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# Inquiry into assessment and support services for people with ADHD Submission

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# Introduction

Suicide Prevention Australia welcomes the opportunity to provide input to the Inquiry into assessment and support services for people with attention deficit hyperactivity disorder (ADHD).

Suicide Prevention Australia is the national peak body for the suicide prevention sector. We have over 370 members representing more than 140,000 employees, workers, and volunteers across Australia. We provide a collective voice for service providers, practitioners, researchers, local collaboratives, and people with lived experience.

Over 3,000 people tragically die by suicide and an estimated 65,000 people attempt suicide each year. Over 7.5 million Australians have been close to someone who has taken or attempt suicide. Our shared vision is a world without suicide and with our members, we work to inform through data and evidence; influence systemic changes that drive down suicide rates and build capability and capacity for suicide prevention.

We are concerned about the increased risk of suicide for people living with ADHD.[1],[2] ADHD symptoms such as hyperactivity, impulsivity and inattention can have a profoundly debilitating and disruptive impact on people's lives and can cause significant behavioural, emotional, and social difficulties.[3],[4]

International research shows that people with ADHD may be up to five times more likely to attempt suicide, and three times more likely to die by suicide compared to the broader population.[5],[6],[7] While a study undertaken in New South Wales found that children and young adolescents hospitalised for suicidal behaviour were four times more likely to be diagnosed with ADHD.[8]

We are concerned that structural and financial barriers prevent many Australians from obtaining a formal ADHD diagnosis and accessing care.[9] Approximately 5% of all children and 2.5% of adults in Australia are living with ADHD symptoms. [10] Yet ADHD Australia suggest that 75% of people with ADHD remain undiagnosed.[11] Concerningly, research finds that only one in ten adults and approximately one third of all children in Australia with ADHD are recognised and receive treatment.[12],[13] Considering the elevated risk of suicide for people in Australia with ADHD there is a strong need for early identification, access to diagnosis and treatment, and robust support services.

On this basis we would like to provide input relating to four of the Terms of Reference of this inquiry:

a) adequacy of access to ADHD diagnosis;

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

f) the role of the National Disability Insurance Scheme (NDIS) in supporting people with ADHD;

i) the social and economic costs of failing to provide adequate and appropriate ADHD services.

# **Summary of Recommendations**

1. The Commonwealth Government should work with State and Territory Governments to ensure that all ADHD practitioners have received appropriate training and can identify and diagnose people with ADHD.

2. The Commonwealth Government fund a national education and awareness campaign for ADHD to improve knowledge of symptoms and encourage people with symptoms to seek diagnosis and treatment.

3. The Commonwealth Government fund a suite of resources for parents, teachers, and practitioners to increase awareness of ADHD symptoms to improve rates of diagnosis in children.

4. The Commonwealth Government fund 7,500 new university places for paediatricians, psychologists, and psychiatrists to expand the ADHD practitioner workforce.

5. The Commonwealth Government fund ADHD assessment training to upskill the current paediatric, psychology, and psychiatric workforce.

6. The Commonwealth Government ensure that ADHD medication regulations are consistent across all states and territories to improve access to treatment.

7. The Commonwealth Government recognise ADHD as a primary disability under the National Disability Insurance Scheme to help people struggling with the financial costs of ADHD.

8. The Commonwealth Government include subsidised ADHD assessments within the psychiatric workforce within the Better Access initiative to facilitate equitable access to diagnosis.

9. The Commonwealth Government fund suicide prevention training for general practitioners to improve ability to recognise and support people at risk of suicide.

# Improve access to ADHD diagnosis

While ADHD appears in childhood, research indicates that only one in five children who meet the criteria for an ADHD diagnosis are diagnosed by the age of seven. [14],[15],[16] This is concerning as living with untreated ADHD can lead to lifelong impairment and poor quality of life.[17] Research also shows that people with undiagnosed and untreated ADHD are more likely to die by suicide compared to the broader population.[18],[19],[20] An international study identified that children and adolescents aged 3-18 years who are living with untreated ADHD are significantly more likely to experience suicidal behaviour compared to their peers.[21]

Research finds that ADHD occurs at a similar rate in people of all genders.[22],[23],[24] Yet males are between two to ten times more likely to receive an ADHD diagnosis in comparison to females.[25],[26] Concerningly it is estimated that at least half of all women with ADHD remain undiagnosed.[27],[28],[29] Research indicates that this is due to referral bias and the failure of health professionals to recognise ADHD symptoms in women.[30],[31]

