



Carers Tasmania's Submission

on the

**Inquiry into Assessment and Treatment of ADHD and
Support Services in Tasmania**

August 2024



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 87,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

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1. Background

Carers Tasmania is the Peak Body representing the more than 87,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Australian Government Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania welcomes the opportunity to respond to the Inquiry by the Tasmanian Government Administration Committee B: *The Assessment and Treatment of ADHD and Support Services*.¹ We thank the Tasmanian Government for this important inquiry, which we are hopeful will build on the findings and recommendations of the 2023 Australian Senate Inquiry (*Senate Report*) into Attention Deficit Hyperactivity Disorder (ADHD),² to create much needed change for people with ADHD and their carers.

Carers Tasmania's response addresses the current Tasmanian Inquiry Terms of Reference (ToR). The primary focus of our submission is to emphasise that inadequate access to diagnosis and support for people with ADHD not only impacts people who have ADHD but also their carers. In addition, we highlight that many family and friend carers have ADHD. Although the ToR do not specifically include a question around the impact of ADHD on family and friend carers, we seek for carers' needs and experiences to be considered alongside other feedback collected throughout this inquiry process. Carer recognition, inclusion, and ability to access support, aligns with the aims of the Tasmanian *Carer Recognition Act 2023*, and the Carer Charter that sits within it.³

Although not all carers relate to the term 'carer', the act of providing additional care and support to another person because it is required, is distinct from what is considered as 'normal' interactions with family or friends. Carers provide additional care such as check-ins, motivation, practical or emotional support, monitoring and organising. Importantly, being recognised as a carer opens pathways to support for carers.

Carers Tasmania receives significant feedback highlighting the need for better recognition, inclusion and support of carers across a multitude of service systems. Carers supporting a person with ADHD often experience significant difficulty in accessing adequate support. Carers who have ADHD experience additional complexity.

Carers Tasmania thanks and acknowledges the carers who have shared their experiences to assist in raising awareness about the challenges and benefits in caring for someone who has ADHD, or being a carer who has ADHD.

Content warning:

This submission intends to raise awareness about the impacts of ADHD on carers. Due to the sensitive nature of this topic, we encourage you to seek immediate support from **Lifeline on 13 11 14** or from a trusted person if you experience any distress.

¹ Parliament of Tasmania. (2024). [Resolution-for-the-inquiry-into-the-assessment-and-treatment-of-ADHD-and-support-services.pdf \(parliament.tas.gov.au\)](https://www.parliament.tas.gov.au/~/media/parliament/committees/committee_b/assessment_and_treatment_of_adhd_and_support_services.pdf)

² Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://www.aph.gov.au/~/media/parliament/committees/senate/community_affairs_reference_committee/assessment_and_support_services_for_people_with_adhd)

³ Tasmanian Carer Recognition Act (2023). <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

3. The impacts of ADHD on carers

The 2032 Senate Inquiry Report into ADHD describes ADHD as “a chronic and complex neurodevelopment condition, for which the diagnostic criteria are focused on persistent patterns of inattention and/or hyperactivity or impulsivity.”⁴ ADHD can impact many elements of a person’s life and their life outcomes, but the experience differs from person to person. Providing care to someone who has ADHD is different in every situation and can be both challenging and rewarding. Some of the additional supports that are often provided by carers when supporting a person with ADHD include:

- Carrying an additional ‘mental load’, for example, needing to be highly organised and on top of planning day-to-day tasks and appointments
- Holding a higher burden of responsibility for household tasks such as cleaning, cooking, and maintenance
- Providing support with reminders, motivation and prompting to start or complete certain tasks
- Prompting or assisting with medication management
- Providing emotional, behavioural, and regulatory support
- Supporting decision-making
- Providing support with managing finances and other administrative tasks
- Accompanying the person to appointments and communicating with professionals
- When supporting children who have ADHD, additional communications may be required with school staff
- Children may be more likely to be sent home from school, or refuse to attend school
- Providing informal advocacy, especially within school settings
- Preparing different foods, or monitoring food additives
- Provision of social support and stimulation
- Support to help the person stay on track with tasks.^{5,6}

Research suggests that approximately 65% of people who have ADHD also have co-morbid conditions such as autism spectrum disorder, obsessive compulsive disorder, pathological demand avoidance, anxiety, depression or learning disabilities, and may have an increased risk of suicide and/or self-harm.⁷ This means that most carers supporting a person with ADHD, are not only supporting them to manage their ADHD, they are also supporting them to manage any co-occurring conditions simultaneously.

