

Submission for the Assessment and support service for people with ADHD

ADHD Connect Australian T/A as ADDults with ADHD.

ADDults with ADHD is a not-for-profit volunteer run organisation that provides support and assistance to those living with ADHD and the wider ADHD community. Our submission is based on information received from those in the ADHD community and the difficulties they have had in relation to the terms of reference. We wanted to provide the thoughts of those that were not able to do a submission so their voices could be heard.

Please get in touch if you would like any further information. Thank you for your time

a). Adequacy of access to ADHD diagnosis:

Getting Diagnosed	
There is the difficulty for those who were not diagnosed as a child and the costs associated are even worse	
The diagnosis process needs to be streamlined; support networks and services and NDIS etc informed after diagnosis	
I saw a different psychiatrist first for few years trying to treat depression, I saw him for about 12 months after asking to explore ADHD since my treatment was doing nothing, but he kept delaying doing screening saying my depression needed to be under control first. He pushed hard for me to get private health insurance and do TMS treatment in the hospital he worked for before he would screen me. Not sure if he genuinely is not ADHD informed or wanted to generate more income.	
It is very difficult to get appointments with a psychologist or psychiatrist where I live so I need to attend telehealth via online services, the paperwork and process I was involved in was also daunting and overwhelming. I am currently waiting for an "urgent" review of my meds as per my GPs request but have to wait a minimum of 6months for an appointment although it was marked as urgent on my GP referral letter.	
"I don't understand why, after I've just paid \$1600 for an ADHD assessment, I'm now asked to provide further evidence for the psychiatrist appointment. I'm being asked for school reports I don't have, which I had explained to my psychologist for my assessment. But for medication, apparently, they need these. I'm 43, I don't have these documents, I didn't keep my report cards Why is my assessment not enough, after paying so much & having to revisit so much past trauma? It's so completely confounding & insulting. The lack of visibility of this condition, & how it shows up in women, is heartbreaking. So many parts of myself which I just thought were disparate now make sense. But I didn't get to know this about myself until I was 43. There is such grief over what happened & how things could have been different. This needs to change."	
I have to wait for over a year for an appointment to a Psychiatrist. The expense of initially speaking to Psychiatrist is so expensive and the brain-mapping is a standby situation and costly. Brain-mapping should be made accessible before putting people on medication.	I should not have had to become broken before I find out I can't be fixed. Mental health units should be able to assess and diagnose inpatients for developmental disorders/conditions that are known to be comorbid with mental health conditions
Struggled with a high level of internal frustration, outward irritability. pattern of starting and not finishing things. quick to anger when something annoyed me. Couldn't sit for any length of time. Felt mentally drained. Saw one psychologist for six sessions for procrastination, who finally said I can't do any more for you. Dealt with depression on and off for 20 years and seen multiple psychologists and a few psychiatrist. Despite the number of times I said I can no longer sit and focus or that I told them about my earlier working life (which I was doubted on a couple of occasions as having done), not once was ADHD suggested.	

b). Adequacy of access to supports after an ADHD assessment:

Support those living with ADHD would have liked before, during and after diagnosis	
Provided with approximate costing of services that would be needed as well as timeframes to get medicated.	
Feeling socially isolated and don't know where to turn to	Affordable and accessible treatment plans
Be provided with fact sheets on all facets on ADHD from reputable sources.	Have access to information on support groups and where to access reliable information for further education.

Transparency for what services are available & provided in a way that people can comprehend.	More resource list providing workable pragmatic strategies to deal with daily difficulties.
A support plan to assist spouse's, family and friends with the stigma and misinformation.	Support person coming to their home to aid in organising their messy life as is overwhelming.
Psychiatrists to provide more information regarding ADHD and how it can run in families especially when a parent.	Access to information about the impact on diet and to be added to teacher training for children in schools.
Access to affordable information providing practical strategies and advise to help manage home life.	Financial support available as living with ADHD is very costly.
Better access to education on what ADHD actually is, what are the symptoms to be able to learn to live with it.	More access and assistance for work opportunities as can have a major impact on daily living.
Accurate information on how to connect with others with similar challenges and feeling alienating and isolated.	Information on medicated/non-medicated options & potential side effects to make informed decision.
78% have not attended any support groups	82% have not attended any workshops

