



Understanding ADHD: Breaking down barriers to ADHD communities thriving (May 2023)

Submission to the Senate Community Affairs References Committee's inquiry into Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD

1. Background

ADHD Australia is the leading national organisation engaging in public awareness, education and advocacy to make Australia a better place for people living with ADHD. Our mission is to achieve positive systemic change for people with ADHD through access to better evidence-based information, resources, services, and community awareness of ADHD. We are passionate advocates for people living with ADHD, and strongly believe in the power of inclusivity and equal opportunities for every member of our society.

We welcome the Senate Committee's inquiry and the opportunity to provide recommendations for the Australian Government to make Australia a better place for people living with ADHD. This submission has been prepared drawing on previous research, insights and expertise from people living with ADHD and their families, carers, clinicians, teachers, employers, partner organisations, and government. ADHD Australia engaged in community consultation through an online survey of 656 people impacted by ADHD from across Australia, which has informed this submission. We have also prepared a ADHD Community Submissions report, summarising key themes from the online submissions and collating the responses to support the Senate Committee to understand ADHD community concerns as they relate to the Senate inquiry's Terms of Reference.

In recent years, public awareness of ADHD has increased due to advocacy by ADHD organisations such as ADHD Australia, mainstreaming of mental health awareness during COVID-19, and as online content sharing and media reporting has increased. Approximately 1 in 20 people in Australia - over 1.25 million - are living with ADHD.¹ The figure of people impacted by this inquiry grows when you add families, carers, educators, workplaces, and healthcare workers supporting people living with ADHD, and the fact that ADHD is often underdiagnosed. However, many misunderstandings and misconceptions about the experience of living with ADHD persist in our community, in schools, healthcare, justice settings, workplaces, and political decision-makers.

Attention Deficit Hyperactivity Disorder (**ADHD**) is a complex neurodevelopmental disorder characterised by persistent patterns of inattentive, impulsive, and sometimes hyperactive behaviour, frequently accompanied by emotional regulation challenges. The ADHD community is diverse and ADHD impacts people's lives in very different ways. ADHD advocates have raised awareness about positive attributes of living with ADHD, such as: problem-solving skills; imagination and creativity; compassion and empathy; resilience and perseverance; hyperfocus

¹ Health Direct, [Attention deficit hyperactivity disorder \(ADHD\)](#).

and deep knowledge of specific topics; and productive multitasking.² However, living with ADHD can also create lifelong challenges in educational achievement, mental health and wellbeing, securing stable employment, and avoiding interactions with the criminal justice system.³

Despite recent progress, outdated public and policy understandings as well as limited resources, funding and awareness of ADHD continue to create barriers for people living with ADHD seeking assessment, treatment and crucial supports. We are committed to working collaboratively with the ADHD community, families, carers, teachers, clinicians, employers, partner organisations, and government departments to prioritise national funding, awareness and reform for ADHD in Australia.

This Senate inquiry is an opportunity to shine a spotlight on the experiences of people living with ADHD right now, and prioritise action to finally change this.

2. Summary of recommendations

There are a broad range of interventions needed to ensure people living with ADHD facing barriers to study, work, and pursuing their life goals can be supported to thrive. We urge the Senate Committee to recommend that the Australian Government:

1. **Assessment + diagnosis:** Improve access to ADHD assessment and diagnosis by expanding clinical care and support services, making funding available for ADHD assessments, funding additional research including pilot studies to unblock care pathways, providing additional training for frontline healthcare workers, and facilitating engagement with the Primary Health Networks to investigate innovative solutions to access in primary health care.
2. **Training + awareness:**
 - a. **Individuals, families + carers:** Improve access to information, advice, resources and peer support for people living with ADHD, families and carers by funding ADHD community organisations
 - b. **Teachers:** Improve workplace readiness for pre-service teachers by directing universities to add compulsory course content on ADHD to undergraduate teaching degrees, and providing professional development for in-service teachers on conditions that affect learning in the classroom, including ADHD and co-existing conditions.
 - c. **Professionals:** Improve access to nationally consistent trainings and resources for healthcare workers, justice system staff, and employers through university-based compulsory course content and coordination between relevant government departments
 - d. **Public awareness:** Fund evidence-based public awareness campaigns to reduce community judgement, misunderstanding and stigma.
3. **Treatment + support:** Improve access to medical and social supports through Medicare subsidies and additional funding for ADHD-related counselling, therapy and treatment.
4. **Funding:** Increase funding for the ADHD community, including targeted funding based on need, and for early intervention, research and national system coordination.