⁴ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/Assessment-and-support-services-for-people-with-ADHD)

⁵ Carers Tasmania. (2023). [Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf](https://carerstas.org/Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf) (carerstas.org)

⁶ Carers NSW. (2023). Submission number 72. <https://www.aph.gov.au/DocumentStore.ashx?id=510c8b55-6a69-471f-8047-7a61f853c837&subId=744962>

⁷ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/Assessment-and-support-services-for-people-with-ADHD)

Many people caring for a person with ADHD experience high levels of stress. This is particularly relevant to carers of children who have ADHD, who often worry about how their child is coping at school, or if the school is going to call and ask for the child to be picked up early. This can lead to parents being absent from employment, having to reduce their employment hours, or giving up employment entirely. This can also lead to the child not wanting to attend school, missing out on social opportunities with other children, and falling behind in their schoolwork. There may also be appointments related to ADHD treatment requiring a child to be away from school.

Many carers, especially those of children with ADHD, face stigma and judgement from others on their parenting approaches. This can cause stress to the parent, as well as conflict between parents of the child regarding decisions around how to manage behaviour. Experts such as William Dodson, estimate that by the age of 10, a child with ADHD will have received 20,000 more negative messages on average than their non-ADHD peers.⁸ Many parents caring for a child with ADHD are balancing helping their child to understand societal rules and appropriate ways of behaving, with supporting their child to be happy.

Carer quote:

There's a lot of judgement and stigma from other parents or people who just don't understand. I've had to learn to deal with all of the comments and 'unwanted advice' that people give, for example, I've had people tell me I should just smack the kids or discipline them better, I've had people tell me it's due to the food they eat, it's because they watch too much tv, it's because we have raised them wrong, it's because they are or aren't vaccinated for certain things. The list goes on. Sometimes, I feel that people are more understanding when I tell them they also have a diagnosis of Autism. For that, there is much more understanding, advocacy support, funding and awareness. I have found it really difficult to get support for their ADHD compared to Autism and their other diagnoses.⁹

Other impacts on carers of people who have ADHD include:

- Emotional impacts such as stress, frustration, and confusion
- Financial difficulty or distress
- Physical impacts of increased practical tasks
- Social isolation, impacts on relationships, lack of time for self
- Poor physical and mental health, lack of sleep, and tiredness

⁸ ADDitude. (2021). [Children with ADHD Avoid Failure and Punishment More Than Do Their Peers, Study Says \(additudemag.com\)](https://www.additudemag.com)

⁹ Carers Tasmania. (2023). [Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf \(carerstas.org\)](https://www.carerstas.org)

In their response to the 2023 Senate Inquiry into ADHD,¹⁰ Carers NSW shared some relevant findings from their 2022 National Carer Survey (figure 1 below) which found that across Australia, approximately 2 in 3 carers of people with ADHD experienced high or very high levels of psychological distress and that approximately 3 in 4 carers were socially isolated.^{11, 12}