There are differences in how ADHD manifests, and research finds that males are more likely to present with impulsive type ADHD and display more observable symptoms while females more commonly present with inattentive type ADHD which is often overlooked by clinicians. [32] A study with 2,332 twins and siblings found that males tend to experience more extreme symptoms such as hyperactivity and disruptive behaviours which are more likely to lead to referral for evaluation of ADHD.[33] In comparison, females with ADHD can experience more subtle symptoms and are more likely to be forgetful, daydream and interrupt conversations.[34]

ADHD is poorly understood by the broader community and health professionals often lack the skills to recognise ADHD in females.[35],[36] In particular, a literature review found that ADHD symptoms in women are likely to be overlooked, and that females with undiagnosed ADHD are more likely to receive treatment for co-occurring conditions such as anxiety or depression.[37] Of key concern, a study found that healthcare professionals were unlikely to diagnose ADHD in girls aged 7-12 years unless they displayed signs of an emotional disorder.[38]

While it is imperative that health professionals have the skills and expertise to identify ADHD in all genders, it is particularly important that ADHD in females is detected to reduce disparities and the risk of suicide among females. Research indicates that females with ADHD are at greater risk of suicide compared to those without ADHD.[39] A study which followed an ethnically and socioeconomically diverse group of girls over two decades found that those who had been diagnosed with ADHD in childhood were significantly more likely to engage in self-harm and attempt suicide.[40] While a study undertaken in Canada found that 24% of women with ADHD have attempted suicide compared to 3% of women without ADHD.[41]

Sadly, for women, the impacts of living with undiagnosed ADHD can be severe. A literature review found that living with untreated ADHD can lead to poor wellbeing, low self-esteem, shame, and self-loathing.[42] To improve outcomes it is essential that all people in Australia including women with ADHD are identified and diagnosed. The ADHD practitioner workforce must have the skills to identify and diagnose people with ADHD and the government should work with service providers to ensure that all healthcare professionals employed in the sector have received adequate training.

The government should also invest in a national public awareness campaign to educate the community on ADHD and how symptoms can manifest in both males and females. This will increase awareness among the general population including health professionals and will ensure that people presenting with ADHD symptoms are identified and receive treatment. An awareness campaign will also encourage and empower Australians with ADHD symptoms to advocate for themselves and seek diagnosis and treatment.

Education on ADHD should be targeted to parents, teachers, and practitioners to enable early intervention and improve health outcomes. A suite of resources for parents, teachers and practitioners to ensure that the signs of ADHD in children are recognised should be funded by the Commonwealth Government. This should include referral resources and a guide for teachers on how to communicate effectively with parents when a student is suspected to have ADHD. This will improve parent-teacher communication and ensure that children with ADHD are appropriately supported in the school environment.

#### Recommendations

1. The Commonwealth Government should work with State and Territory Governments to ensure that all ADHD practitioners have received appropriate training and can identify and diagnose people with ADHD.

2. The Commonwealth Government fund a national education and awareness campaign for ADHD to improve knowledge of symptoms and encourage people with symptoms to seek diagnosis and treatment.

The Commonwealth Government fund a suite of resources for parents, teachers, and practitioners to increase awareness of ADHD symptoms to improve rates of diagnosis in children.

# Expand the ADHD practitioner workforce

Concerningly, reports indicate that it is exceedingly difficult for people with ADHD symptoms to obtain a formal diagnosis due to the complexity of the system, significant costs involved and long wait times for assessment.[43] For children, a child psychologist, psychiatrist or paediatrician with training and expertise in ADHD can provide diagnosis and this requires a referral from a general practitioner.[44],[45] Similarly, adults also require a referral from a general practitioner, and can be diagnosed by either a psychiatrist or psychologist skilled in ADHD assessment. [46]

While children can access paediatricians at no cost through Medicare, in many areas across Australia the wait time to see a local paediatrician is more than a year.[47],[48] Several media reports indicate that the system is short of specialists leading to unnecessarily long wait times for assessment. [49] Worryingly, a news article published in 2022 notes that in New South Wales the wait time in the public system for a child neurodevelopmental assessment is over two years.[50] While for those living in Victoria the wait time to see a paediatrician is between one and two years.[51],[52] Correspondingly, a news article from March 2023 indicates that there is a two-year wait to see a paediatrician in Western Australia.[53]

For adults, the current wait time for ADHD assessment is between approximately four to eight months.[54],[55] However, the ABC have reported that there is a wait time in Victoria of eleven months due to the current workforce shortage.[56] Worryingly, media reports also indicate that due to the acute shortage of qualified health professionals capable of diagnosing ADHD that Australians have been forced to travel interstate to access care which is time consuming and expensive.[57],[58]