² ADHD Australia (2021) [Building Brighter Pathways: Education Survey Report](#) 16 (**Brighter Pathways report**). See also, ADDitude Magazine, [What I Would Never Trade Away](#) (2022).

³ Gnanavel, S. et al. (2019). World J Clin Cases, 7(17): 2420-2426.

5. **NDIS:** Allow people with ADHD who meet the disability requirements of the NDIS Act to access the NDIS.

3. Assessment + diagnosis

If not diagnosed early and correctly, people with ADHD don't receive access to the treatments and support to manage their ADHD. Early identification of ADHD facilitates early intervention to address everyday challenges ADHD people experience. For example, when children are assessed and diagnosed with ADHD early, they're more likely to experience supportive teaching and learning environments which improves educational outcomes and social integration. Teachers also report an increase in the numbers of young adults studying at TAFE or university seeking an ADHD diagnosis, after talking to their peers and beginning to 'self-diagnose' to try to understand their own disengagement and challenges in pursuing further study.

In our 2020 survey of more than 1,600 people in Australia impacted by ADHD, almost 1 in 3 people confirmed that the steps to getting a diagnosis were difficult.⁴ Some barriers to accessing an ADHD assessment include:

- Not recognising signs of ADHD to facilitate getting an assessment early
- Misdiagnosis of ADHD as a different health condition or viewed as behavioural problems
- Avoiding seeking a diagnosis due to misunderstandings of what ADHD is or stigma
- Being dismissed by healthcare workers or support people when seeking an assessment
- Inaccessible triage processes to access assessments (eg. administrative or bureaucratic processes or time limits which are challenging for people with ADHD to complete)
- Lengthy waitlists of 6-12 months or more to begin the diagnostic process, and
- Prohibitively high costs involved with seeking an assessment, including multiple GP, psychologist and psychiatrist appointments.

Delays in accessing a correct ADHD diagnosis can cause significant distress and exacerbate mental health issues for people waiting months or years to access diagnosis, treatment and support.

People with ADHD and their families also report the harm caused by not receiving support or receiving inappropriate treatment when ADHD is misdiagnosed or attributed to behavioural problems. This includes very long waits to get an appointment with a medical professional, appointments being short and the GP, psychologist or psychiatrist not having all the information required to accurately make a diagnosis.

There are a range of reasons why waitlists for accessing a diagnosis are so long, including the lack of public health services supporting ADHD diagnosis and treatment. ADHD assessments require a psychiatrist or paediatrician to facilitate ADHD medication for the person seeking an ADHD diagnosis. However, there is a very limited number of psychiatrists and paediatricians available to diagnose ADHD. People living with ADHD and their families and carers face significant challenges getting appointments, including because psychiatrists and paediatricians have to limit the number of new patients seeking ADHD appointments to continue supporting patients with a range of other medical conditions. Waitlists for psychologists are also very long, but psychologists are unable to diagnose ADHD medication, which means that people with ADHD are often required to

⁴ Brighter Pathways report.

undergo a second ADHD assessment process with a psychiatrist even after being diagnosed by a psychologist if they want to trial ADHD medication.

The Australian Evidence-Based Clinical Practice Guideline For ADHD (**Guideline**) recommends that a thorough assessment by an appropriately trained medical professional is required to diagnose a person with ADHD, including to identify coexisting or alternative conditions requiring treatment and support.⁵ There are different views in the ADHD community about the different ways to unblock care pathways to ADHD assessments, and diagnoses. We support

Recommendation 1: The Australian Government should improve access to ADHD assessment and diagnosis by expanding clinical care and support services, making funding available for ADHD assessments, funding additional research including pilot studies to unblock care pathways, providing additional training for frontline healthcare workers, and facilitating engagement with the PHN network to investigate innovative solutions to access in primary health care.