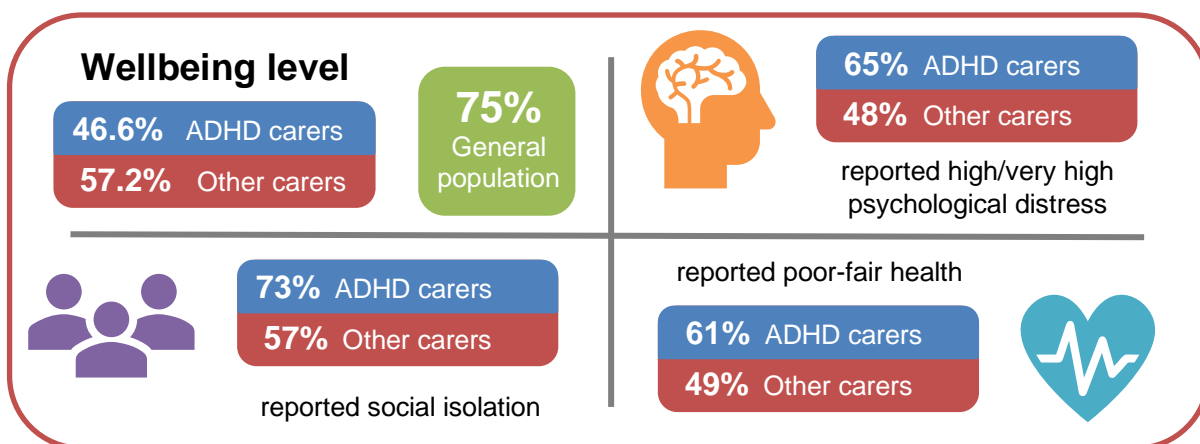


Figure 1: Carers NSW Australian data on ADHD from the 2022 National Carer Survey

Some specific feedback from Tasmanian carers is outlined below, providing snapshots of what it is like to care for someone who has ADHD.

Carer quote:

I care for my son who has multiple disabilities as well as ADHD. I also have ADHD myself and it can be really challenging to stay on top of everything, especially managing multiple appointments. We both have NDIS plans and wouldn't be able to manage them effectively without support coordination. ADHD is a highly heritable condition and I think many parents who have a child with ADHD probably have it themselves.

We found many barriers in trying to access the NDIS. The NDIS doesn't support our ADHD, even though for me, my ADHD has more significant impacts than my Autism. I wonder and worry about what support will end up being available for my son. I'd like to see more research into this, especially for females as ADHD is really underdiagnosed in that cohort.

I'd like to see encouragement to participate and the lived experience around this valued, for both people with ADHD and their carers. I don't know that many other carers or people with ADHD know about this inquiry and if they do, is it really accessible and realistic for them to have their say? For carers, most wouldn't get the time, and for carers who have ADHD as well (like me), providing input into something like this is really difficult.¹³

¹⁰ Carers NSW. (2023). Submission number 72 in the Senate Inquiry into ADHD. <https://www.aph.gov.au/DocumentStore.ashx?id=510c8b55-6a69-471f-8047-7a61f853c837&subId=744962>

¹¹ Ibid.

¹² Carers NSW. (2022). National Carer Survey 2022, Unpublished data.

¹³ Carers Tasmania. (2023). [Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf](https://carerstas.org) (carerstas.org)

Carer quote:

Caring for my partner who has ADHD has its ups and downs. It can be socially isolating at times because his friendships seem to move in waves. I'm not sure if it's because people just don't get him, or if it's too much effort. I've seen him build friendships, but then things go wrong. This not only affects him, but it affects me too. Some of these people have been nice people, but then suddenly they are gone. The social interaction is important to him, but just as much to me too, as those opportunities give me time to take care of tasks or to have some quiet time. I enjoy his company, but sometimes I need me time.

Carer quote:

It's difficult being a carer to children who have complex needs whilst also having ADHD myself. I have always struggled with things like having the motivation to just do the normal things at home. It's hard to ask for help, especially when you get judged by others. I wish ADHD could be seen and acknowledged for everything that it is, especially also for carers who have it. For me, when I was diagnosed it was such a relief to learn that there is a reason behind everything. I really think services need to understand these challenges. This lack of awareness also reinforces stigma, which makes it hard for people to feel as though it's ok to ask for help. Before my diagnosis, I tried my whole life to counter these feeling of stigma, or not fitting in, feeling silly or stupid. Knowing the reasons why have really helped me, but it is hard to get the right type of help. It's hard enough being a carer, but being a carer who has ADHD and not enough support takes the challenges to a whole other level.