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

Information regarding getting diagnosed and health professional	
Living in a rural remote area has proved financially difficult as wait times for treatment are lengthy and at times feel completely inadequate for our society.	Lack of experience and knowledge by health professional so can assume the wrong disorder. E.g. diagnosed with BPD because of age/gender but ADHD not considered.
Being knocked back for referrals with no explanation and told not to take it personally.	Doctors dismissing symptoms as depression and anxiety so feeling shame and embarrassment to question them.
GP's not believing my opinion and refusing to refer.	Closed waiting lists for paediatricians/psychiatrists in Tasmania.
Statistics regarding getting diagnosed and health professional	
57%	Raised the issue with their GP on possibility of having ADHD
70%	Only had to raise it once with their GP before getting a referral
40%	Found their GP knowledgeable on ADHD
21%	Raised with it with their Psychologist before their GP
50%	Found the GP's view was encouraging/acknowledging 19% neutral, 31% Questioning/skeptical/other
60%	Had to find their own health professional 40% the GP had a name
32%	The Psychiatrist name were recommended by GP
64%	of GP's didn't ask them to complete any questionnaires or surveys for the referral
67%	received a referral from GP to Psychiatrist 13% to a psychologist 23% didn't get one.
50%	were NOT explained the difference between Psychologist and a Psychiatrist for prescribed medication
48%	Of patients were not suggested a Mental health plan by their GP.
77%	Those that saw a Psychiatrist were diagnosed
40%	Of those diagnosed were over 46 years old 50% were between 26 and 45
60%	See their psychiatrist every 6 months
68%	Approached only 1 psychiatrist
56%	Waited 3 months for Psychiatrist appointment
45%	Paid over \$450 for the first appointment with the psychiatrist
68%	Where diagnosed in first appointment 32% more than 1 (77% 2 appts 23% 4 or more)
46%	Subsequent appointments cost < \$300 15% \$300 - \$450 15% \$450 - \$600 23% > \$600
68%	Waited between 0-2 months between appointments for diagnosis 28% over 3 months
45%	Also see a psychologist
78%	psychologist and psychiatrist don't liase with each other regarding mgmt of ADHD
60%	of GP's didn't request any tests for Psychiatrist 15% requested ECG 30% requested Blood test 12% requested urine tests
47%	of Psychiatrist asked for school reports. 52.5% talked to family members 37.5% requested blood tests. 32.5% requested ECG 15% urine test and 25% none were asked

25%	told by Psychiatrist about support services available 72% told how medication works	55%	how regular to see Psych
80%	don't have a co-management situation with supplying medication with GP/Psychiatrist		
17%	Knew what support services where available	48%	did not
		34%	where unsure

d). Impact of gender bias in ADHD assessment, support services and research:

Barriers to getting an ADHD Assessment were	
Was labelled as more disruptive then inattentive or hyperactive.	Being female and not having the same symptoms has boys so ADHD not considered.
Feel that if you were a man, you would have been diagnosed early if you were male.	Being looked down on by people without ADHD and wish people understood the condition more.
For people to stop saying that it is easy to manage if you just 'focussed more'! Or everyone gets distracted in the middle of tasks.	Stereotype that men are Hyperactive Type and women are Inattentive Type so diagnosis may not be considered which can become damaging to their mental health.
Not being believed due to other things like depression and anxiety when voice that ADHD is more prominent.	Coming across doctors who believe that ADHD is overrated and overused.
Poor understanding of how ADHD affects women, and doctors dismissing difficulties as being a mum.	Stereotype regarding being female and seemingly capable so not taken seriously or believed.
Labelled talkative and needs to concentrate more for most of my life and no one saw beyond that.	Perception that as a woman I am diagnosis seeking given recent media attention about adult ADHD.
Finding support as an adult as don't want to use social media but can't find anywhere else and have no money.	Didn't have learning difficulties, not hyperactive, but was dreamy with emotional outburst so wasn't ADHD!
Stigma, misunderstanding symptoms and presentation in older women.	Lack of knowledge in general population about the caused of ADHD symptoms
More community awareness of symptoms and underlying reasons. More community awareness and acceptance of neurodiversity and strengths but also challenges. More education for health professionals and teachers.	
83 % said they felt there was a Stigma when discussing ADHD with others	

