Submission to the Parliamentary inquiry into ADHD services in Tasmania 2024

Regional Autistic
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Acknowledgement of Country

RAEN acknowledges the traditional owners of the land on Lutruwita/Tasmania, in

which this submission was written. We acknowledge and pay our respects to all

Tasmanian Aboriginal Communities; all of whom have survived invasion and

dispossession, and continue to practice and maintain their identity and culture across

Tasmania. Sovereignty never ceded.

Acknowledgement of Community

RAEN acknowledges the Autistic, Autism and ADHD Community in Tasmania, made

up of Autistic and ADHD people, their families, carers and loved ones. We

acknowledge the ongoing systemic disadvantage our community faces and celebrate

the voices of their lived experience, affirming that neurodivergent culture,

communication and community is valid and valuable.

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1. Introduction

Created and run "for us by us". The Regional Autistic Engagement Network (RAEN) is an organisation run by and for Autistic and ADHD people that started as a grassroots peer network in the North-West of Tasmania in 2021 and has since expanded across the rest of Tasmania.

In 2024 RAEN now facilitates a number of peer groups across the state and provides community, training and advocacy to improve the experiences of Autistic and ADHD people in Tasmania.

Since the closure of Autism Tasmania in June 2024, RAEN has stepped in as the only non-for-profit and community run peak body for Autistic and ADHD people in Tasmania, putting us in a unique position to respond to the recently announced Parliamentary inquiry into ADHD services in Tasmania^[i].

2. ADHD and Neurodivergence

Definitionally, ADHD is considered to be a neurodevelopmental condition or neurotype characterised by patterns of inattention, hyperactivity, and impulsivity, that create barriers to participating in a society designed for neurotypical people. [ii]

As a neurotype that differs from that which is considered 'typical,' people with ADHD are broadly considered to be part of the neurodivergent community, along with Autistic people and people with learning disabilities such as Dyslexia, Dyspraxia and Dyscalculia and others iv

The term neurodivergence, while often collated with, is different to the terms 'neurodiverse' or 'neurodiversity,' which refer to the presence of both neurodivergent and neurotypical people. [V] However, people who are neurodivergent, often have multiple diagnoses or conditions which fall under the neurodivergent umbrella. [Vi] For

example, up to 80% of Autistic people are thought to also meet the criteria for a diagnosis with ADHD. [vii]

3. A Social Model Lens

RAEN approaches its work and this submission using the lens of the Social Model of Disability, which views disability as a result of barriers in society, rather than deficiencies within individuals.^[viii]

While RAEN recognises that not all Autistic and ADHD individuals identify as people with disability, RAEN approaches ADHD within the context of disability, noting that people with ADHD often experience challenges that meet the criteria of disability under the Social Model of Disability theory.

4. Approach to this Submission

In order to ensure this submission was representative, RAEN conducted a comprehensive survey to gather data on the experiences of individuals with ADHD across Tasmania. The survey was distributed online and targeted both adults with ADHD and parents or caregivers of children with ADHD. The survey included 10 questions which covered access to diagnoses and support services, interactions with healthcare providers and the impact of ADHD on individuals' daily lives. The survey received 109 responses, providing a rich dataset that informs the findings presented in this submission.

In this submission, we draw on the results of the survey as well as other broader forms of evidence such as the report from the 2023 Federal Senate Inquiry into 'Assessment and Support Services for people with ADHD,' in Australia [ix]. Quotes used throughout this submission have been drawn from the survey and been de-identified to protect the privacy and safety of individuals.

5. Demographics of Respondents

The survey respondents were predominantly women, with 78% of the participants identifying as female, while 17% identified as male and 5% identified as non-binary.

Geographically, the majority of respondents were located in the southern region of Tasmania (53.21%), followed by the North-West (28%) and the North (15%).

Among the 109 respondents, 83% were identified as ADHD, 50% identified as Autistic and 63% were parents or carers of a child with ADHD; with many people indicating that they were part of multiple cohorts.