Chapter Two of the Senate Report provides a further exploration of how ADHD impacts individuals with ADHD and their carers. More specifically, the chapter describes how ADHD may contribute to family stress, relationship and marriage difficulties, parenting disputes, conflict and isolation from non-immediate family members who may not understand.¹⁴

Carers Tasmania highlights that for siblings, or children of people who have ADHD, the impacts can be significant, especially if the child is a young carer who helps to support the person with ADHD. A young carer is a person aged 25 or under, who either fully or partially supports another person due to their additional needs. In Tasmania, it is estimated that there are 9,300 young carers.¹⁵ Whilst being a young carer can bring about many positive experiences and skills, young carers who don't have access to the right support, can face negative impacts such as isolation, financial difficulties, poor educational and employment outcomes, and may also experience bullying and stigma from other young people. Given that young people spend a significant time at school, we believe that educational settings are well placed to help identify and support families where additional care needs exist.

¹⁴ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au)

¹⁵ Tasmanian Government, Department of Premier and Cabinet. (n,d). https://www.dpac.tas.gov.au/divisions/cpp/community-policy-andengagement/carer_policy_and_action_plan/carer-action-plan-2021-2025/what-the-data-tells-us-about-carers

4. Response to the Terms of Reference (ToR)

The following section responds to the Inquiry Terms of Reference (ToR), in particular highlighting areas of impact and need for carers.

a) Adequacy of access to ADHD diagnosis

Most estimates now report that around one in 20, or over 1.25 million Australians have ADHD, however, the ADHD Foundation suggests that this number may be as high as 1.5 million Australians.¹⁶ This makes ADHD “*the most common neurodevelopmental disorder in both children and adolescents*” and suggests that it is one of the most common adult neurological conditions.¹⁷ ADHD is diagnosed two to three times more often in males than in females,¹⁸ however, this may also be because research is finding that gender differences are contributing to differences in ADHD presentation. In Tasmania, there is inadequate evidence of the actual prevalence of ADHD within the state, with further research required.

As highlighted in the Senate Report, there are many pathways to obtain an ADHD diagnosis.¹⁹ In Tasmania, the process to diagnose ADHD differs between children and adults, and between individuals in terms of timeframe, cost, diagnostic processes, and professionals involved.

ADHD is usually diagnosed in children by either a paediatrician or clinical psychologist. The first step to access either of these professionals is by obtaining a referral from a GP. Even if a clinical psychologist can provide the diagnosis, to enable access to medication, a paediatrician must also agree to the assessment.

For adults, the first step involves accessing a GP, who will then make a referral to a psychiatrist. Although it seems like a simple process, there continues to be an ongoing shortage of GPs in Tasmania, which is exacerbated in regional and remote areas. In addition, findings show that Tasmania has extremely low incidences of bulk-billing when compared to other states.²⁰ In Tasmania, there is overwhelming feedback highlighting difficulties in obtaining an ADHD diagnosis for both children and adults.

For those able to obtain a referral from their GP to a paediatrician, clinical psychologist or psychiatrist, they are then faced with significantly long waitlists, as well as access difficulties in regional and remote areas. Tasmania is still experiencing major workforce issues, resulting in most private paediatricians, psychologists, and psychiatrists being unable to accept new clients.

¹⁶ ADHD Australia, Submission 11, p. [1]; ADHD Foundation, Submission 12, p. 2. Senate Inquiry into ADHD. https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ADHD/Submissions

¹⁷ Deloitte Access Economics. (2019). The social and economic costs of ADHD in Australia. <https://www.deloitte.com/content/dam/assets-zone1/au/en/docs/services/economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf>

¹⁸ Ibid.

¹⁹ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://www.aph.gov.au)

²⁰ Mental Health Council of Tasmania. (2023). Access and Affordability Report Two. [MHCT-Access-and-Affordability-Report-2.pdf](https://www.mhct.org.au/Access-and-Affordability-Report-2.pdf)

Assessment and diagnosis are accessible through the Tasmanian public health system, but the waitlists are often very long. Additionally, Tasmania currently has only one specialised ADHD clinic, the Hobart ADHD Clinic, which has, at times, paused accepting new clients due to extreme demand. For many families, the costs of these assessments are unaffordable.