4. Training + awareness

The number 1 priority for the ADHD community is education on ADHD for patients, carers, doctors, educators, justice, workplaces, etc, followed closely by improving other people's understanding of the impact of ADHD.⁶ Importantly, information, trainings and resources for different stakeholders requires stable funding and central coordination to ensure it centres people living with ADHD to make it easier for people living with ADHD and their families to navigate supports across different systems and areas of their lives (eg. transitions from high school to work, or embedding healthcare supports in justice settings).

Parents + families

For nearly three quarters of parents of children with ADHD, schooling a child with ADHD is their most difficult challenge,⁷ and access to evidence-based resources and training for parents, carers and families of people with ADHD is a serious gap. There is a genetic component to ADHD; ADHD runs in families. This means multiple people in families are likely to be living with ADHD, which can have a significant impact on family dynamics. For example, if parents cannot access timely, accurate and supportive diagnosis and treatment, this impacts their ability to hold employment and create supportive environments for a child living with ADHD.

Schools + teachers

Students living with ADHD experience serious barriers to their learning at school, including stigma, compromised relationships with teachers and peers, academic underachievement, suspension and leaving school early.⁸ School classrooms are often the first environment where ADHD related behaviours are observed when teachers notice them getting in the way of a student's learning. There are inconsistent approaches being taken by teachers when they observe behaviours they think could be related to ADHD; including discussing referrals for assessment with parents, but also accessing inaccurate information or assuming a student has ADHD without a confirmed diagnosis. Developing the expertise and knowledge of teachers is one of the most effective ways to increase student achievement, reduce classroom disruption and facilitate more positive

⁵ Australian ADHD Guideline.

⁶ Brighter Pathways report 31.

⁷ Brighter Pathways report 26.

⁸ Parents for ADHD Advocacy, *Parent and Carer experiences of ADHD in Australian Schools: Critical Gaps* (2019).

outcomes for students living with ADHD.⁹ When surveyed, a majority of teachers indicated they have knowledge of ADHD and can recognise a student with ADHD in their classroom, but at the same time a majority of teachers reported being unsure or not knowing how to support students with ADHD.¹⁰ 9 in 10 Australian teachers we surveyed reported they were not adequately trained at university to identify and support ADHD students, and that they would benefit from further professional learning in ADHD.¹¹

As a teacher explains:

"[T]here isn't enough support or training for teachers or [School Learning Support Officers] in schools for ADHD or behaviour and education of the effects of medications ... kids with ADHD quite often get ignored or put in the too hard basket."

Teachers across the country are in urgent need of support and resources to teach students living with ADHD within complex teaching environments and for children with ADHD and co-existing conditions. ADHD specific training should start in undergraduate teaching courses, and continue for teachers with students living with ADHD in classrooms through ongoing professional development and resources, including referral pathways for diagnosis, treatment and support. As a starting point, the Federal Department of Education should acknowledge ADHD as a priority requiring appropriate intervention and support in classrooms and schools, similar to recent changes in government approaches to Autism.

Healthcare

Access to accurate diagnosis and treatment is exacerbated by a lack of ADHD trained healthcare workers.¹² Consistent, funded and high quality professional training for healthcare workers is required to: identify and accurately diagnose ADHD; recognise commonly coexisting conditions; provide positive post-diagnosis information; prescribe effective treatment; and make referrals to community support options. Training is also required on how to support a person with ADHD across their lifespan (eg. as a young person transitions from adolescent to adult services).¹³ Young people with ADHD aged 25 and under believe more information on ADHD medications, including the pro's and con's, needs to be prioritised.¹⁴

Workplaces

Workplaces and employers rarely have access to information, training or resources to understand how to support their staff members living with ADHD. People with ADHD experience reduced workforce participation, are more likely to be absent from work, and can have reduced productivity at work.¹⁵ Many people with ADHD are reluctant to disclose their ADHD diagnosis with employers due to stigma and fear of negative responses. In addition, people with ADHD who have disclosed their ADHD diagnosis with employers report their manager or workplace's fail to understand or are unwilling to support their requests for flexible working arrangements or reasonable accommodations. As a worker with ADHD explains:

⁹ Smit, S., et al. (2020). African J. of Disability, 9, 1-9.

¹⁰ Brighter Pathways report.

¹¹ Brighter Pathways report.

¹² Australian ADHD Guideline.

¹³ Australian ADHD Guideline.

¹⁴ Brighter Pathways report 36.