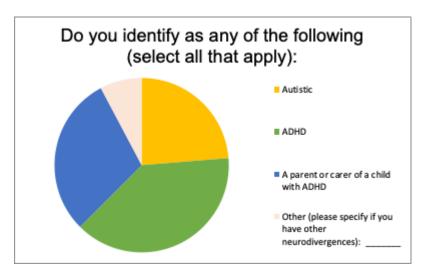


Figure 1: Pie chart showing the percentage of participants who were Autistic (50%), the percentage of participants who had ADHD (83%) and the percentage who were parents or carers of a child with ADHD (63%). Among those that selected 'other,' very few specified what they were indicating.

6. Response to the Terms of Reference

a. Adequacy of Access to ADHD Diagnosis:

The survey revealed significant challenges in accessing ADHD diagnosis services in Tasmania. Over 60% of respondents reported that obtaining a diagnosis was 'very difficult' (33%) or 'difficult' (32%) and less than 10% indicated that accessing their diagnosis was 'Easy' (9%) or 'Very Easy' (2%).

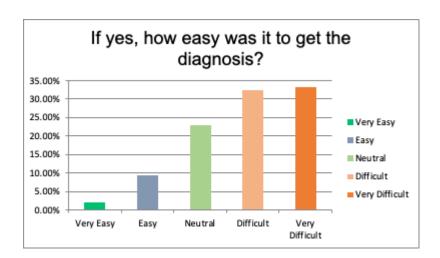


Figure 2: Bar graph showing how easy participants found it to access a diagnosis, with options ranging from 'Easy' to 'Very Easy.'

When responding to the question 'how access to diagnosis could be improved in Tasmania,' common and repeated suggestions related primarily to decreasing costs, increasing understanding, increasing the availability of diagnosticians and increasing understanding and awareness among General Practitioners (GPs); all of which align with barriers that were outlined in the Federal Senate Inquiry report.

"More services at a more accessible cost."

"More available clinicians trained in ADHD assessment to reduce wait times."

"More practitioners qualified and licensed to conduct assessment."

"More specialists that are qualified to do so, which will help with wait times and cost."

"Greater GP awareness and training."

"Increased funding for diagnosis and treatment increased funding for ADHD awareness; GP education etc more diagnosticians - too few clinicians"

"We need more ADHD specialists. There was a news article from a year or so ago which said there was only 3 ADHD specialists in the state, this is highly insufficient for the population. We need neuro-affirming education on neurodivergence within schools. More professional development around neurodivergent awareness. Above all, significant measures are required to drive down cost and waiting period for diagnosis."

i. Medicare Rebates

A repeated specific suggestion to improve access to diagnoses was to increase / create Medicare subsidies for all ADHD assessments.

"Medicare subsidies for assessments as they are extremely expensive."

"Put it on Medicare."

The Senate report similarly emphasised that the Medicare rebate for ADHD assessments is insufficient. It noted that the current Medicare Benefits Scheme (MBS) rebate covers just \$90 for up to three hours of assessment, while the recommended hourly rate is \$300. This creates a significant out-of-pocket expense for individuals seeking a diagnosis or assessment.

Another key recommendation respondents made to decrease the cost of diagnoses and increase accessibility, was to increase the number of publicly funded services that provide ADHD diagnoses. In the survey, many respondents highlighted that access to public diagnoses was very limited, especially for adults; and said that there are very long wait times for those services that do exist. A number of respondents also flagged that there are similar problems with accessing Autism diagnoses; highlighting a need for combined diagnostic services.

"I was lucky to be zoned for subsidised psych assessment but many aren't and I still had a 12 month wait.

"Stop making kids wait for 2+ years to see a paed. Adult community mental health needs to recognise, support and diagnose people with adhd/asd. I was literally being seen by the ACMH team and advised by the psychologist that the public system doesn't recognise autism or adhd in adults so he linked me up with a private psych for diagnosis. I had been misdiagnosed repeatedly for over 10 years. Even AFTER I had received a formal diagnosis by a private psych, upon admission to the (public) psych ward they told me that they didn't recognise adhd in adults and insisted

that I didn't have it. I have since been re-diagnosed by another private psych with adhd because I felt so gaslit by the public system."

"The lack of state government support is seeing desperate and vulnerable individuals spend several thousand dollars for diagnosis."