For those able to undertake the assessment process privately, it can be quite costly, with no Medicare rebate available, unless being assessed for an eligible condition such as Autism, at the same time. These experiences are consistent with those outlined in the Senate Final Report, which stated:

“The committee has heard how peoples’ experiences of accessing an attention deficit hyperactivity disorder (ADHD) medical diagnosis are generally long, difficult, expensive and time consuming, causing significant stress, anxiety and pressure on family relationships and school systems.”²¹

Not being able to access a diagnosis early on can have profound impacts on educational and social outcomes for children. For carers in these situations, it can be a stressful process trying to support the person they care for to access diagnosis for ADHD. Without the diagnosis it can be difficult for other people to acknowledge that the difficulties sometimes experienced by a person with ADHD are not a choice. This is especially true for children who are often labelled as ‘naughty’ or ‘disruptive’, and due to these negative stereotypes, their strengths are often not seen or supported. Through the process of diagnosis for their children, many parents also come to the realisation they may have ADHD themselves, however, may not go down the path of formal diagnosis.

b) Adequacy of access to supports after an ADHD assessment

Despite the complexities of the assessment process, obtaining a diagnosis can bring about some benefits when support can be accessed. However, receiving an ADHD diagnosis does not necessarily mean that it’s easy to access the right type of support. There is only one specialised clinic in Tasmania that provides specific support for people with ADHD. This service provides valuable diagnosis, information, and non-pharmacological support such as psychological, cognitive-behavioural intervention, and ADHD coaching.²² Unfortunately this service is not easily accessible for people who are unable to travel to Hobart or use telehealth effectively. For others, it is unaffordable due to limitations around the subsidies available through Medicare.

Although some supports can be delivered by psychologists and other allied health professionals (such as occupational therapy or behaviour support), due to significant workforce issues in Tasmania, the high costs of these supports, lack of coverage under NDIS and lack of availability in regional and remote areas, many people are unable to secure these services.

Within the context of Tasmanian schools, Carers Tasmania often hears from parents of children with ADHD who are not able to obtain the support that they need at school. We hear stories of children who have ADHD who are sent home because they are said to be disruptive to others, or disobeying rules. These experiences occur across public, private and independent schools, and sometimes result in home-schooling, taking parents out of the workforce.

²¹ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au)

²² Hobart ADHD Consultants. (n.d). [Services - ADHD services | Hobart ADHD](#)

Often within school settings, children with ADHD are made to try and conform to rules that may not be fully achievable, such as being quiet, staying still, and keeping on task, but for many this is simply not possible. There are physiological reasons that can inhibit children with ADHD to 'conforming' to the same expectations for children without ADHD. Schools must be resourced effectively to support these children to engage and complete their schoolwork, in ways that suit their specific needs, rather than sending them home or punishing them. Carers Tasmania sometimes hears of children who have ADHD who do not have an individual learning plan in place, scenarios where the plan is not followed or monitored, or the plan includes ableist goals that are not realistic. Many parents caring for school-aged children with ADHD are referred to individual advocacy services such as The Association for Children with Disability.

There are also differing processes between schools in terms of applying for educational adjustments and additional funding requests, with some schools not taking advantage of this support unless there is formal diagnosis of ADHD. This means that although there are systems in place that could provide some level of support, they are not always fully utilised.

Concerns have been raised regarding high suspensions rates in Tasmanian schools, particularly for children with disability. A report from June 2023 indicated that approximately 10,000 suspensions were expected across Tasmanian public schools in 2023.²³ Furthermore, in 2022, 55% of all Tasmanian public-school suspensions were given to students with disability, students who identified as Aboriginal or Torres Strait Islander, or students who were in out-of-home care. This is despite research showing that frequent suspensions can lead to long-lasting negative impacts on educational outcomes for young people. Carers Tasmania acknowledges and welcomes the Tasmanian Inquiry into Education that has recently been initiated²⁴ and we hope that bringing to light the challenges experienced, will foster better ways of working, in the best interests of all children.

In Tasmania, there is limited access to appropriate resources for family and friend carers of people who have ADHD. Some businesses and consulting services provide information sessions and workshops for parents, carers, and other family members, but as there is limited financial support available to assist people who cannot pay, many people are often not able to access these resources.²⁵

In 2022 and 2023, a Tasmanian ADHD Conference was facilitated, with an online Australian ADHD conference scheduled for later in 2024.²⁶ Unfortunately, for many families, the cost to register for these conferences is unaffordable. Understandably, the registration fees support the cost of running the conferences, but if the cost of such conferences could in some way be subsidised, it would support more carers to attend. There are various online webinar and training options available, but again these are not accessible to a large range of people, for a variety of reasons such as timing, cost, issues with internet connectivity, or literacy/digital literacy challenges.

