



# ADHD Community Submissions

## Survey info + summary of key themes

### Submissions 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

*"I think diagnosis should be free for everyone. Psychologist and psychiatrist appointments should be free or at least bulk billed on Medicare. We need to educate doctors fast on the new research on ADHD so our specialists actually have knowledge of what they supposedly specialise in - AND we desperately need to reduce waiting times to less than a month (currently they are 6+ months). We need rules that say official diagnoses should be respected and are not allowed to be questioned by ignorant and stigmatising doctors. ADHD coaching should be free and much easier to access - perhaps with a national database or a social worker to assist you in finding one. Stigma against ADHD should be called out and considered hate speech - shows like A Current Affair should not be allowed to feature misinformation on our disability without featuring an ADHD specialist to counteract their claims. ADHD must be declared a primary diagnosis and included in the NDIS."*

(Online submission response from a person living with ADHD (32), VIC - City / Metropolitan)

This report contains submissions from 664 members of the ADHD community in Australia who decided to lodge their submission using an online survey set up by ADHD Australia in May and June 2023 to make it easier and more accessible for people living with ADHD to have their say.

There are four parts:

- A. Survey methodology + demographic information:** A summary of the survey methodology, including a brief demographic breakdown of people who shared their views and experiences
- B. Summary of key themes + recommendations:** A summary of key themes and recommendations which were commonly raised across a number of survey responses
- C. Submissions by question:** The full text of submissions organised by question - to make it easier for the Senate Committee to read responses connected to a particular term of reference (**attached** as a separate document), and
- D. Individual submissions:** The full text of individual submissions - to ensure that the Senate Committee can read each individual submission and understand how problems are interconnected across the different terms of reference for the inquiry (**attached** as a separate document).

ADHD Australia has not edited or changed the wording of any of the full text of the submissions in parts C and D. These submissions are lodged entirely in the own words of members of the ADHD community. We recognise that the ADHD community has diverse experiences and opinions, including a range of different views on current barriers and the best recommendations to address them. We encourage the Senate Committee to engage with the diversity of submissions but note that any views expressed in this report are not necessarily the views of ADHD Australia.

## A. Survey methodology

ADHD Australia set up an online survey form to make it easier and more accessible for people living with ADHD to have their say between 31 May and 7 June 2023, completed by 664 people.

### Survey questions

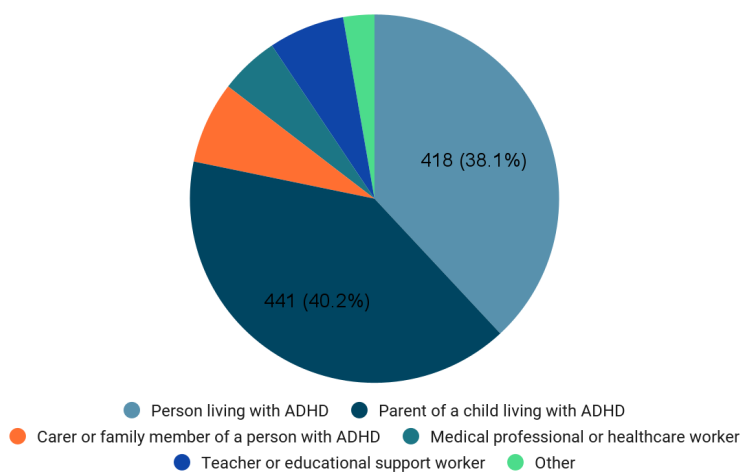
The survey asked the following questions:

1. What was your experience of getting an ADHD diagnosis?
2. What do you think could be done to improve access to ADHD assessments in Australia?
3. How does ADHD impact your life?
4. What is other people's awareness or understanding of ADHD and how it impacts your life? (e.g. Do you have an example of how another person not understanding how ADHD works has had an impact on you?)
5. What information or training do you think needs to be available? (e.g. for people living with ADHD, and/or families, carers, teachers, employers, or healthcare workers)
6. What could be done to raise public awareness or reduce stigma surrounding ADHD?
7. What types of treatments or supports have you found the most helpful for ADHD?
8. Have you faced any difficulties accessing treatments or supports for ADHD?
9. What could be done to make it easier for people to access the ADHD treatments and supports that work for them?
10. What key things should the government fund to remove barriers to assessment, treatment and support for people living with ADHD?
11. How would NDIS funding being available for ADHD make a difference?
12. Do you have any other comments or suggestions around barriers to ADHD assessments, treatment or supports you want the Senate inquiry to know about?

### Demographic information

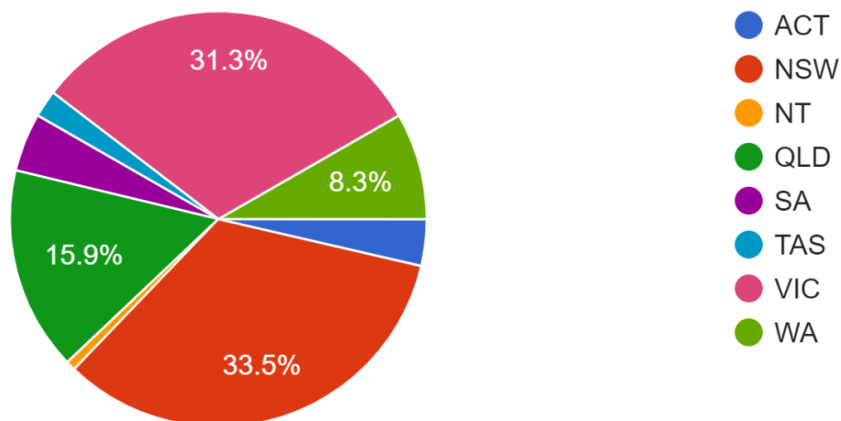
The survey collected basic demographic information to assist the Senate Committee in understanding people's relationship to ADHD, their age, state or territory, and whether they live in a city / metropolitan or rural, regional or remote area.