"Assistance for adult diagnosis cost me over \$2500 for myself over telehealth with a psychiatrist on the mainland. Through Epsychology . My children were diagnosed at 4 privately and also very expensive , then went back again for an autism diagnosis at 9, and my other son who is older was 13 years through the public system but we had huge waitlists to get through first."

"More specialists available to diagnose. Provision in the public health system."

"Better healthcare system, I waited 2 1/2 years for my son to be diagnosed. It took me a year and this is on the public waiting list. I saw a psychologist and my son saw a paediatrician at the hospital. The waiting list for children is ridiculous."

b. Adequacy of Access to Supports After an ADHD Assessment:

i. Barriers to Supports

In regards to support services post diagnosis, the RAEN survey indicated that individuals are significantly dissatisfied. Out of 109 respondents, nearly half (48%) rated the support services as 'Very Inadequate,' and an additional 35% rated them as 'Inadequate.' Only 1.83% found the services to be 'Adequate,' while no respondents rated them as 'Very Adequate.'

Similar to the barriers to diagnosis outlined, the most common barriers to service access that were reported related to costs and availability of professionals well versed in neurodivergence, as well as a lack of clear information about supports available and a lack of ADHD specific programs and support groups. When asked about how support services could be improved, respondents said things like:

Shorten waitlists for ADHD therapy, and medication

- Increase bulk-billing options and provide financial assistance for ADHD-related services.
- Provide more training for GPs, teachers, and professionals to better support ADHD individuals.
- Offer more ADHD-specific services, including support groups, therapy, and educational programs.
- More support groups and resources for both individuals with ADHD and their families.

A significant number of respondents also reported issues with accessing medication, including long waiting lists for prescriptions and restrictions on professionals when prescribing and managing medications; which are issues discussed in more depth under point **d**) in the Terms of Reference.

ii. NDIS Access

Some respondents also said that people with ADHD should be able to access more support under the National Disability Insurance Scheme (NDIS), which is a common view that was also noted in the Federal Senate Inquiry report.

"More recognition from ndis that adhd is a disability that needs way more support."

"Create supports to assist people and push the NDIS to understand that people with ADHD have the right to access. I tried for years to get into the NDIS and I didn't receive it till I found out that I am Autistic."

"My middle children has an official diagnosis of ADHD/ASD2. This means that he qualifies for NDIS so has a lot of support for both ADHD and ASD. My eldest with ADHD/ASD1 did not qualify for NDIS so doesn't receive any external support."

Despite some individuals with ADHD being NDIS participants, as of the 2023 Senate Inquiry, only 40 adults across Australia have ADHD listed as their primary disability within the scheme. [X]

This starkly low number is likely due to multiple factors, with the Senate Inquiry highlighting a significant one: the widespread belief that ADHD is ineligible as a primary disability under the NDIS based on the exclusion of ADHD from the NDIS List A and B Access Lists, which results in reduced access for ADHD individuals. [XI]

While it is understood that oversight of NDIS individual support plans is not within the jurisdiction of the Tasmanian Government conducting this inquiry, RAEN emphasises that the roll out of NDIS Foundational Supports, planned via the states and territories, is a key opportunity for the Tasmanian Government to prioritise the provision of community based supports for neurodivergent individuals; including support groups and educational programs, as recommended by RAEN survey respondents.

It is notable here that RAEN is well positioned to receive funding for these community programs, as it is the only disability-led peak body for Autism and ADHD in Tasmania. RAEN already operates a comprehensive peer support program, which has the potential for significant expansion with additional funding. Additionally, RAEN has a well-developed strategy to implement a self-advocacy service, a community learning roster, and impactful community education programs, all of which could be successfully executed with the appropriate funding support.

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

In addition to a reported significant lack of ADHD specialists, many survey respondents highlighted gaps in the training of general practitioners (GPs) and other healthcare providers regarding ADHD. Many respondents reported that their GPs lacked the knowledge to manage ADHD effectively, leading to misdiagnosis or inadequate treatment.

When asked about 'how ADHD services could be improved in Tasmania,' many respondents cited a need for clinicians and professionals to receive significant

training and education. RAEN's own observance is that this training should be delivered in partnership with expert community bodies such as RAEN to ensure neurodivergent affirming and accurate evidence based delivery.