²³ The Mercury. (2023). Tasmanian government schools in crisis. <https://www.themercury.com.au/tasmania-education/tasmanian-government-schools-in-crisis-as-suspensions-escalate/newsstory/c09db>

²⁴ [Independent Education Review - Tasmanian Government \(ier.tas.gov.au\)](https://www.independenteducationreview.gov.au/)

²⁵ Carers Tasmania. (2023). [Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf](https://www.carerstas.org.au/wp-content/uploads/2023/06/Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf) ([carerstas.org](https://www.carerstas.org))

²⁶ [Australian ADHD Conference ONLINE 2024 Tickets | TryBooking Australia](https://www.australianadhdconference.com.au/tickets)

Carer Quote:

*Parents and other carers supporting someone with ADHD need better support, more knowledge about their rights and what help is available. We need advocacy support, and access to behavioural support programs that help us and the whole family unit cope better when we are overloaded. We also need programs for children who have siblings with ADHD so that they can understand it and learn skills to help them as well.*²⁷

Carers Tasmania draws attention to the following Senate Report Recommendations:

“Recommendation Two

The committee recommends the Australian Government consult with people with lived experience of ADHD, healthcare colleges and organisations to identify additional supports to improve access to ADHD healthcare and support. This should encompass reviewing bulk billing incentives to reduce out-of-pocket expenses for diagnosis and ongoing support, shared care models, telehealth, and improving access in rural, regional and remote areas.

Recommendation Three

*The committee recommends the Australian Government review the Medicare Benefits Schedule with a view to improving the accessibility of assessment, diagnosis and support services for people with ADHD.”*²⁸

Carers Tasmania encourages all state government funded departments, including health, mental health, and education services to identify and refer family and friend carers for support when they recognise them as supporting someone with or ADHD or suspected ADHD. This connection to support for carers is crucial, to enable them to access support for their own wellbeing and information purposes. Ensuring carers have access to as much support possible sustains them in their caring roles. Recognition, routine identification and referral are key pillars of the Tasmanian *Carer Recognition Act 2023*.²⁹

Because people who have ADHD as their primary or only diagnosis are not eligible for support such as the NDIS, there is usually a higher responsibility burden felt by carers, because they can't access the additional layers of support that NDIS may be able to provide. Care2Serve is the Tasmanian Carer Gateway provider and is able to broker some forms of support to assist carers in their caring role. However, this support is short term. The Tasmanian Community Care Referral Service (TCCRS) exists to support people aged 65 and under who need additional support at home. However, TCCRS will usually decline referrals for supports such as domestic assistance if there is a carer living in the household who is 'able bodied'. This places the responsibility back onto the carer, who will often have their own competing responsibilities and needs to look after.

²⁷ Carers Tasmania. (2023). [Carers-Tasmania-submission-on-the-Senate-Inquiry-into-ADHD-2023.pdf](https://www.carerstas.org) ([carerstas.org](https://www.carerstas.org))

²⁸ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia](https://aph.gov.au) (aph.gov.au)

²⁹ Tasmanian Carer Recognition Act (2023). <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

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

As previously highlighted, there are workforce challenges and lengthy waitlists when trying to access paediatricians, psychiatrists, clinical psychologists and allied health professionals. Through the public education system, although schools have psychologists and wellbeing staff employed, the waiting time to access an appointment with a school psychologist is in excess of 12-18 months in some schools. This does not ensure adequate and accessible support is available within schools within the timeframes that it is needed.

We have heard anecdotally from some carers, that they have had experiences whereby GP's or school staff do not believe that ADHD is 'real'. There have been other scenarios shared where practitioners will not refer or assess children under the age of 6 for ADHD, despite the benefits that early intervention can have. Whilst there is some level of understanding by some health professionals regarding ADHD, there is still much room for improvement.

