the Specialist Advanced College Training program.

**Recommendation:** Australian General Practice Training (AGPT) to include ADHD management.

**Recommendation:** Mandate minimum training for healthcare professionals on ADHD patient management.

**Recommendation:** Provide funding to ADHD Foundation to establish additional professional education and awareness programmes.

**Recommendation:** Provide funding to ADHD Foundation to establish additional primary and secondary school education and awareness programmes.

**Recommendation:** Improve the understanding of ADHD in workplaces and include provisions of reasonable adjustment for workers with ADHD.

**Recommendation:** The government to support public awareness campaigns to inform the public of the correct pathway and guidelines for diagnosis including but not limited to destigmatising the condition.

**Recommendation:** Invest in research to better understand the barriers to the diagnosis of ADHD in women.

## Key Recommendation 3: .

### Fund the current ADHD Foundation National Helpline incorporating it as part of the national mental healthcare support framework

**Recommendation:** Fund the current ADHD Foundation Helpline to provide timely access to information, advice, and support for the ADHD community.



## Responses to the Terms of Reference

### A) Adequacy of access to ADHD diagnosis

With only a small percentage of the medical profession prepared to diagnose and treat ADHD, the ADHD Foundation helpline consistently receives feedback from consumers on the grossly inadequate access to diagnosis and treatment services. This is largely due to the lack of public health services available and long waitlists for assessments from psychiatrists.

**Recommendation:** The public health system include ADHD diagnosis and treatment for adults, adolescents, and children as part of their services.

Diagnosis through the public health system is not available to people with suspected ADHD. People seeking an ADHD diagnosis must do so privately, which for those on low incomes can be prohibitive. Many ADHD Foundation members report they will either delay or not seek a diagnosis due to prohibitive costs resulting in negative mental health outcomes and potential negative personal, community and economic impacts.

**Recommendation:** Mental Health Public Policy recognises ADHD as a lifelong mental health condition and includes it within the mental health policy framework.

Our members report feeling disadvantaged with their mental health needs compared to those with other neurodiverse conditions such as Autism who can access public health services. This systemic barrier further re-enforces the stigma associated with ADHD. The ADHD community must have the same pathways afforded to them as other neurodiverse conditions to improve equity issues and remove barriers to diagnosis.

The ADHD Foundation Helpline volunteers spend much of their time assisting people to find available specialists who can diagnose and treat ADHD. The foundation is now in the fortunate position of being informed when new services become available, which can be actively shared with the members. The helpline has limited funding and resourcing through volunteers. With adequate resourcing, it could provide timely information and support to a greater percentage of the Australian population with ADHD. In the meantime, many consumers report delays of up to 18 months for an ADHD diagnosis. In some cases, professionals have closed their books due to over-demand.

**Recommendation:** Fully fund the ADHD Helpline to provide evidenced based access to information, advice, and support for the ADHD community.



The lack of awareness of a definitive set of diagnostic procedures, has led to widely different practices which are confusing to consumers and has led to excessive costs. The Guidelines provide this clarity and must be widely communicated and enforced if this issue is to be overcome.

**Recommendation:** All qualified healthcare providers to adopt the Australian Evidence Based Guidelines for ADHD diagnosis and treatment guidelines.

**Recommendation:** The government to support public awareness campaigns to inform the public of the correct guidelines for diagnosis.

It is important to note there has been an increase of other “professionals” offering diagnostic services which are exploiting people desperate for a diagnosis. We have heard of professionals charging up to \$5000 for assessments. An increase in public awareness of the assessment process and who can diagnose ADHD is required to ensure people are making informed decisions when seeking professional advice and in particular diagnosis for ADHD. If necessary, separating the diagnostic process from the treatment process would enable greater flow through.

**Recommendation:** Support the Australian Evidence-Based Guidelines for ADHD recommendation to expand ongoing management following successful treatment for ADHD to include GP’s and appropriately qualified psychologists.

## B) Adequacy of access to support after an ADHD Assessment

The ADHD Foundation supports the recommendation in the recent Australian ADHD guidelines highlighting the need for psychoeducation after diagnosis. Whilst many people may require medication to manage their ADHD the ADHD Foundation can report a large cohort of consumers have either no access or inadequate access to support post-diagnosis.

For adults with ADHD, there is little formal support through health services. Professionals working in public health services often have a poor understanding of ADHD and find it difficult to provide adequate support to people with ADHD. In some cases, consumers have reported being mistreated by outreach services.

**Recommendation:** Include post ADHD diagnosis management as part of Psychiatrist, GP and Psychologist training courses.

**Recommendation:** Ensure all public hospitals have ADHD patient management training professionals on staff.





### C) Availability, training and attitudes of treating practitioners

ADHD training is often undertaken as an option rather than core topic. This lack of priority leads to a medical system ill-equipped to deal with the condition and can often result in misdiagnosis and incorrect treatment.