"Training to improve awareness and knowledge about ADHD for professionals - including pharmacists, GPs and educators - would be a good first step to de-stigmatise the condition and ADHDers. Attitudes and knowledge of a significant many professionals leave a lot to be desired."

"GP education."

"Awareness and education, including with health practitioners."

"Increased funding for ADHD awareness; GP education etc."

d. Regulations Regarding Access to ADHD Medications:

i. Bureaucracy around prescriptions

Respondents frequently cited difficulties in accessing ADHD medications due to restrictive regulations under regulations such as the Tasmanian Poisons Act 1971 and the Commonwealth Poisons Standard, which classifies medications used for the management of ADHD symptoms as Schedule 8 'controlled drugs' under the legislation. [Xii]

The administration of ADHD medication in Tasmania by the Pharmaceutical Services Branch (PSB) was also described as overly bureaucratic, with some individuals citing delays in receiving their prescriptions.

"Getting medication prescribed was incredibly difficult due to the strict regulations. I had to jump through so many hoops just to get something that finally helped me manage my symptoms."

One significant issue reported was difficulty with accessing practitioners who are willing and able to prescribe ADHD medication. Under the regulations, prescriptions must be prescribed by specialists such as Psychiatrists and Pediatricians, rather than solely by GPs. While the regulations currently allow for GP's to register as

co-prescribers of a medication that has been approved by a specialist, [xiii] survey respondents noted that it is extremely difficult to find a GP willing to do so and said that the co-prescribing approval processes take too long.

"Even after being diagnosed, it took a long time to find a doctor who was willing to prescribe medication. The regulations around ADHD medications are so restrictive, it's frustrating."

"PBS Tas should approve co-prescribing applications in a timely manner and not insist on new applications for small medication changes that have been prescribed by specialists. They penalise people who seek treatment for ADHD and add to stigma and discrimination. There should be an independent body that investigates complaints to PBS to ensure patients do not experience adverse treatment if they raise legitimate complaints."

"Less restrictive PSB regulations on stimulant medication. Some adults can only access 2 tablets at a time."

ii .State Inconsistencies

Some respondents also noted issues with Tasmanian regulations not being consistent with those in other states and territories and as a result, having issues with accessing medication after moving from a different state.

"We moved from Vic to Tas. We had a good paediatrician there giving our scripts for my child's adhd medication. When moving, there was a huge amount of stress around this. Not being able to fill our Vic scripts here. Being told all the paeds in Tas (except hobart Hosp) had closed their books. Being put on a waitlist for a paed Hobart Hosp. Lack of information about gps being able to give scripts for adhd meds under restricted circumstances. There are a lot of barriers for a child to receive the care and meds they require."

This feedback echoes the findings in the Federal Senate Inquiry report, which highlighted significant inconsistencies across states and territories that make it harder for individuals to access ADHD medications. [xiv]

iii .Cost of ADHD medication

Another issue raised by survey respondents was the cost of ADHD medication, with respondents noting the cost can be difficult to cover, especially when it is required by multiple family members.

"Medication for 3 people per month is expensive and if I do decide to see a therapist my out of pocket costs are still more than I can afford."

As outlined in the Federal Senate Inquiry report on 'Assessment and support services for people with ADHD, the clinical practice guidelines recommend several psychostimulant medications for treating ADHD in children and adults, including methylphenidate, dexamphetamine, and lisdexamphetamine as first-line therapies, and atomoxetine and guanfacine as second-line options. However, atomoxetine and guanfacine are only subsidised through the PBS if the diagnosis is made between the ages of 6 and 18. [XV].

e. Adequacy of, and Interaction Between, State and Commonwealth Services:

The interaction between State and Commonwealth services was generally perceived as fragmented and inconsistent. Many respondents expressed frustration with the lack of coordination between services, leading to gaps in crucial care. For example, the transition from paediatric to adult services was highlighted as a particularly challenging period, with many individuals falling through the cracks due to poor communication between governments and service providers.

"Follow up support or coaching with better communication between all parties involved."