¹⁵ Deloitte Access Economics, [The Social and Economic Cost of ADHD in Australia](#) (2019) (Deloitte report).

*"The stigma of ADHD discourages letting people know. Work and relationships are made difficult due to not feeling comfortable disclosing and yet the right information and understanding would make a massive difference"*¹⁶

Education and training is needed for workplaces on how to support employees living with ADHD would greatly improve the career outcomes, workforce participation rates, financial security and wellbeing of people living with ADHD in Australia.¹⁷ Accessible and easy to understand information and resources is also important on the other side - for employees, including early school leavers, to access information on securing stable and meaningful work, and to understand their workplace rights and entitlements (eg. requesting reasonable accommodations).

Justice

The above challenges are often exacerbated by interactions with police, courts, prisons and first officers who are not provided with adequate professional development or training to recognise and understand the challenges people living with ADHD experience. People living with ADHD are often underdiagnosed or misdiagnosed in criminal justice systems - with ADHD experts estimating that nearly 40 per cent of Australia's prison population has untreated and undiagnosed ADHD.¹⁸ Inadequate training and understanding of ADHD creates challenges with communication, understanding and participation with police processes, prison systems and courts. In many cases, appropriate supports are not made available, and people living with ADHD can be subjected to disproportionate sentencing, and inadequate support for rehabilitation which can lead to higher rates of recidivism. In addition, there are significant barriers to people living with ADHD in justice settings accessing ADHD treatment, including when they're frequently moved or when correctional staff are not trained to recognise 'behaviours of concern' as potential signs of ADHD.

Public awareness + stigma

Everyday challenges of living with ADHD are exacerbated by a lack of awareness and understanding in the general Australian population about the ADHD community and our needs. People with ADHD experience daily community judgement due to common misconceptions and misunderstanding the different realities of living with ADHD. The ADHD community has long called for greater public awareness and understanding of the challenges people at all ages with ADHD face in day-to-day aspects of work, social and family life.

Recommendation 2: The Australian Government should:

- a. Improve access to information and resources for people living with ADHD and their families and carers
- b. Improve workplace readiness for pre-service teachers by directing universities to add compulsory course content on ADHD to undergraduate teaching degrees, and providing professional development for in-service teachers on conditions that affect learning in the classroom, including ADHD and co-existing conditions.
- c. Improve access to nationally consistent trainings and resources for healthcare workers, justice system staff, and employers through university-based compulsory course content and coordination between relevant government departments), and
- d. Fund evidence-based public awareness campaigns to reduce community judgement, misunderstanding and stigma.

¹⁶ Brighter Pathways report 41.

¹⁷ Deloitte report.

¹⁸ David Nolte, [Judiciary need to recognise importance of ADHD on crime](#) (10 July 2018).

5. Treatment + support

People living with ADHD thrive when they are supported with different types of treatments and support, including:

- Lifestyle changes to improve sleep, diet and exercise
- Educating a person's school, university or workplace on how to support people with ADHD
- Cognitive behavioural interventions for people living with ADHD and their parents and families, including 1:1 counselling and family therapy
- Cognitive training to improve attention and memory (eg. online training programs)
- ADHD coaching and peer support, and
- Medication / pharmacological interventions.¹⁹

Medical treatment

Almost 8 in 10 ADHD community members we surveyed report access to psychologists and therapists to help with ADHD-related behaviour as the biggest barrier to finding the right medications and therapies, followed by access to ADHD medical specialists.²⁰ As a parent explains:

"There does not seem to be easy access to doctors for example my [young adult] son is currently experiencing what I would call a crisis and is spiraling out of control, he has way too much going on in his life and is burnt out. He doesn't recognise this so he's reluctant to seek help. However, it's difficult to get a referral and or an appointment for him to be seen, the wait period for an appointment can be 2-5 months, with a psychiatrist or psychologist."²¹

Access to supports to manage different coexisting conditions such as anxiety, Autism or depression is also a challenge.²² As a patient with co-existing conditions explains:

"Most patients with ADHD have other mental health issues, which are compounded by ADHD, which is compounded by additional issues, etc. My biggest challenge has been accessing/finding psychologists or counsellors who treat comorbid conditions (eating disorder and past trauma) who have specialised in a treatment modality outside of CBT talk therapy AND have significant knowledge/understanding of ADHD, specifically ADHD medications."²³