People with different experiences of ADHD completed the survey.

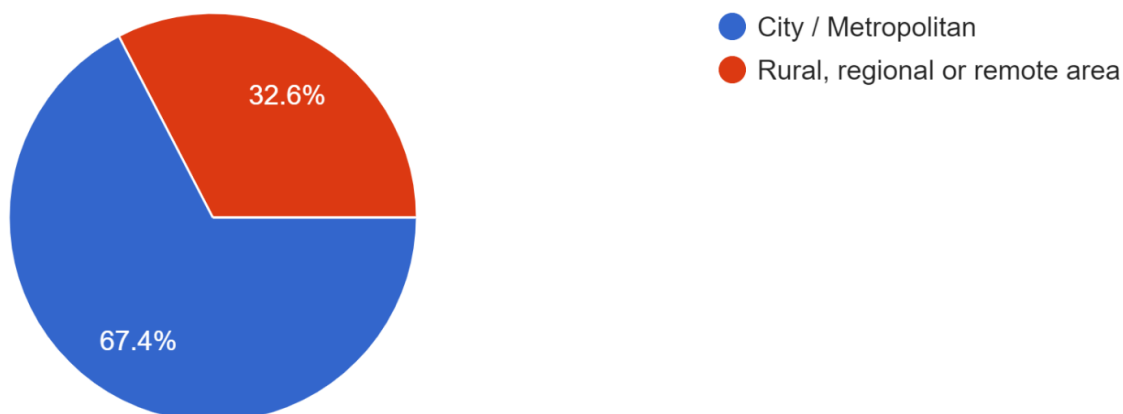


People could select multiple categories (e.g. a person could select that they were a person living with ADHD and a parent of a child with ADHD).

People completed the survey from different states and territories:



Survey respondents were living in city / metropolitan, and rural, regional, and remote areas.



## B. Summary of key themes + recommendations

ADHD Australia has reviewed the survey responses and prepared high-level summaries of the key themes and recommendations which emerged, and examples of direct quotes,<sup>1</sup> to assist the Committee in analysing the individual submissions.

<sup>1</sup> Note: We have corrected minor typos in the direct quotes in this summary to aid understanding, but not edited or changed the meaning of any of these submissions from the online survey.

## 1. Access to ADHD assessments + diagnoses

There was a range of different responses to questions about access to ADHD assessments and diagnoses.

The majority of survey responses outlined how accessing an ADHD diagnosis was long, difficult, inaccessible, expensive and time-consuming for people living with ADHD. Many people explained how the ADHD assessment and diagnosis process negatively impacted their mental health and well-being, describing it as “traumatic”, “terrible”, “horrific”, “shockingly bad”, “disgraceful” and “a nightmare”. Some people had self-diagnosed but hadn’t been officially diagnosed because of barriers to accessing an ADHD diagnosis. Barriers to accessing an ADHD diagnosis caused a range of negative consequences, including stress, anxiety, the process being “exhausting”, “draining” and “infuriating”, and creating pressure on family relationships and the school system. Some examples of not getting diagnosed with ADHD in time include not being supported in school or being able to find work, family breakdown and homelessness.

Some of the survey respondents had a positive experience of accessing ADHD assessments - describing their experience as “easy”, “straightforward”, and “accessible”. These submissions often attributed their positive experience to particular support people who had facilitated access, such as an “amazing” doctor or psychiatrist, or a “fantastic social worker”.

### Key themes

- Very expensive, often costing thousands of dollars in out-of-pocket expenses
- Challenging / difficult process - both in terms of mental energy / frustration, but also the actual intake process not being ADHD friendly (e.g. multiple forms, administrative barriers)
- Long and time consuming, often taking years or even decades
- Complicated / fragmented process that isn’t accessible for people living with ADHD (e.g. complex booking systems.), and
- Confusing / unclear process (e.g. hard to find out how to access a streamlined assessment process).

There were also concerns raised which affect particular groups within the ADHD community, such as:

- Women being diagnosed late, ignored or experiencing gendered bias around whether they had ADHD
- Barriers to people living in rural, regional and remote areas where there is a lack of trained psychiatrists or paediatricians able to diagnose ADHD
- Experiences of people with estranged relationships or traumatic childhoods whose parents don’t support a diagnosis creating barriers to accessing an ADHD diagnosis (e.g. weight given to parents’ views during assessment process)
- Challenges of obtaining a diagnosis again as an adult after having been diagnosed as a child
- Parents’ ADHD not being diagnosed until later in life, despite their child’s or children’s diagnoses, and
- Misdiagnosis or missed diagnosis while seeking an assessment for a co-existing condition.