The ADHD Foundation report that many psychiatrists have long waitlists and will not accept new clients seeking an ADHD diagnosis.[59] The Australian Psychological Society also state that one in three psychologists are not taking on new clients. [60] Concerningly, a 2021 consultation paper for the 10-year National Mental Health Workforce Strategy indicates that there is a shortfall of nearly 8,000 full-time workers across Australia which indicates an urgent need to expand the workforce to address unmet need.[61]

The recent 2023-2024 Commonwealth Budget includes funding for 500 additional psychology post-graduate placements however this boost to the workforce is not sufficient to meet the current high levels of demand.[62] The government should provide further funding for an additional 7,500 university places to target the skills shortage and expand the paediatric, psychology and psychiatry workforce to improve access to ADHD diagnosis. The government should also provide funding to upskill the current psychology, psychiatry, and paediatric workforce in ADHD assessment to immediately increase the number of qualified health professionals able to perform ADHD assessments to reduce the long wait times experienced by adults and children across Australia.

#### **Recommendations**

4. The Commonwealth Government fund 7,500 new university places for paediatricians, psychologists, and psychiatrists to expand the ADHD practitioner workforce.

5. The Commonwealth Government fund ADHD assessment training to upskill the current paediatric, psychology, and psychiatric workforce.

# **Include ADHD on the NDIS**

Media reports indicate that due to the acute shortage of qualified health professionals capable of diagnosing and treating ADHD that Australians have been forced to travel interstate to access care which is time consuming and expensive.[63], [64] Concerningly, states and territories across Australia have different regulations for ADHD medication, and medication prescribed in one state may be illegal to dispense in another.[65]

It is important that people experiencing ADHD symptoms have access to treatment. ADHD medication can reduce the effects of distressing ADHD symptoms and improve functioning and wellbeing.[66],[67] A large population-based study found that when adults have access to stimulant medication to treat ADHD symptoms this significantly lowers suicide risk. [68] While a cohort study identified that children diagnosed with ADHD showing hyperactive-impulsive behaviour have a lower risk of suicide if treated with ADHD medication.[69] Regulations for prescribing ADHD need to be consistent across Australia to improve access to ADHD treatment.

Concerningly, there are no government funded health services which can diagnosis adult ADHD at no cost. This needs to be urgently rectified. The cost of an ADHD assessment is significant, and it is reported that an initial appointment with a private psychiatrist or psychologist can cost up to \$700.[70] However, fees available online from psychology clinics across Australia for an ADHD assessment and initial treatment show costs can range between \$1,000 to \$2,200.[71],[72],[73] The high cost of getting assessed for ADHD presents a major financial barrier and prevents people from lower income households from getting diagnosed. Concerningly, data from the Western Australia Health Department indicates that there are 26,000 people living within metro areas receiving ADHD treatment compared with only 5,000 people in Western Australia's regional areas.[74] This highlights an urgent need to improve access to diagnosis in rural, regional, and remote and lower socioeconomic areas.

To address financial barriers in accessing diagnosis and treatment, the government should include subsidised neurodivergent diagnosis assessments with the psychiatric workforce under the Better Access initiative. Access to Medicare rebates for assessment would significantly help alleviate the financial impact of ADHD for many Australians. It would also ensure that people from lower socioeconomic backgrounds can receive a diagnostic evaluation for ADHD.

Regarding treatment for ADHD cognitive behaviour therapy (CBT) can help improve symptoms however many Australians cannot access treatment due to the significant cost of therapy. [75] The Australian Psychological Society suggest that private psychologists charge \$280 per session and Australians can access ten Medicare-funded standard psychological therapy sessions per year through the Better Access Scheme. [76],[77]

Under the Better Access Scheme, the rebate for a \$280 therapy session is only \$131 leaving people with significant out of pocket costs.[78] People with ADHD symptoms also require more than 10 therapy sessions and require at least 12-14 sessions of CBT to see progress.[79] However, the high cost of treatment is a major barrier preventing many from accessing care. Worryingly, a Productivity Commission report shows that nearly a quarter of people are delaying seeking treatment due to the high cost.[80]