As well as addressing the significant workforce issues within the health and education sectors, more education and awareness raising is needed for both professionals employed in health, education and community roles, as well as for the broader community.

d) Regulations regarding access to ADHD medications, including the Tasmanian Poisons Act 1971 and related regulations, and administration by the Pharmaceutical Services Branch (PSB), including options to improve access to ADHD medications

Carers Tasmania often hear about difficulties in accessing ADHD medications, with some people experiencing this because they have sought assessment and diagnosis from outside of Tasmania due to incredibly long wait times. We highlight that although medication is not the only option, nor a cure for ADHD, for some people, ADHD medication when prescribed and used correctly, can bring some significant benefits. Carers Tasmania supports the following Senate Report Recommendation Five:

"The committee recommends that the Commonwealth expedite the development of uniform prescribing rules to ensure consistency between state and territory jurisdictions, through the Ministerial Council on Health"³⁰

We hope that more carers can be supported to help the person they care for access adequate medication when required, and with less stigma, by developing and implementing consistent prescribing rules across Australia.

³⁰ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au)

e) The adequacy of, and interaction between the State Government and Commonwealth services to meet the needs of people with ADHD at all life stages

As previously highlighted, despite the significant amount of reform happening within the NDIS space, this is an area in which people with ADHD and their carers can be better supported if changes are implemented. We highlight and support the Senate Recommendation Eight:

*“The committee recommends the National Disability Insurance Agency improve the accessibility and quality of information around the eligibility of ADHD as a condition under the National Disability Insurance Scheme (NDIS).”*³¹

In addition, we are hopeful that consideration is taken when developing state-based foundational supports, to ensure that there will be affordable and accessible pathways to support for people with ADHD and their carers. There is a significant need for this to occur, which is also reinforced by the Australian Evidence-Based Clinical Practice Guideline stating that *“funding should be made available to expand services for people with ADHD, and to deliver timely and accessible assessment, support and intervention, and an ADHD helpline accessible to all Australians.”*³²

Carers Tasmania highlights Recommendation Nine from the Senate Report:

*“The committee recommends that the Department of Social Services provide ongoing funding for disability advocacy organisations, including ADHD advocacy organisations, to support people with ADHD.”*³³

Recently in Tasmania, several disability support or advocacy organisations have not had their Australian Government funding renewed, despite being providers of important supports that could be accessed both within and outside of the NDIS. This has left gaps in terms of support and advocacy for people with disability within the state, which also impacts carers.

As highlighted by many submissions to the Senate Inquiry, there is no Medicare rebate available for ADHD assessment. We reinforce the need as previously highlighted within this response to accept the Senate Report Recommendation Three on *reviewing the Medicare Benefits Schedule with a view to improving the accessibility of assessment, diagnosis and support services for people with ADHD.*³⁴

³¹ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au)

³² Australasian Evidenced-Based Clinical Guideline for ADHD. [Australian Evidence-Based Clinical Practice Guideline For Attention Deficit Hyperactivity Disorder \(ADHD\) \(aadpa.com.au\)](https://aadpa.com.au)

³³ Commonwealth of Australia. (2023). The Senate. Community Affairs Reference Committee. Assessment and support services for people with ADHD. [Assessment and support services for people with ADHD – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au)

³⁴ Ibid.

f) The social and economic cost of failing to provide adequate and appropriate ADHD services

There are many social and economic costs associated with the failure to provide adequate and appropriate ADHD diagnosis and support. These costs are felt by not only those who have ADHD, but also their carers. Although we refer to national data in this section, we urge careful consideration to be taken on social and economic impacts, also acknowledging that these costs are likely increased with the rising costs of living. The Senate Report illustrates some of these costs on a national level.³⁵

In 2019, the economic and wellbeing costs of ADHD in Australia were estimated to be \$20 billion annually.³⁶ In addition to this, the *Caring Costs Us Report*, which was commissioned by the Carers Australia Network of State and Territory organisations, found that on average, for every year a person is a primary carer, they will lose \$39,600 in employment earnings and \$17,700 in superannuation. Furthermore, by the age of 67, these carers would have on average lost \$392,500 in employment income and \$175,000 in superannuation.³⁷ Whilst this report doesn't specifically focus on carers of people with ADHD, carers supporting someone with ADHD are covered under the broad banner of these carers.