## Direct quotes

*"It was tough. I went for years without seeing anyone mainly due to the exorbitant cost of seeing a psychiatrist AND the availability of a good one. The waiting lists are ridiculous. It was hard enough to get there in the first place let alone deal with all the roadblocks."*

*"It took a long time, and was one of the least ADHD friendly experiences ever. I felt like I was second guessing myself every step of the way."*

*"Long! I had to wait months for my first appointment with a mental health nurse and then had to wait another couple of months for a Telehealth appointment with a psychiatrist who didn't even prescribe my medication. I had to pay for another doctor's visit another few weeks later (who doesn't bulk bill) and start my medication before the authority went through. I paid full price, about \$120 a month for my medication for the first couple of months because the alternative was to wait another month without medication and suffer with the debilitating symptoms I've been experiencing in the last few years. I've backed into closed garage doors, I've left gas burners on at home for a whole day with nobody home and other possibly life threatening errors I've made due to brain fog, inability to focus and more."*

*"It was extremely difficult. I raised the topic with my psychologist who was extremely sceptical about ADHD and claimed it was a zeitgeist. I asked to complete an assessment which they did through a proforma template. The outcome of the automated assessment was that I had a 99.88% likelihood of having severe ADHD. The psychologist refused to diagnose or refer to a psychiatrist. A couple of years passed until I found a GP who was an ADHD specialist. They referred me immediately but it took 8 months to get an appointment with a psychiatrist. I could not get an appointment in my own state so appointments are via zoom."*

*"Difficult. Expensive. Long. In my late 20s. Had to contact nearly 100 psychologists & psychiatrists to find how & where to get an assessment. Ambiguous. The processes required are the areas ADHD people struggle with! Took ages to get on a waitlist. Lead up to the appointment was hard & long."*

## Key recommendations

Submissions raised many different suggestions and recommendations for how to ensure accessing an ADHD assessment could be short, easy, affordable and accessible, including:

- Making funding available for ADHD assessments, including Medicare rebates or subsidies, bulk billing, controlled costs
- Improving access to early diagnosis in schools, including making ADHD assessments automatic for children in schools, more professionals trained to recognise and diagnose ADHD in schools
- Better training for psychologists, psychiatrists and healthcare workers
- Broadening the categories and numbers of healthcare workers able to diagnose ADHD and prescribe medication, including allowing GPs, nurses and trained ADHD assessors to conduct assessments
- Combining assessments for ADHD and common co-existing conditions, such as ASD and learning difficulties
- Ensuring ADHD assessment intake systems are designed to be streamlined and easy-to-use for people with ADHD, including having healthcare workers go through the

forms / questionnaires with you in the appointment instead of requiring you to fill them out in advance

- Opening public ADHD clinics for people to access assessments, and
- Prioritising access to ADHD assessments for people in at-risk categories.

### Direct quotes

*“Reduce waiting times. Financial support either through ndis or another scheme. Maybe free access to a standardised support course that educates families and individuals re diagnosis, something involving multiple allied health professionals that runs over several weeks for example. Especially helpful at the time of diagnosis or soon after.”*

*“Better resources for all health professionals to pick up on traits. Better Medicare subsidies to reduce out of pocket costs.”*

*“Easier more centralised information about the process, We worked it all out ourselves. Our doctor had no clue. An easy explanation of process options and costs state by state. I’ve found out most information from a facebook group!!!!!!”*

*“A different assessment process, having an in school assessor who can flag children and start the process (not teachers - they have enough on their plate!). An instant referral for all family members once someone is diagnosed due to the genetic condition.”*

*“Making it easier to get a diagnosis by allowing GP’s to diagnose or accept a diagnosis from a psychologist to be able to prescribe medications, not just a psychiatrist.”*

*“I think you should have child development jobs with all the different types of experts under the one roof where there is a case manager assigned to each child to help you navigate the medical and school support systems. Early intervention should be more available to families with young children who are presenting with complex issues even if they are too young to receive a definite diagnosis of ADHD. Don’t wait til they have started being distributive at school to offer families support. The hubs should be well funded by government and pay according to family income so all can access. The hubs should also help educate schools in how they can support kids at school ro take some of that advocating that load off parents and because teachers don’t always believe parents. Better linked government health & education systems.”*

*“Perhaps a referral system via your GP with Medicare and/or private health rebates that includes specialist psychologists as well as psychiatrists. Psychiatry wait times are lengthy and prevent people from getting an assessment sooner.”*

## 2. Public understanding + awareness of ADHD

People responded in a range of ways about how ADHD impacts their lives, other people’s understandings of ADHD, and training and public awareness needed.

## Key themes and recommendations

- ADHD impacts on every aspect of people's lives, including at home, school, work, relationships, families and in public.
- There are deeply entrenched misunderstandings about what ADHD is and negative stereotypes and views about people who have ADHD, which make people afraid to talk about ADHD and cause further social isolation, stigma and barriers to seeking support.
- A range of measures were recommended to improve awareness and understanding of ADHD, including: improved education, training, information, resources and support for people living with ADHD, families and carers, doctors, psychiatrists, teachers, the mental health sector, employers, etc; renaming ADHD to more accurately describes what it is; widely available online information and resources; specialist training for healthcare workers (including psychiatrists and mental health sector); mandatory university curriculum and in-school training for teachers and the education sector; and public awareness campaigns about ADHD.

### *Impact of ADHD*

The majority of respondents shared how ADHD impacts on every aspect of their lives, and their quality of life on a daily basis. People shared how ADHD affects your everyday life, including planning, sleeping, responding to texts / emails, focusing, and keeping the household running. When it came to home life or "life admin", people with ADHD shared how "life is chaos" and how hard it is to get stuff done, and the piling up consequences of incomplete tasks, late fees, forgetting to pay bills, impacts of impulsive decisions, being constantly late, being forgetful, clumsy, disorganised, not completing chores, and more. In terms of work, people shared how ADHD affects being able to hold down secure jobs, the impacts of low wages and unstable jobs, the challenges of missing work, and ADHD limiting career progression.