**Recommendation:** Professionals should be trained on the Guidelines in their formative undergraduate and post-graduate degrees. Peak bodies can also play a role in ensuring professionals have access to information and ongoing training through professional development training.

ADHD is not treated or recognised within the public health system and therefore many psychiatrists do not accept ADHD as a valid psychological disorder. ADHD is often misdiagnosed due to a lack of education and training in this condition.

This can result in a concerning attitude, impacting the support provided to people with ADHD. Common widespread misinformation identified by The ADHD Foundation includes:

- *ADHD is a childhood condition and children will grow out of it.* This is an outdated theory and has serious repercussions, especially for adolescence. There is a risk they will dismiss support when their executive functioning needs the most help.
- *You cannot have ADHD unless you are hyperactive.* This leads to lower rates of Inattentive ADHD being diagnosed. Women have a higher prevalence of this type of ADHD, which leads to lower diagnosis rates in this cohort.
- *If you are over 65 years your symptoms are likely to be early signs of dementia.* The aging brain does not have the same attentional capacity as a younger brain; therefore, this can be one of the times that more active treatment is needed.

ADHD can lead to other mental health issues and by treating ADHD first, or at the same time, has the potential to change the trajectory of psychiatric morbidity later in life<sup>1</sup>

Child psychiatrists consider that diagnosis and treatment of ADHD is the province of paediatricians, who are not trained in complex mental health presentations. This reinforces the erroneous view that it is a simple behaviour disorder. Yet more than 65% of children with ADHD have at least one other co-morbid condition<sup>1</sup>.

Other professionals also lack the training to adequately support people with ADHD. For example, ADHD is not part of the training for Geriatricians and very few addiction specialists accept ADHD as a valid diagnosis even in the face of the high co-morbidity and prevalence of self-medication of symptoms.

<sup>1</sup> Katzman MA, Bilkey TS, Chokka PR, Fallu A, Klassen LJ. Adult ADHD and comorbid disorders: clinical implications of a dimensional approach. *BMC Psychiatry*. 2017 Aug 22;17(1):302. doi: 10.1186/s12888-017-1463-3. PMID: 28830387; PMCID: PMC5567978.



**Recommendation:** Mandate recognition for ADHD as a primary condition in the public and private healthcare systems, with the same standing as existing primary mental health conditions.

**Recommendation:** Mandate expansion in training standards that streamline education and training in ADHD in university curriculums and qualifications and professional development requirements.

**Recommendation:** Provide better ADHD education in primary schools to educators for early diagnosis recommendations resulting in earlier interventions.

#### **D) Impact of gender bias in ADHD assessment, support services and research**

The ADHD National Helpline statistics show equal number of males and females coming forward for assessment. However, lack of knowledge of how ADHD presents especially in women, leads to ADHD being overlooked by untrained professionals as a diagnosis. More education for professionals is needed to support better diagnosis of ADHD in women.

**Recommendation:** Invest in research to better understand the barriers to diagnosis of ADHD in women.

#### **E) Access to and cost of ADHD medication**

The ADHD Foundation Helpline feedback from a large percentage of consumers confirms the costs associated with obtaining prescriptions for medication and the cost of the medication itself to be prohibitive.

Paediatricians and psychiatrists are the only professionals permitted to prescribe ADHD medication. Such specialists are in high demand and short supply. Appointments are difficult to secure with waiting lists ranging from 6-24 months. Specialist appointments are expensive and can cost over \$500. Lack of specialist availability and high appointment costs will result in a large percentage of ADHD patients remaining un-treated. This can result in the development of comorbidity such as depression and has the potential to translate into added pressure on the community, social security and healthcare system as well as in some cases, the judicial system. National productivity will be negatively impacted in most cases.

**Recommendation:** ADHD must be recognised as a chronic lifelong condition by the Australian healthcare system and treated as such.

**Recommendation:** Move responsibility for ongoing ADHD medication management from specialists to GPs, to free up specialist availability for diagnosis and medication stabilisation. Thus, reducing bottlenecks, reduce costs as the supply and demand imbalance will be reduced.

**Recommendation:** Provide public hospital and bulk billing access to ADHD diagnosis and treatment.



Each State and Territory apply and enforce different prescribing, dosing and dispensing regulations, making it difficult for those with ADHD to obtain their tailored medication when traveling or relocating.

**Recommendation:** Develop national harmonised standards for the prescribing and dispensing of ADHD medication.

### **F) The role of the National Disability Insurance Scheme in supporting people with ADHD**

ADHD is considered a disability under the *Disability Discrimination Act 1992*. However, is currently not included under the NDIS. There has not been a willingness to consult the ADHD community in the same way as they have done for its fellow neuro-developmental disorder such as Autism Spectrum Disorder.

The ADHD Foundation supports the philosophy and aims of the NDIS. We agree that inclusion in the Scheme should be based on the impairment of a permanent condition. ADHD is an incurable lifelong condition, the level of impairment depends on many factors and we accept that to gain access, the impairment should be detailed, along with the support plan.