The findings of these reports, for both people with ADHD and their carers, illustrates the significant social and economic costs associated with ADHD. As it is unclear how many people in Tasmania have ADHD, it is difficult to determine the total and current economic and social costs of ADHD in Tasmania.

Carers of people with ADHD experience significant financial impacts associated with their caring role. Caring for someone with ADHD can limit their capacity to participate in paid employment or education to further their employment. Carers of people with ADHD are also likely to incur additional costs associated with assessment and support for ADHD. Half of the carers of people with ADHD who responded to the 2022 National Carer Survey reported they had additional expenses related to providing care, compared to less than 30% of other carer respondents.³⁸ As previously highlighted, there is also a significant cost socially for carers of people with ADHD due to real or perceived stigma, misunderstanding, judgement, isolation and limited time.

g) Any other related matters

As mentioned already, a large proportion of people who have ADHD also live with other comorbid conditions. Carers Tasmania hears feedback from parents of children who have both ADHD and Autism (sometimes referred to as AuDHD)³⁹ and the significant concerns they raise about the lack of education and awareness within services and the education system as to how these two diagnoses relate. Both conditions need to be supported simultaneously, and person-centred approaches must be taken.

³⁵ Ibid.

³⁶ Deloitte Access Economics. (2019). The social and economic costs of ADHD in Australia. <https://www.deloitte.com/content/dam/assets-zone1/au/en/docs/services/economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf>

³⁷ <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>

³⁸ Carers NSW (2022). National Carer Survey 2022, Unpublished data.

³⁹ Embrace Autism. (2024). [An introduction to AuDHD | Embrace Autism \(embrace-autism.com\)](https://embrace-autism.com)

Due to the differences in diagnosis and support access, especially within the NDIS and Medicare, supports provided may be siloed. A holistic approach must be taken, and there must be adequate and sustainable resourcing to support this approach.

This is being recognised in some states, with the ACT in the process of discussing the possibility of developing an ACT Neurodiverse Strategy and supports.^{40,41} Given this and the high correlation between ADHD and Autism, the Tasmanian Government could explore the possibility of developing a joint strategy to support Tasmanians with ADHD and/or Autism. This strategy should outline a plan to support services, community, healthcare, and education settings to better understand and respond to the needs of people with ADHD (and Autism if relevant) and their carers.

It must include a strong focus on education and awareness raising, stigma reduction, and building an inclusive society with accessible supports, rather than expecting everyone to fit into programs designed for neurotypical people.

5. Conclusion

Carers Tasmania thanks the Tasmanian Government for providing an opportunity to respond to the Tasmanian Parliamentary B Inquiry into ADHD assessment and supports in Tasmania. We are hopeful that the findings of this Inquiry will build on the findings and recommendations from the 2023 Australian Government Senate Inquiry into ADHD.

Carers Tasmania supports the recommendations from the 2023 Senate Report and are hopeful that the Australian Government can work together with state and territory governments to develop relevant plans to advance the ability for people with ADHD to obtain diagnosis earlier, through an easier process, so that people with ADHD and their carers can access adequate support. Any developments must ensure authentic co-design with people who have ADHD and their carers and must be underpinned by the principles of the United Nations Convention on Persons with Disabilities.⁴²

By improving access to diagnosis and supports for people with ADHD in Tasmania, carers of people with ADHD will also be better supported. This will assist carers to maintain their own wellbeing, employment, education, social inclusion and financial stability. We hope a sustainable and collaborative approach can be agreed to ensure that people with ADHD and their carers are not disadvantaged by barriers to accessing diagnosis and supports.

⁴⁰ [ACT Neurodiversity Strategy \(michaelpettersson.com.au\)](https://michaelpettersson.com.au)

⁴¹ [ACT Greens propose establishing free centre for neurodivergence as part disability pride platform | Riotact \(the-riotact.com\)](https://the-riotact.com)

⁴² United Nations. (2006). Convention on the Rights of Persons with Disabilities. OHCHR. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>