People also shared the impacts of ADHD on maintaining relationships and family dynamics, including challenges with children's emotional regulation and schooling, including "constant conflict", "regular meltdowns" and children feeling like they're "always in trouble". These were exacerbated by negative reactions and stereotypes at work and in public, and the lack of support systems available for people living with ADHD. As a result, many people also shared the mental health issues they experienced due to their ADHD and it not being understood, including "feeling worthless", burnout, overwhelm, Rejection Sensitive Dysphoria, irritability, anxiety and the connection between challenges with self-regulation and mental health.

### Direct quotes

*"I am unable to attend work most days, I will have a good week or two here and there but otherwise I will be unable to work or socialise. I don't leave the house. I don't talk to family. I completely withdraw because I am overwhelmed and can't handle it. I don't feel comfortable in the world."*

*"I feel like it restricts my employment opportunities- I don't think I could ever commit to an office job and struggle to adhere to strict procedures and not having the autonomy to switch between tasks to get things done. At home I struggle the most, forgetting things, not completing chores, not having the organisation to do weekly shops so often going to the shops several times a day, etc . Parenting is also a challenge as I struggle to adhere to routines the kids need like homework."*

*“Immensely. I know I’ll never reach my full potential as things which come easily to others such as basic life skills take a great deal of mental energy. I suffer financially through the ADHD tax and suffer constantly with imposter syndrome even since my diagnosis.”*

*“My 4 year old child has explosive emotional outbursts that significantly affect his well being. He can be inconsolable at kinder, even though support is lovingly given. My husband and I often leave work to pick him up, even though we have occupational therapy support with this. He is significantly delayed in his speech and therefore is delayed in all social skills. My son will be completing a 2nd year of year 4 kindergarten (Victoria) due to his delays.”*

*“I have figured out that basic daily life and interactions are not supposed to be as hard as they are for me. I forget important tasks and information, forget to communicate with people, struggle to maintain my house, waste money on things I lose, forget or wear more quickly than I should due to my fidgeting and slapdash manner, am permanently exhausted by the effort involved in caring for my kids properly, overweight from my binge eating and pray to impulsive actions or speeches that I regret later.”*

#### *Public awareness of ADHD*

When asked about other people’s understanding or awareness of ADHD, the majority of responses shared that people in Australia don’t understand what ADHD or how it impacts people’s daily lives. These ranged from people thinking ADHD only had to do with attention and hyperactivity and not the range of other ways it could affect people’s lives, to believing medication would “cure” all ADHD symptoms, to not understanding why it was so hard to complete tasks or not believing ADHD exists at all - seeing ADHD as a “fad” or “trendy diagnosis”.

There was a range of negatives views and stereotypes people experienced, including:

- Outdated misunderstandings of ADHD being a problem around “naughty little boys” / “hyperactive schoolkids” and not an issue that affected adults or was broader in how it looks for different people
- Stigma and deeply entrenched negative views held by most people around having ADHD
- Lack of empathy and understanding (e.g. people being dismissive or belittling, saying “everyone does that sometimes”)
- Being seen as “lazy, rude, stupid and selfish”, “flaky”, “self-involved”, “unreliable”, “thoughtless”, “annoying”, “unsuccessful”, and
- Not understanding why people with ADHD can’t just “change” or “get over it” (e.g. common beliefs that people use ADHD as an “excuse for bad behaviour”.

As a result of people’s ignorance and misunderstandings around ADHD, people shared that they were afraid to talk about having ADHD or disclosing it to friends, family or colleagues. In particular, people feared that if they shared it at work, they would be seen as underperforming. Many parents also shared how their children with ADHD were treated at school, including being “isolated”, “shunned”, “ignored”, and “bullied”.



### Direct quotes (experiences)

*"Every day nearly every moment I feel the isolation knowing that others don't understand my pain. I hide everything and the aspect that hurts me the most is emotional dysregulation and rejection. Not only does it hurt when others don't know it's real. But it is mentally damaging as I convince myself it might not be real."*

*"There is a general lack of understanding from those who do not know someone with the condition or don't have it themselves and it is seen as an issue with ability to focus which isn't accurate and has negative connotations for employees. I've personally been told I lack confidence or need to be more organised (just write a list!) which invalidates the huge amount of strategies I have put in place to 'mask' my symptoms and work at the expected level."*

*"I don't open up to many people about my ADHD as so many are quick to judge. Someone else at work was open about their ADHD when they started and everyone was making fun of her and gossiping about her behind her back. I always stayed away from those conversations but if someone would try to talk to me about it I would tell them that it's not their brain and you can't judge someone from a diagnosis."*

*"I do not think people fully understand how ADHD impacts a person's life. With a focus on work, I am very capable and recognised as such. However, I have always been open about my ADHD so as to manage expectations. In my last role no allowances were made and I would be frequently penalized for not working in the manner my supervisor (neurotypical) would expect. I was also told to "change" or "get over it" or "grow up." People either see ADHD as a behaviour issue that is not really their problem (which has some merit to be fair) or too difficult. People should understand ADHD as an executive dysfunction but that does not necessarily inhibit or prevent any given outcome. It is just a difference in process."*

*"It's still seen as the "disruptive, unruly and undisciplined bullshit syndrome". It's not taken seriously at all."*

*"The primary school was awful. No understanding, no trying to improve. Constantly getting in trouble to the point that by year 6 he hated school and despite being academically gifted, he was at risk of school refusal. What they expected of his ND brain was akin to walking up to a kid in a wheelchair and telling them to walk. He had massive anxiety and negative self image in large part because of the education system."*