ADHD is highly treatable with up to 70% of symptoms able to be controlled by medication.

To reduce human suffering and reduce the negative impacts on society of untreated ADHD, it is essential that the condition be included within the NDIS.

It must be noted that a significant percentage of those with undiagnosed and untreated ADHD will develop comorbidities and other dependencies such as; Anxiety, Depression, Drug and Alcohol Abuse and Eating Disorders with some moving to Suicide. Inclusion in the NDIS would prevent many of these conditions from developing.

**Recommendation:** Include ADHD as a disability under the NDIS to allow people with ADHD to access the Scheme.

### **G) The social and economic cost of not providing adequate and appropriate ADHD services**

According to the Deloitte Access Economics report of 2019, it is estimated that the cost of ADHD to the Australian economy exceeds \$20.4 billion. Given the significant increase in demand as experienced by the ADHD Foundation's Helpline, since this report was issued, we can only assume the amount initially quoted has also significantly increased.

The costs to our nation must be measured across multiple levels, including but not limited to: Personal hardship; Comorbidity leading to increased pressure on the healthcare system; Dysfunctional behaviours leading to impacts on the judicial system (note a recent study has shown that 25% of juveniles and adults in the judicial system have ADHD); People dropping out of the education system; Children being



bullied at school; Absenteeism; Employment loss creating a burden on the social security system; Relationship breakdowns; Homelessness; Gambling problems; Drug addiction; Overall national productivity losses and Suicide. Our society does not benefit in any way from lack of ADHD diagnosis and treatment.

Financial costs for individuals can include assessments which can exceed \$3,000; Specialist appointments for scripts which can cost up to \$500 per appointment; Professional psychological appointments can be up to \$300 per session; and ongoing costs of non PBS medications amount to prohibitive costs for many. Certain providers require payment in advance and holding deposits for future appointments.

Sadly we have anecdotal evidence gleaned from the ADHD Foundation Helpline that more people with ADHD are now turning to the black market for medication.

**Recommendation:** Increase the number of specialists permitted to diagnose ADHD, regulating the costs whilst also allowing ADHD diagnosis and treatment in the public healthcare system.

**Recommendation:** Include ADHD medication on the PBS.

**Recommendation:** Provide more education and awareness of ADHD in primary, secondary and higher educational settings.

**Recommendation:** Improve the understanding of ADHD in workplaces and include provisions of reasonable adjustment for workers with ADHD.

## H) The viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD

The ADHD Foundation sees these guidelines as an excellent step towards addressing many of the current issues.

**Recommendation:** The ADHD Foundation supports and recommends the adoption of these Guidelines. It is recommended these Guidelines are regularly reviewed to maintain currency and ensure they provide adequate guidance for professionals working with people with ADHD.



## Conclusion

The current healthcare system is inadequately managing ADHD in the community. With insufficient ADHD-trained medical professionals, lack of recognition of ADHD as a primary condition in the public healthcare system and cost-prohibitive diagnosis and treatment options sometimes leading to predatory supplier behaviour, government intervention is critically required.

The ADHD Foundation has provided a set of recommendations it believes will resolve many of the issues currently being faced. The adoption of the ADHD Foundation recommendations should result in;

- Reductions in cases of comorbidity such as ADHD symptom related anxiety and depression
- Reductions in public healthcare demand and hospitalisations
- Reductions in suicide
- Reductions in crime leading to less juvenile and adult detention
- Reductions in domestic violence
- Reductions in family separations
- Reductions in absenteeism
- Reductions in unemployment leading to a reduction in social security payments
- Reductions in homelessness
- Fewer school/apprenticeship drop-outs
- Reductions in car accidents
- Increases in productivity leading to better performance and more income tax payments

The ADHD Foundation's comments and recommendations are supported by defensible and extensive validated research and anecdotal evidence gleaned from its extensive Helpline operations, education program participants, and research. This includes case studies which can be made available to the Senate Inquiry Committee upon request. In addition, all ADHD Foundation recommendations have incorporated extensive local and international research data resulting in what we believe to be a best practice approach to rectifying current Australian health system issues as they relate to ADHD identification, treatment, and management. Source data used to derive these recommendations, including case studies, will be made available to the Senate Inquiry Committee upon request.

The ADHD Foundation acknowledges this as an essential inquiry and looks forward to further contributing to the development of effective and sustainable outcomes.

# Thank you

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The ADHD Foundation thanks, supports and stands ready to participate in the next stage of this critical Senate inquiry. The ADHD Foundation anticipates that the findings and resulting actions from this Senate inquiry will deliver positive improvements in the wellbeing of those with ADHD and will destigmatise the condition, which for decades has contributed to human suffering and hardship. It is clear that the benefits associated with effective diagnosis and treatment of ADHD will far outweigh the associated costs across all measures.

With kind regards

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