Healthcare professionals are required to take into account a range of factors when prescribing, monitoring or discontinuing medication to manage ADHD.²⁴

Different types of treatment are effective at supporting people living with ADHD. People living with ADHD have very different experiences of ADHD medication: it can be life-changing for some people in removing everyday challenges related to ADHD. However, other people with ADHD do not find medication effective, including side effects and not liking how they feel while taking medication for ADHD. Uniform evidence-based laws on ADHD medications across state borders is an issue for adults with ADHD, but the cost of ADHD medication is a more significant concern (see below).²⁵

Social supports

¹⁹ Australian ADHD Guideline.

²⁰ Brighter Pathways report, 36.

²¹ Brighter Pathways report 37.

²² Brighter Pathways report 39.

²³ Brighter Pathways report 38.

²⁴ Australian ADHD Guideline.

²⁵ Brighter Pathways report 46.

In Australia, 3 in 10 people impacted by ADHD we surveyed find it hard to get support, and 1 in 10 do not get any support.²⁶ People with ADHD and their families view the best source of support for ADHD coming from doctors and other health professionals, followed by family and friends, Facebook groups, ADHD support groups and website information.²⁷ While Facebook groups are a useful source of information, there are also risks around people sharing comments or suggestions which aren't evidence-based, and people with ADHD not being supported to access professional counselling, treatment or support to manage their ADHD long-term. The Australian Government has an important role to play in ensuring people can access clear, up-to-date and evidence-based information and resources about ADHD.

Cost of accessing medical treatment + social supports

Help managing the costs associated with living with ADHD is a priority for the ADHD community in Australia.²⁸ Many people living with ADHD and their families face significant financial barriers to medication, counselling, medical treatment, and additional school costs to manage their ADHD. On average, adults with ADHD with a child with ADHD spend \$6,672.45 on ADHD per year. Parents with a child with ADHD spend \$5,543.69, and adults with ADHD spend \$3,401.01 each year.²⁹ The cost is exacerbated by lower incomes due to ADHD affecting work, and the impact of ADHD on impulsive spending and life admin skills including budgeting.

For many people living with ADHD, 10 subsidised counselling sessions per year under a Mental Health Care Plan through Medicare is inadequate to manage everyday challenges of living with ADHD. In addition, many people living with ADHD are unable to access medication to manage their ADHD as they are unable to afford it.

Recommendation 4: The Australian Government should improve access to medical and social supports through Medicare subsidies and additional funding for ADHD-related counselling, therapy and treatment.

6. Cost to society + funding needed

In 2019, the total cost of supporting people with ADHD in Australia was estimated at \$20.42 billion annually: \$12.8 billion in financial and \$7.6 billion in wellbeing costs.³⁰ This figure will likely be higher in 2023 due to inflation, and increases in recent diagnosis rates triggered by the COVID-19 pandemic.³¹ As awareness and diagnosis rates of ADHD increase but barriers to effective medical treatment and support to manage ADHD remain, the costs to society will increase. We are already seeing the strain this is placing on Australia's already overstretched health and mental health systems, which will worsen over time.³²

The ADHD community is chronically underfunded. The majority of ADHD community organisations are run by passionate volunteers with limited time and funding. As a result, people living with ADHD and their families face challenges finding access to practical, up-to-date and evidence based information about ADHD in Australia.

²⁶ Brighter Pathways report.

²⁷ Brighter Pathways report 48.

²⁸ Brighter Pathways report 46.

²⁹ Brighter Pathways report 47.

³⁰ Deloitte report.

³¹ Monash Health (20 December 2021) [Pandemic triggers rise in ADHD referrals](#).

³² ADHD Australia, *Pre-Budget Submission 2023-2024* (January 2023) (**ADHDA Pre-budget submission**).

This Senate inquiry is a welcome opportunity to invest in much needed early intervention, assessment, treatment, support and research for the ADHD community.