*"People don't understand that it is a neurological condition and you can't change the way your brain is wired. People think you just need to focus more or be more reliable. They don't understand that you can have good days and bad days and it's hard to articulate what you are feeling."*

### Direct quotes (recommendations)

*"I feel teachers and principals should be given training on awareness and how to help children in the classroom. Particularly around girls with adhd and how that presents. We have had to push for help from the school as our daughter masks a lot of her ADHD."*

*"If an adult is going to the effort to get a GP referral, to get on waitlists, they are not after drugs - and that stigma needs to stop. The looks and the discrimination I've endured over trying to get medication is just awful. I go to sleep after I take my meds.. I have no idea what the hoo ha is. Get GPs to prescribe medication, so we don't have to pay outrageous fees to Psychiatrists who do not care about humans. Educate everyone PLEASE!!!"*

*“Provide training to other health professionals to either diagnose ADHD or at least test for the ADHD and provide this evidence to a psychiatrist so that medication, etc can be administered more promptly. For want of a better term, kind of like a triage psychiatrist that can do the initial testing to gain the diagnosis and then the patient can go and see the psychiatrist with the pre-diagnosis and then the appointments can be shorter allowing the psychiatrist to see more patients. Let’s use the psychiatrists only for the medication and counselling with the diagnosis handled beforehand.”*

*“I think the training and information needs to be based on how to assist someone with ADHD rather than trying to manage it for them.”*

*“There needs to be a mass educational campaign to educate the general public. This will remove some of the stigma. There needs to be compulsory training for new teachers on all aspects of adhd, particularly how it affects emotional regulation and how to foster friendships in the classroom.”*

*“Training for ALL social support staff, teachers, mental health workers, GP. My GP knows just about nothing about ADHD. Given how prevalent this condition is - it MUST BE MANDATORY. Also - assessment on the public health system. Please. We have been able to afford everything privately - I know people who have lost their homes because they decided to get their kids treated. So they live with relatives. So - we are lucky in that we got some treatment. But still the treatment is not adequate and we will find it hard to retire. EARLY INTERVENTION - it would be amazing to prevent kids from feeling so bad about themselves. By the time they get diagnosed, their self esteem is in ruins and it is near impossible to build it up again. This is so inefficient in financial terms. And devastating in emotional terms.”*

### **3. Medical treatments + support for ADHD**

#### **Key themes**

People who completed the survey shared a range of treatments and supports they found the most helpful for ADHD, including:

- Medication
- Therapy / counselling
- Occupational therapy
- Support groups / online forums / peer support and talking with friends who have ADHD
- Behavioural strategies
- Habits + structure - e.g. routines, calendars, to-do lists
- Lifestyle changes - e.g. exercise, nutrition, goals
- Resources - e.g. books, ADHD magazine, Youtube, social media, podcasts, TikTok
- Speech pathology
- Coaching, and
- Supports at school or work - e.g. note-takers, flexibility.

Importantly, people identified a range of different treatments and supports that were effective. For example, many people found medication to be the “only thing” to work and “life-changing”, while others describe how medication doesn’t help or work for them.

## Direct quotes

*“Medication to calm the racing thoughts in my head, enabling me to focus. Coaching to learn practical strategies for planning, organising, decision-making, time-sense, and dealing with shame. Psychology to support developing new ways of thinking and challenge unhelpful beliefs and behaviours. Connecting with other people living with ADHD for shared experience, insights, understanding, advice and encouragement, and finding accountability buddies to help each other get things done.”*

*“Medication has been the main treatment that’s helped us. Our son also sees a counsellor to help with his emotional regulation. He’s still on waiting lists for occupational therapy after 12 months.”*

*“I am currently medicated and see a psychologist. I feel an OT and ADHD coach would also help but cannot afford this as I can barely afford the cost of what I am accessing even with a mental health plan. My daughter also has ADHD and I have to preference her treatment. OT has been great for her in terms of regulation and psychology is essential as she has severe anxiety and is self-harming. Medication helps her keep it together at school most of the time but is not a cure and this is part of the problem as many think that it fixes everything when it is only a small component of what is needed.”*

*“Peer support from other Mums. Sharing advice, laughing and supporting each other when required. Occupational therapists to help kids with social skills, listening skills etc. Good paediatricians that have time to support the whole family unit. An adhd coach would be awesome. Exercise. Minimal screen time.”*

*“Regular talk therapy through a psychologist that supports emotional regulation, as well as the need for movement. Medication helps, but it doesn’t support a child or adult to learn how to regulate emotions and to function in the world.”*

*“Medication for me, though it has only been a month. The difference has made myself feel like myself again, like an old friend who I hadn’t known in a while came back. Supports such as my uni’s disability learning unit and learning access plans were very supportive and helpful for being able to easily ask for extensions when needed as well as accommodations for things like class attendance or exam duration being longer was a relief and helped reduce my stress and anxiety which i’m also on a ssri for. Having more psychiatrists who have an expertise in ADHD and not those who can do the assessment but do not have a holistic knowledge or clinical expertise of how ADHD presents in different ages, gender and race cohorts too. My psychiatrist was very helpful and understood how my experiences and life impacts were. I didn’t feel like I had to “prove” it as a female.”*

*“Medication, a supportive doctor, friendly and supportive pharmacists, adjustments at university.”*

*“Having a professional tell you that you have traits or the condition of x, y, z is so beneficial. It reinforces to you that you’re not alone, there is a reason why you think or act the way that you do. That there are ways of managing things and you have options available. Sometimes just knowing is enough of a relief. Medication has helped calm the storm so I can be more focused and productive. Psychology appts have also helped with some tips or tricks to counter losing track and centering oneself.”*

*“Body doubling, external stimulus, positive pressure, medication specifically vyvanse was revolutionary but is in my view only temporary relief. It does not address root causes, and is not sustainable past about 5 years of use without having a negative impact on the system.”*

## Key barriers

People also shared the difficulties they faced accessing treatments or supports for ADHD, which were wide-ranging, including costs of assessment, therapy, medication and supports, and multiple barriers accessing medical treatment (including long wait lists, cost and inaccessible systems, etc) and other ADHD supports.