The significant cost of ADHD treatment is concerning as we know that people with ADHD can have reduced earning capability and that ADHD symptoms can make it difficult to manage money.[81] Symptoms such as distractibility, impatience and difficulty listening can make it hard for people to complete work tasks or perform to a high level.[82] A large study undertaken in Sweden found that people with ADHD earn on average 17% less than their peers.[83] While a systematic review found that adults with ADHD are twice as likely to be unemployed compared to their peers.[84]

ADHD Australia's National Survey found that 40% of Australians with ADHD believe that the financial burden of ADHD is one of the biggest challenges of living with ADHD. [85] The survey also found that average spending per year on ADHD for people under the age of 26 is \$2,188, with carers spending \$5,543 per child.[86] These costs are significant particularly as there are many households in Australia with a parent and multiple children diagnosed with ADHD.[87] ADHD is considered a disability under the 1992 Disability Discrimination Act, but is not covered under the National Disability Insurance Scheme (NDIS).

If ADHD were considered a primary disorder under the NDIS this would help people living with ADHD meet their living costs and pay for diagnosis and treatment. This will allow all Australians regardless of income and wealth to have the means to obtain an ADHD diagnosis and receive treatment. ADHD can cause significant impairments and people living with ADHD should have access to financial assistance under the NDIS to improve assessment, treatment, and support accessibility. This would make a significant difference to the lives of people and families impacted by ADHD who are burdened with significant living costs.

#### **Recommendations**

6. The Commonwealth Government ensure that ADHD medication regulations are consistent across all states and territories to improve access to treatment.

7. The Commonwealth Government recognise ADHD as a primary disability on the National Disability Insurance Scheme to help people struggling with the financial costs of ADHD.

8. The Commonwealth Government include subsidised ADHD assessments with the psychiatric workforce within the Better Access initiative to facilitate equitable access to diagnosis.

# The social cost of inadequate support

The research shows that living with ADHD can be challenging and symptoms can negatively impact every aspect of a person's life.[88] Experiencing ADHD symptoms such as restlessness, concentration difficulties and forgetfulness can be highly distressing and lead to poor mental wellbeing.[89],[90] Research finds that individuals with ADHD report higher levels of self-perceived stress compared to those without a diagnosis.[91]

A study with adults aged between 18 and 30 found that people with ADHD were more likely to experience suicidal thoughts due to the increased likelihood of experiencing unpleasant and stressful events compared to the broader population. [92] While a large population-based study undertaken in Canada which assessed the presence of social and psychological wellbeing among people with ADHD found that only 42% of people with ADHD report complete mental health compared to 74% of people without a diagnosis.[93]

The drivers of suicide are broad, yet there are several factors which can increase the potential risk of suicide for people with ADHD.[94],[95] Impulsivity, a primary trait of ADHD, has been linked to engaging in risk taking behaviour and is considered a strong risk factor for suicide.[96],[97],[98] Research also finds that people living with ADHD can have difficulty managing their emotions.[99] In particular it has been identified that emotional dysregulation affects 70% of adults with ADHD.[100],[101] Concerningly a systematic review found that people who experience difficulty regulating their emotions report experiencing higher levels of suicidal thoughts and are more likely to attempt suicide.[102]

Research indicates that up to 80% of adults with ADHD have one or more co-occurring mental health conditions such as a mood, anxiety, or a substance use disorder.[103],[104] Findings from the National Comorbidity Survey undertaken in the United States of America found that adults with ADHD are at least four times more likely to develop a mood disorder.[105] Worryingly, a systematic review which examined the comorbidity between ADHD and anxiety disorders identified that at least a quarter of all adults with ADHD have an anxiety disorder.[106],[107] We know that experiencing poor mental health is a strong risk factor for suicide.[108] Sadly, research finds that people with ADHD who are also diagnosed with a mental health disorder are ten times more likely to die by suicide compared to people without ADHD.[109]

Approximately 45% of people who die by suicide contact a primary care provider within one month of their death. [110] Given the increased risk of suicide for people with ADHD it is crucial that general practitioners can identify people with an elevated risk of suicide and have the confidence and expertise to discuss suicide with patients. The government should invest in suicide prevention training for general practitioners to improve knowledge and suicide prevention skills. Suicide prevention training will equip general practitioners with the ability to communicate effectively with people showing signs of distress to help prevent the immediate risk of suicide.

#### **Recommendations**

9. The Commonwealth Government fund suicide prevention training for general practitioners to improve ability to recognise and support people at risk of suicide.

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## If you or someone you know require 24/7 crisis support, please contact:

Lifeline: 13 11 14	Suicide Call Back Service: 1300 659 467
www.lifeline.org.au	www.suicidecallbackservice.org.au

## For general enquiries