""There appears to be no coordinated public health response. Given the comorbidities that can arise with adhd and the benefits of diagnosis and treatment, it would be in the states interest to take a more proactive approach."

As mentioned earlier, respondents also raised issues with the severe lack of NDIS support received by ADHD individuals. While it was recognised that this is a Federal,

rather than state issue, survey respondents indicated they wanted governments to coordinate better to ensure ADHD people are supported and communicated with.

"We can't solely rely on market based approaches, the naivety of relying on incentives and market policies is clear. We need a more proactive approach with local community based support. Especially when ADHD by itself isn't entitled to any assistance by the federal run NDIS. The states and federal government can squabble over how things are funded, and how to support us, but its obvious that when asking for our input we ask for rather radical and grandiose things to happen. Obviously we don't expect these things to be fixed in a day, but we expect progress to be made, and this requires the community to stay informed. There is an inherent problem with the format, we give the same advice over and over again, but since there isn't much presence of this discussion in the media its hard to stay up to date. The state and federal governments need to be realistic about the PR aspect of all things regarding disability inclusion. The disabled community needs more active media coverage in an accessible format. It's unfair to keep the vast majority of the community in the dark about these matters solely because such information is obscured to us. Perhaps there could be an app for this information and the state and federal governments using this could share even small updates with the community, and perhaps feedback could be conducted through this. Access may need to be gated to prevent spam, but this is merely a suggestion because this isn't the 20th century anymore, communications is an essential part of inclusion and we need to bring government-community communications into the 21st century as well. If we could pioneer this, that would be great. But obviously this is slightly beyond the scope of this inquiry but I think in the case of ADHD, it would help us in particular because as a distractible lot, cognitive accessibility is almost always an afterthought. Twitter/X certainly has a lot of information regarding political updates but these platforms actively prey upon our attention spans in a way which runs counter to cognitive accessibility."

f. Social and Economic Cost of Failing to Provide Adequate ADHD Services:

The social and economic costs of inadequate ADHD services was documented clearly in survey responses. Respondents consistently reported significant impacts on their educational and employment outcomes, with many unable to reach their full potential due to a lack of support and difficulties with unmanaged hyperactivity, impulsivity and inattention, characteristic of the ADHD experience.

"I am a parent of 3- 2 now diagnosed and was always told there was nothing wrong! 2 girls struggled academically despite high iqs, suffered bullying, self harm, eating disorders, no recognition at school of any learning accommodations because they masked. All we've achieved has been driven privately at great expense financially and emotionally and efforts are too late when benchmarking against for example year 12 exams on the horizon."

"Our children are falling through the cracks in the education system"

In order to address these systemic issues, respondents highlighted a number of suggestions which mostly related to funding for schools and employers to ensure supports are available for ADHD individuals.

"We need more community based support for ADHD, alongside better public awareness and stricter anti-discrimination oversight. We need access to more therapists, and different kinds of therapies which may be not typically associated with ADHD treatment, like DBT. We need more OT's. We should have more teachers aids in schools, TAFE, and Uni for ADHD."

"More therapy, more diagnostic services, support groups, even a network or provider to help adhd people find comfortable employment and help to get them through studying!"

As documented in the broader literature, providing these supports is essential to ensure the broader community also bears the cost, with increased demand on social services, healthcare, and the justice system due to people with unsupported ADHD being more likely to develop substance addictions and chronic conditions [XVI] and

being more likely to engage in risk taking and dangerous activities which result costly outcomes like severe injuries and incarceration. [xvii]

The total cost of ADHD in Australia in 2019 was estimated to be \$20.4 billion, which comprised \$12.8 billion in financial costs and \$7.6 billion in wellbeing costs. [XVIII]

Investing in comprehensive ADHD services would yield significant long-term savings and improve the quality of life for individuals with ADHD.

g. Other Related Matters:

As mentioned at the beginning of this submission, RAEN also wishes to draw attention to the co-occurrence of ADHD with other forms of neurodivergence, such as autism. Individuals with multiple diagnoses often face compounded challenges in accessing appropriate care. Additionally, there is currently minimal research into intersectional experiences of those with ADHD or other types of neurodivergence who also have experiences in other minority groups such as Indigenous Peoples, CALD, those with trauma and those who have been part of the justice system (as well as others). For this reason, it is crucial that any reforms and service improvements consider the holistic needs and experiences of neurodivergent individuals and ensure that services are inclusive and accessible to the whole person and delivery considers a whole of life support approach.