## Direct quotes

*“The cost is insane. We spend about \$20000 a year on medication, appts, time off work to go to appts, etc. We are lucky enough that we can just manage this but it is a stretch, even with both parents working full time.”*

*“Living rurally made it difficult to access all services in person, so appointments were mostly conducted virtually. I couldn’t possibly express how life changing disability support services would be, in particular a cleaner and someone to help me navigate life admin tasks such as organising mechanic services etc.”*

*“The waitlists are very long for all services from pediatrician to OTs to tutoring. For example we waited two years to get access to a speech therapist for an assessment. The prices are astronomical, we paid \$1800 alone with no rebate for the educational psychologist to undertake an assessment. The same for tutoring. The early childhood years are the most important to diagnose and have support services in place, and yet our daughter is 9 and only just accessing some of these despite being with the pediatrician four years now.”*

*“Psych appointments are hard to get, very expensive, medication ridiculously hard to get as most need a psychiatrist to sign off, very hard to get into, very expensive.”*

## Key recommendations

ADHD community members made a range of recommendations around what could be done to make it easier for people to access patient-centred ADHD treatments and supports tailored for neurodivergent people living with ADHD:

### Cost

- Funding for services / research / resources
- Bulk billing for appointments
- Increase Medicare rebates
- Standard prices for assessment / diagnosis
- ADHD access to a Health Care Card regardless of income
- Recognise ADHD on the NDIS

### Access to appropriate health practitioners (assessment / diagnosis)

- Reduce wait times for assessment
- Increase number of psychiatrists and paediatricians trained in ADHD
- Educate / provide incentives for practitioners to skill up in ADHD
- Increase rural / regional access - telehealth, rural incentives
- Empower GPs (appropriately trained) to take on assessment and prescription duties, relieving the burden on specialists

- Allow adults to self-refer for ADHD assessments

#### *Streamline processes*

- Simplify processes for accessing assessment, diagnosis and treatment
- Standardise and centralise nationally
- Create a centralised register of ADHD practitioners with accreditation and continuing education standards, that is publicly accessible to people seeking referral (e.g. showing availability)
- Reduce administrative burden on people with ADHD, recognising particular barriers present to people with executive functioning challenges (e.g. disability support to navigate processes)

#### *Quality of care*

- Increased continuing education and training for relevant practitioners, including psychiatrists, psychologists, paediatricians, GPs, and pharmacists
- Trainings to covers ADHD presentation in all genders, ages, and other demographics
- Education in the full range of treatments and strategies, including medication, skills and strategies, psychology, OT, coaching, etc
- Ensuring continuing education, up to date with current research

#### *Medication*

- Ensuring all ADHD medication is subsidised on the PBS regardless of your age when you were diagnosed
- Easier access to ongoing medication, including improving access to GP prescriptions, increasing the duration of scripts and allowing more than 1 month to be dispensed at a time
- Improving pharmacists' education to reduce stigma

#### *Non-pharmaceutical treatments + supports*

- Free, bulk-billed or heavily subsidised psychology, ADHD coaching, OT and other supports
- Enable / promote holistic, whole of life supports - e.g. mental health, physical health, OT, education and employment support

#### *Processes / quality of care*

- GP coordinated care model incorporating referrals to psychiatrists, psychologists, paediatricians, coaching, OT, employment / education / life skills support, peer support, etc - centralised, coordinated, multidisciplinary approach
- Train health, education, social services and other relevant professionals broadly to recognise signs of ADHD and refer for assessment
- Government funded 'one stop shop' ADHD hubs - clinics with relevant services, resources and information

#### *Resources*

- Single 'source of truth' website for key information, links, resources and services available and how to navigate ADHD supports and the health system
- ADHD info phone hotline
- Standard education and support course for ADHD adults and carers of children with ADHD following a diagnosis

- ADHD community information and advice sessions
- Peer support programs

#### *Education*

- Government funded hubs for child development support, with a special focus on neurodivergent children
- Compulsory requirements to equip schools to support students with ADHD, including continuing education for teachers, teaching aids, school administrators, etc
- Compulsory ADHD supports for tertiary students

#### *Employment*

- Workplace protections for employees with ADHD, including clarifying obligations and entitlements for both employees and employers

#### *Research*

- Fund research into ADHD, its presentation and treatments across all ages, genders and demographics, including adults and women and non-binary people previously neglected
- Publicise findings for health professionals and the general public

#### **Direct quotes**

*“More holistic support for families and not just the person with ADHD. Wrap around services for comorbidities like mental health issues and access to intensive support in a timely way and an affordable way. Trying to navigate a system with a distressed child where services are only available when you need them if you’re in crisis is not good enough. Even if you can pay, the system is so stretched you wait months for support. Given the heritable nature of ADHD I also think it would be beneficial to provide a fast and affordable pathway to assessment and treatment for family members - including parents and siblings.”*