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

Medication costs
It should be easier to get our medication. Just to get a script made up, they charge expensive amounts which is hard on a pension or extremely low incomes. Let alone having to get the scripts filled for our children's ADHD medication. Then add psychiatrist appointments for kids and myself. Even when you have an appointment and pay for that u still have to pay extra for them to write you up a prescription for your medication
I can't afford the out-of-pocket cost for Psychologist or extra OT sessions. My ADHD drugs (Concerta). are \$50 per month and my anti-depressant is \$80 per month (vortioxetine).
Because of my financial situation I've either had to miss psychiatrist appointments and/or medication. It's a difficult situation, made worse when you have to choose between living expenses and medical expenses.

h). The adequacy of Commonwealth funding allocated to ADHD research:

Not enough research on ADHD and impact on female biology
Would like more research on female biology and ADHD particularly because of the difference it can make with our hormonal changes (monthly and menopause)

i). The social and economic cost of failing to provide adequate and appropriate ADHD services:

The impact ADHD has had on their working life.	
Impacts financial obligations if struggle to find work	Get distracted easily at work so get in trouble a lot
Have time management problems and prioritising tasks	Hyper focusing on tasks so taking too long to complete
Having learning difficulties	Struggle with organisation
Trouble focussing for long periods in the day.	Lacking an understanding of social rules
Feel inadequate in position even though competent.	Difficulty learning and study makes me overwhelmed/
Couldn't finish uni so trouble getting a better job.	Getting too attached to ideas.
Hard to communicate effectively	Speaking before you think.
Being Misunderstood	Misunderstanding direction on tasks
Hard to communicate effectively;	Difficulty in planning ahead
Missing work because of meltdowns	Lack of attention to detail
ADHD seen as an excuse.	poor self esteem which impacts confidence."
Changing jobs frequently as trouble being motivated.	Rejection sensitivity
Conflicts with co-worker's due emotional dysregulation.	I tend to manifest tasks.
Colleagues are either intimidated or find me arrogant and thus I have issues fitting in.	
ADHD often leaves me completing tasks at the last minute and not always to the best of my ability.	
Feeling overwhelmed with new information and no support or allowances in workplace.	Can only work part time due to being overwhelmed, feeling anxious or depression.
Being late for work a lot or given warnings about lack of attendance	Lack of self-worth and feeling insecure about keeping a job leading to anxiety and making mistakes.
Difficulty in verbalizing ideas and contributing to group discussions	Difficulty with completing tasks when not given a reason why I am doing it.
Only seen as someone with issues so not respected and ideas rejected.	ADHD brain not seen as a strength with the thinking outside of the box
Lack of training, support and awareness for neurodiverse employees	Emotional regulation in the workplace so could get angry or fly off the handle.
Worked in jobs unsuited to capacity but only work that could be found without further education	Anger management so quit jobs when feeling overwhelmed or unsupported or listened to.
My productivity suffers when I cannot decide on one task and flick constantly between multiple.	Difficulty with perfectionism as don't want to make mistakes for fear of underperforming.
Getting distracted easily by open office set up with noises and movement of others.	Sometimes my communication style can be more abrupt or literal.
These rushed scenarios make me feel inadequate in my position even though I am competent.	Having to work unpaid hours than required to get job done then feeling exhausted and extremely anxious
Trouble remembering verbal conversation and instructions and spend extra time checking everything I do just to ensure I do not make careless mistakes.	Get too involved in too many projects without understanding the context first, then "disappear" when people ask for help
Statistics on Employment and education	
92%	Attempted further study since leaving school however only 44% finished those studies.
65%	Are employees 10% are self-employed 13% are looking for work
61%	Told their employer they have ADHD 39% did not tell their employer
59%	Didn't receive accommodations through work 21% did receive them
45%	Have had more than 5 jobs that have lasted longer than 6 months
45%	The longest they have worked for one employer was less than 6 years
60%	Believe they have lost their job because of ADHD

l). any other related matters.

The reasons why people were seeking a diagnosis	
Their children were diagnosed and noticed similarities.	Having a lot of trouble completing university
Feeling overwhelmed and want to quit everything	Had trouble interacting with co-workers.