The Australian Government can play a key role in prioritising funding towards:

- National coordination to improve quality and consistency of state and territory approaches to ADHD, including coordination between federal, state and territory departments responsible for health, education and justice
- ADHD supports for people experiencing financial hardship
- Culturally safe ADHD supports for Aboriginal and Torres Strait Islander people living with ADHD and their communities
- Resources to support early intervention for children with ADHD in schools
- Specialist funding for support programs and treatment options for people with ADHD and coexisting conditions or substance use disorders
- Programs to better support adults living with ADHD in workplaces
- Practical resources, learning and training programs for law enforcement and correctional services to better identify, understand and engage with people living with ADHD in correctional settings
- An evidence-based and updated online library of resources for people living with ADHD, their parents, carers, educators, healthcare professionals and employers
- Establishing a School of Excellence for ADHD, drawing on Griffith University's model for the School of Excellence for Autism, to improve concentrated resource to improve the learning, job and learning outcomes for people living with ADHD
- Research into ADHD, including complementary medicines and effective behavioural support approaches for people living with ADHD.³³

Funding is also needed for ADHD community-led advocacy and to facilitate collaboration both within sectors (eg. greater collaboration between healthcare professionals), across sectors (eg. an ADHD National Support Network to coordinate efforts to remove barriers to people living with ADHD across public, private and not-for-profit sectors, a national conference bringing together stakeholders across education, justice, employment, health, education and ADHD communities) and to explore opportunities for digital or technological innovation to enable information-sharing and collaboration. We support the development of a national ADHD collective research centre to leverage relationships and expertise across Australian and international academic institutions to facilitate up-to-date research on ADHD. We refer to our pre-budget submission which seeks organisational funding to support education, program design and delivery and research.³⁴

Recommendation 6: The Australian Government should increase funding for the ADHD community, including funding for ADHD community organisations to provide evidence-based information, advice and peer support, and targeted funding based on need, and for early intervention, research and national system coordination.

7. National Disability Insurance Scheme (NDIS)

The ADHD community currently cannot seek support from the NDIS, as the NDIS as currently implemented by the National Disability Insurance Agency (**NDIA**) does not recognise or fund ADHD as a primary disorder, though funding may be received for a coexisting condition. Only 1 in 70 adults

³³ ADHDA Pre-budget submission.

³⁴ ADHDA Pre-budget submission.

with ADHD receive financial support from the NDIS for a coexisting condition.³⁵ When surveyed, 7 in 10 Aboriginal and Torres Strait Islander people impacted by ADHD view accessing the NDIS and other financial support as a priority.³⁶

The NDIS was intended to provide support for people based on their individual support needs, not their diagnosis. Complex cases of ADHD meet the criteria in the NDIS Act, but the fact that ADHD is not included in the NDIA's lists of conditions for eligibility³⁷ undermines the goals of the NDIS Act. ADHD does not affect people in the same way. Similar to Autism, there are different levels of functional impairment which affect the everyday challenges a person living with ADHD experiences. ADHD is a lifelong condition; where a person clearly meets the NDIS criteria, they should be able to access reasonable and necessary supports under the NDIS.

People living with ADHD with substantially reduced functional capacity have the same right as other members of Australian society to participate in social and economic life, to pursue their goals, live independently, and take part in community activities and employment. Eligibility for the NDIS should be determined following the core principles of the NDIS Act; taking into account a person's strengths, challenges and functional capacity, instead of their diagnosis.

Recommendation 6: The Australian Government should allow people with ADHD who meet the disability requirements of the NDIS Act to access the NDIS.

8. Conclusion

Despite recent increases in public awareness of what ADHD looks like and the everyday challenges it can present, ADHD has not been prioritised by successive Australian parliaments. As a result, evidence-based and inclusive policy reform, sector coordination and resource investment is long overdue. This submission has summarised the key ways that government systems and services, as well as our schools, healthcare settings, workplaces, and everyday spaces, can inadvertently reinforce barriers to people living with ADHD having the opportunity to fully thrive and pursue their dreams. This Senate inquiry is a valuable opportunity for parliamentarians to truly listen to the real experiences of people living with ADHD today and leave outdated stereotypes in the past. By taking decisive action - guided by empathy and evidence - the Australian Parliament has an opportunity to create a society that truly values and supports people living with ADHD in all our diversity.

For more information, contact ADHD Australia's Chair Matthew Tice at

³⁵ Brighter Pathways report 45.

³⁶ Brighter Pathways report.

³⁷ National Disability Insurance Scheme, [Our Guidelines: Applying to the NDIS](#). See Lists A - D.