*“Add ADHD to the NDIS. Give us more rebated psychology sessions at a higher rebated price. regular therapy along with the medication is the recognised best form of treatment for ADHD but that hasn’t been factored into what medicare covers us for. If ADHD was on the NDIS we could get help with ADHD coaching and help with practical things like cleaning and organisation. reduce fees for psychiatry and increase access to diagnosis by finding more psychiatrists or find a way for other health practitioners to be able to manage medication. I see that a lot of psychiatrists only work part time and I wonder if that’s because they charge so much money they don’t need to work more regularly. I think GPs that had special ADHD qualifications would be a good idea.”*

*“Availability of timely and reasonably priced appointments with qualified and informed health professionals. Central register of availability (rather than each new case ringing the same 50 providers with closed books. GPs providing scrips once diagnosed and stable. Not having to wait until the last 2 days of medication to refill (drives family schedule and prevents holidays etc).”*

*“As mentioned, I would like the government to create hubs for child development support. A one-stop shop, well funded by the government that includes all the relevant professionals you might need for neurite diverse children with case managers that take some of the load of parents for working out what to do next, whether they’re eligible for government support, and to help them educate and communicate with schools to help provide the best classroom support for children. This would take the financial and administrative burden off of parents, which is huge. It should be a child scented fun place to go that promotes confidence for neuro diverse children without long*

*waitlists, and with subsidised fees, where the subsidy relates to the Families income, so everyone can access it."*

*"Recognition that there needs to be a combined approach to therapies and skill building. Not locking people into the most expensive route to get medication. Better training for the mental health profession. Recognising that support needs to be continual but I think that is everyone, not just people with ADHD. Less expensive coaching and skill building options."*

#### **4. Government + NDIS funding**

##### **Government funding**

People from the ADHD community in Australia recommended that the government should fund a range of measures to reduce barriers to assessment, treatment and support for people living with ADHD. Most online submissions are on increasing funding and subsidies for medical assessments, appointments, medication, therapy, ADHD coaching and allied health (e.g. OT) support. There was also several recommendations around the system or sector-wide funding priorities for the government, including funding to increase the number of psychiatrists and paediatricians available to conduct assessments, training and awareness, increased funding for public schools to support children with ADHD, access to healthcare cards for people living with ADHD, sector coordination and public ADHD clinics and community supports.

##### **Direct quotes**

*"The PBS needs to better fund the medications for this condition. The benefits of ADHD medication are massive despite Ritalin and other medications receiving unfair press over the years. They have been a godsend to me and my 9 year old son. The benefits to society of having both of us medicated and contributing much is money well spent rather than drain on the health system we would be without it."*

*"Challenge stigma, fund public clinics."*

*"NDIS funding. We are out of pocket \$190 a week for speech therapy to help my daughter as she is so far behind in literacy at school. Sports outside of school are hard as she doesn't quite fit in. We tried sense rugby and she loved it but at a cost of \$45 a week we can't afford it as it's NDIS supported for children on the spectrum."*

*"ADHD needs to be included on NDIS to make it more affordable. The focus on medication fixing everything is wrong and the traits of ADHD in my experience are not cured through medication. It helps but "treatment" support needs to be holistic. We are still living in an ableist society which preferences a medical model which impacts so many aspects of life on top of being neurodiverse. Trying to live in this world is hard."*

*"Bulk billing or large refunds on psychiatric visits (all not just the initial one). Effort to increase psychiatrists supportive of ADHD treatment to reduce time delays and mitigate associated shame and embarrassment attached to seeking treatment (with which there is a LOT, even if you are high functioning and successful)."*

*"A central service to advocate and help navigate the various parts of the 'system'. Occupational therapists and Care and community support services that can assist with living tasks when needed. Not always ongoing."*

## NDIS funding

There were a range of responses around the question of how NDIS funding being available for ADHD would make a difference.

The majority of people who completed the online survey explained how access to the NDIS would have a positive impact on their lives, particularly parents of children with ADHD. For people living with ADHD who weren't sure, there were a number of comments around how funding for ADHD is important, but in their situation they would not necessarily qualify for the NDIS or need long-term financial assistance.

## Direct quotes

*"It would change everything. I'm thinking of my 11yo son when I answer this question. He struggles so much at school and really needs an aide alongside him to help him stay on track and clarify the tasks he is set and because he doesn't have funding through NDIS he isn't eligible for that kind of support at school. I don't care about funding for myself at this point, I just want my son to be able to live a full and beautiful life, despite having ADHD."*

*"For my family I have spent thousands on my ADHD son learning to read, having access to him being on NDIS would have allowed more OT sessions than I could afford and he may have had a better start with targeted supports by professionals trained in ADHD. But the main thing is tutoring, many ADHD kids are not learning to read [or do] maths because they cannot concentrate in the limited time at school. This is huge, affecting many children. Schools don't have resources or time to implement this, I feel so bad that I may have not helped my son enough due to not having funds to provide that extra support he needed at that time. Trying to catch-up in High School is so difficult and unfortunately many are broken and feel inadequate with regard to learning. "*

*"More families would have the financial support to seek diagnosis and treatment. More schools would have accurate data on how many students are neurodiverse and begin to change the model of education so it is equitable for all."*

*"NDIS funding would mean consistent weekly therapy to support OT, wellbeing therapy, resources for home/school without sacrificing the family budget. It would allow me to support him as best I can to invest in his future. Medication is not the only or primary solution but it could be the most cost effective if money is that tight."*

*"Financially being able to access psychiatry. Having a case manager do check ins and identifying support needed- which would reduce pressure on doctors/psychs because we have someone who can help with us getting a variety of additional lifestyle support. Holistic support, not just relying on your psych and meds to function. Practical, day to day assistance."*

*"NDIS could assist those with ADHD to have increased participation in employment and study opportunities, better relationships, reduced risk of addiction and/or risk taking behaviours, safer driving, reduced mental health issues/suicide of those with ADHD meaning more people working and contributing to society."*



## 5. Other comments or suggestions

The survey also provided an opportunity for members of the ADHD community to add any other comments or suggestions for the Senate inquiry. The responses were wide-ranging. We have included some examples of direct submissions to Senators about ADHD and the key things people who lodged online submissions wanted you to hear.