7. Recommendations

a. Diagnosis

Recommendation 1: Increase the availability of diagnostic services in Tasmania by investing in at least one additional publicly funded diagnostic service in each major region of Tasmania with additional travelling and telehealth options to ensure regional and rural access. Ensure that these services are multidisciplinary and include diagnosticians who can offer ADHD assessments for both adults and children as well as dual diagnostic assessments for people with both Autism and ADHD.

Recommendation 2: Collaborate with the Federal Government and registered training providers as well as community representative organisations to create incentive programs encouraging healthcare professionals to specialise in ADHD. Offer scholarships and grants to neurodiversity-affirming, evidence based programs for those willing to work in rural, regional and remote areas.

Medicare Benefits Schedule (MBS)

Recommendation 3: Collaborate with the Federal Department of Health and Aged Care to explore options for reducing the cost of diagnostic assessments, including increasing the Medicare rebate available for these assessments.

b. Support Services

Recommendation 4: As part of the rollout of NDIS foundational supports, allocate funding for:

- Community-based supports, such as peer support groups and no cost community education programs, for people diagnosed with ADHD or suspected ADHD, including specific support measures for cohorts including adult women, gender diverse people and people of colour.
- Schools and workplaces to improve identification, accommodation, and support for individuals with ADHD.
- Community integrated self advocacy and service/resource linkage programs to support those diagnosed with ADHD as well as those awaiting diagnosis.

Recommendation 5: Offer state government financial assistance to individuals facing the ongoing costs of ADHD treatment and management. This could include subsidies for medication, therapy, and other essential supports, particularly for those not covered by insurance or PBS rebates.

c. Workforce Development

Recommendation 6: Collaborate with the Federal Government and professional registration bodies, such as the Psychology Board of Australia (PsyBA) and The Royal Australian and New Zealand College of Psychiatrists (RANZCP), to introduce and implement mandatory ADHD training for General Practitioners, Psychiatrists,

Psychologists, and other healthcare providers responsible for ADHD diagnostic assessments and referrals.

d. The reform of ADHD Medication Regulations

Recommendation 7: Amend the Tasmanian Poisons Act 1971 and related regulations to make it simpler and quicker for GPs to prescribe and manage ADHD medications, reducing the over reliance on psychiatrists.

Recommendation 8: Align Tasmania's ADHD medication regulations with those of other states and territories, removing the access barriers that individuals who have received diagnoses and prescriptions interstate face upon relocation to Tasmania.

Government and Service Coordination

Recommendation 9: Work with relevant government agencies, such as the Department of Health and Aged Care and the National Disability Insurance Agency to foster better coordination between State and Commonwealth services for ADHD individuals.

Recommendation 10: Work with the Federal Government and the National Disability Insurance Agency to provide more support for individuals with ADHD under the NDIS as part of the implementation of the NDIS Review and the newly passed NDIS Amendment Bill. Ensure that the support available under the NDIS is well communicated to the ADHD community.

e. Community Engagement

Recommendation 11: Establish a state based working group comprised of sector experts and advocates who have a lived experience of ADHD to work in conjunction with representatives from the State Government, Primary Health Tasmania and other relevant bodies to represent community interests and ensure effective implementation of strategies and to make recommendations for adjustment and advise on continued community engagement.

ENDNOTES

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- Community Affairs References Committee (2023) 'Assessment and support services for people with ADHD,' Commonwealth of Australia, ISBN 978-1-76093-568-9, p. 4.
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- ^[X] Community Affairs References Committee (2023) "<u>Assessment and support services for people with ADHD</u>,' Commonwealth of Australia, ISBN 978-1-76093-568-9, p. 194.
- [xi] Ibid, p. 196.
- [xii] Ibid, p. 17.

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Deloitte (2019) <u>The social and economic costs of ADHD in Australia</u>, Report prepared for the Australian ADHD Professionals Association.

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