Creating problems for myself due to my impulsiveness.	Can't keep a job
mental health distress and lack of recovery	thought I was going crazy and could not cope anymore
Many people identifying my anger, poor relationships, disorganisation and hyper focus.	Always feeling overwhelmed, with work and home and felt that this wasn't normal.
Needed to see whether medication would assist in managing ADHD as struggling at home and work.	Underlying or undiagnosed ADHD as the reason for anxiety and depression
I was diagnosed first with Borderline Personality Disorder at 18, but my psychiatrist re-diagnosed me at 25.	Struggling with basic responsibilities after getting married
I suffered with addiction and was diagnosed in hospital after a traumatic life experience.	I referred to myself as having "Mad cow disease". Suffering depression/anxiety then diagnosed.
Treatment for depression wasn't helping so ADHD was suggested.	Having trouble coping as a parent and needed some assistance.
Diagnosed as a child but told would grow out of it. Children now diagnosed and see impact ADHD had on my life and mental health	On verge of losing marriage, job and social relationships and financial constraints stopped treatment - thought was going mad and lose everything.
Always thought I had anxiety and didn't make connection. Trauma pushed them to psychologist and suggested ADHD	Couldn't handle a Higher level of responsibility. Intelligence was no longer enough to mask, and avoidance was no longer acceptable
Feeling like my life was constantly falling apart regardless of my efforts	My inattentiveness drove my wife to breaking point, causing extreme relationship issues

Life Stories on living with ADHD

Experienced DV relationship, difficulty managing the supports etc around leaving that relationship, likely that having ADHD contributed to not noticing red flags or being able to leave the relationship sooner. Late diagnosis has meant that I have had a lot of missed opportunities through life. If supported earlier, I could have performed and coped better at school and university and potentially would have sought further education.

I feel alone in managing my ADHD. The medication works fantastically, but that's only part of the problem; I still need to fight misinformation / stigma, I still need to develop new/better habits on my own, I still need to overcome decades of self-doubt and negative talk on my own, and I still need to grieve the life that I could have had with an earlier diagnosis. Now I fear for the future of my kids who might inherit my ADHD.

Providing accessible and affordable access to be assessed for ADHD especially for women and girls and the stigmas that involve words such as deficit and disorder is soul crushing and counterproductive and incorrect. Correct terminology and education around ADHD especially for women is vital. A diagnosis validates and empowers us to take control and rebuild/tailor our lives, so we feel comfortable within our communities to be ourselves and not feel the judgements of being too much, too little, or not enough. We have the monopoly on self deprecative thinking, shame and negativity. We don't need others to make us feel like we need to try harder, focus better, grow up or stop procrastinating. Being a wife, parent, and woman with newly diagnosed ADHD has given me permission to be a little more, a little less and lot more like me. Will you help more young girls and women become who are they are, so they can live and love their life and enjoy their life on their own terms?

Had multiple jobs, many in recent years and low level. I've had a broken marriage and other relationships. I've started & not finished or failed at multiple businesses. University post grad courses (which I have significant HELP debt for). I struggle financially. I no longer have my own house and the likelihood of renting for the rest of my life doesn't bring any joy to my life. More help is needed to help adults who have fallen through the cracks and struggled with life. I can't afford the out-of-pocket cost for Psychologist or extra OT sessions. My ADHD drugs (Concerta). are \$50 per month and my anti-depressant is \$80 per month (vortioxetine).

Mother of 3 children with ADHD and Asperger's as well as having it myself. I work and study. My 3 children are NDIS recipients, but I do not qualify as I am 'functional'. My house is a hoarder's paradise. I need someone to help me declutter my house as I am struggling to do it on my own. I no sooner clean one room and my kids trash it again. My children all have their plans put through separately instead of together and the impact of my living situation gets more out of hand as cleaning is 'parent responsibility' when in fact my situation is times 3 and out of control. I spend all of my time walking on egg shells and attempting to diffuse aggressive behaviour that I have no time for cleaning.

I'm 27. I'm intelligent and creative. My undiagnosed ADHD and impulsivity was self-medicated with drugs and alcohol from age 18. I still self-medicate with alcohol. I am in \$20k debt after my finances spiralled out of control due to my drug addiction. I work part time and I struggle to pay my bills. It's extremely difficult for me to hold down a 9 - 5 job. I have no motivation, I'm extremely tired and depressed and I feel like an absolute failure.