### Direct quotes

*"I hope the results of the Senate inquiry will help reduce the stigma around ADHD and raise public awareness on how the condition affects people. The biggest misconception is that people with ADHD are lazy or uninterested but there is research that shows the physiological differences in the brain for people with ADHD which causes executive dysfunction and imbalanced brain chemistry. An increased awareness of the physical symptoms could help in underlying the difficulties that people with ADHD experience and would hopefully create more understanding and acceptance."*

*"Just listen and act as if it's a bloody awful life living with ADHD. There is a high level of ADHD sufferers who have other diseases from ADHD such as mental health and FND."*

*"People with ADHD are not lazy. We put in so much effort that is unseen just to show up in the world in the way society expects. ADHD can often present with other mental health issues and addiction problems and better access to treatment and help would improve the lives of so many and generally benefit society."*

*"This isn't a fad or something cool. Sure for some ADHD is their super power but there's so much stigma around it. It shouldn't be so hard to try and get an assessment. At this stage it's going to take 18 months. By that time my oldest will be attempting the HSC, she needs help now so she can be ready and prepared for the HSC. Waiting times are the killer. Costs are a killer."*

*"If you haven't had to live with a child or loved one with adhd then you have no idea how draining and overwhelming the condition is. Being a parent to a child is hard enough but to one with adhd is life changing and needs to be changed immediately."*

*"Please help. We are at breaking point financially and for our kids struggling at school with no funding and no support. It's inhumane for schools to ignore students and not support them because "ADHD doesn't get any funding" (the school seriously says this as an excuse not to help!!)"*

*"I wouldn't be here today if I didn't find the one doctor to take me seriously and actually listen. He suggested I might have ADHD and referred me for an ADHD assessment. It shouldn't have taken me years of misdiagnoses to get here. I was turned away multiple times or told I just have depression and see a therapist or prescribed an antidepressant. Education for GP's is a must! I don't care how many people claim they have ADHD, the education they receive will be crucial to identifying who actually has it and who doesn't..."*

*"I lost my entire life to date (54 years) due to being undiagnosed. It's been 5 months and my world is still upside down. I lost my childhood, my education, my adolescence, and the majority of my adult life to ADHD. I cannot go to university now, it is too late for me. Finding out at 54 that it could have been possible was life shattering. All of the risk taking behaviours, loss of relationships and jobs because I was different sculpted me into an awful person who hated herself. The minute I was diagnosed, and medicated, I truly experienced living for the first time. It saved my life. I want to see, in my lifetime, that no one else will ever have to go through what I did. Assess and diagnose early*

*through the education system. Give children a chance to live their best life and not be robbed of it because of the stigma associated with ADHD. Opportunity through schools is something that I believe other countries have been doing for years - they pick it up early, and treatment is offered much earlier. Please help. Please."*

*"Misdiagnosis in women is a huge issue. My life has been a nightmare of poor mental health being diagnosed with bipolar and trying every single medication with no improvement. I had to do sex work for 12 years because I could not manage regular jobs with poor mental health, despite having a university degree. Women in their 30s and 40s have been through the wringer of misdiagnosis with bipolar, borderline etc. Do not let this keep happening to younger generations and seeing lives go to waste. I attempted suicide many times because nothing worked and I believed my life would never get better."*

*"ADHD makes a significant impact in every classroom. There are at least 2-3 diagnosed students in every classroom and often 1 or 2 with similar or more severe symptoms that are undiagnosed. We receive zero support and training in assisting these students through their education. Many teachers mismanage and misunderstand students with ADHD causing disengagement and disconnection from education. We are failing ADHD children in education with the majority of suspensions from students with this disability. Their needs are not met in the current education system and the change needs to be systematic."*

*"Kids with ADD fill up our jails, there must be a better way to teach these kids that doesn't crush their self esteem and have them falling through the gaps of traditional education."*

*"I'm 67, retired and stressed and concerned every day about my son. There is no support for me. And now I have to deal with not only his troubled living and conditions, I also have to try to stay stable. Can't tell you how incredibly hard it is."*

*"Having ADHD is not a bad thing, it makes me who I am and I am so thankful for my "quirks." But I have seen others struggle because they can't access assessments and/or meds and life is impossibly difficult for them. If we can help people to get the meds, and therapy like CBT on a regular basis (I forgot to mention that), they will potentially be able to study, work and to engage in life on a whole new level. That is why we need change in this area!"*

*"The ADHD community needs a support system - for our children, young adults, and for us as parents with adhd. Teachers need to be educated on it. Schools should see these children and nurture them as they are rather than try to put them in a box and expect them to learn the same way NT students do. It can feel like torture for us to conform and fight our natural instincts all day long. I see this for so many students at schools I work in, and I feel it myself at times - even though I'm a grown adult!"*

*"Let's not be under any illusions here - this is a difficult area, in no small part due to a lack of (ahem) attention to this issue by previous governments. One thing that you can't go wrong with doing though is putting and keeping people with ADHD and their supporters at the centre of the work that will be done - remember the call - nothing about us without us!"*