Carers Tasmania Submission

on the Australian Government Senate Inquiry

into Assessment and Support Services

for People with ADHD

June 2023

About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 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 80,000 informal carers within the state.

We acknowledge the traditional owners of the lands and waters upon which we work, live, and sustain ourselves. This land was never ceded, and we acknowledge that the Tasmanian Aboriginal people are its continuing custodians. We pay our respects to Elders past and present.

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.

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 are frail or aged. A carer may also be a kinship carer of a child under the age of 18. 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 Commonwealth Carer Gateway program is delivered through Care2Serve, 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 provide feedback on the Australian Government's Senate Inquiry into the assessment and support services available for people with attention deficit hyperactivity disorder (ADHD). Our response addresses aspects of the Terms of Reference (ToR), however, the major focus of our submission is to address that ADHD not only has an impact on the person with the diagnosis, but it also impacts their carers. There wasn't a specific question within the ToR asking about the impact on carers, but we seek for carers to be clearly identified, and their needs and experiences considered alongside other feedback collected throughout this process.

We acknowledge that although not all carers may relate to the term 'carer', providing additional care and support to another person because it is required is distinct from being a family member or friend who is not supporting someone with additional needs. The overwhelming feedback that Carers Tasmania receives highlights that carers want to be recognised, included, and supported, and to not feel invisible. Carers supporting a person with ADHD may certainly be a more hidden cohort of people who have difficulty in accessing adequate support.

Carers Tasmania acknowledges the feedback provided directly from carers that has assisted in informing this submission. We acknowledge the enormous value that can be gained from listening to and sharing, in a safe way, the lived experience voice of carers. This is where important insight often comes from, which is important when considering impact and required change.

In Australia, ADHD is estimated to affect approximately one in every twenty people, which includes both adults and children.[1] Research indicates that the prevalence of ADHD is higher for males than females,[2] which may be due to barriers towards diagnosis for females, as it is quite often masked or goes unnoticed due to differences in presentation and coping mechanisms.[3] ADHD is most frequently diagnosed by psychologists, psychiatrists, and paediatricians, and is classified into the following three categories:

> **Hyperactive-impulsive presentation:** This can include behaviours such as not being able to remain seated in a classroom, being unable to play or take part in activities quietly, talking excessively, difficulties waiting their turn, and often interrupting others
>
> **Inattentive presentation:** This may include behaviours such as not being able to focus on details, not following through on instructions and not seeming to listen when spoken to directly
>
> **Combined presentation**: The person meets some or all of the criteria for both hyperactive-impulsive and inattentive types[4]

[1] https://www.healthdirect.gov.au/attention-deficit-disorder-add-or-adhd#:~:text=Around%201%20in%20every%2020,have%20symptoms%20as%20an%20adult.
[2] https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf
[3] Quinn PO, Madhoo M. A review of attention-deficit/hyperactivity disorder in women and girls: uncovering this hidden diagnosis. Prim Care Companion CNS Disord. 2014;16(3):PCC.13r01596. doi: 10.4088/PCC.13r01596. Epub 2014 Oct 13. PMID: 25317366; PMCID: PMC4195638. Retrieved from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4195638/
[4] Ibid.

ADHD is often comorbid with one or more other conditions,[5] with an estimated 65% of those who have ADHD also presenting with a co-occurring condition.[6] Oppositional defiant disorder (ODD) is the most common comorbidity in children with ADHD with the prevalence ranging between 40% and 60%.[7] Other comorbidities in children with ADHD, sometimes include learning disabilities (dyslexia, dyscalculia, dysgraphia), conduct disorder, anxiety, depression, and speech problems.[8] It has also been found that 28% of people with a diagnosis of Autism also have a diagnosis of ADHD.[9]

3. Feedback on the Terms of Reference (ToR)

Adequacy of access to ADHD diagnosis

In Tasmania, there is overwhelming feedback on the difficulty to access an ADHD diagnosis for both children and adults. There are major workforce issues that have seen the majority of private paediatricians, psychologists, and psychiatrists close their doors to new clients. Assessment is available through the public health system, however, waitlists are even longer for those taking this pathway.

There is currently one specialised ADHD clinic operating in Tasmania, the Hobart ADHD Clinic, and they have temporarily closed their service to new clients due to extreme demand for assessment and other supports. For those currently on their waitlist, the estimated wait time is 12-18 months for both children and adults. In most cases, the assessment costs are quite high and some forms of assessment, especially educational assessments for children that are conducted by psychologists, are not subsidised by Medicare.

Adequacy of support after an ADHD assessment

Having a diagnosis of ADHD does not mean that it's easy to access support. As previously noted, there is currently only one specialised clinic in Tasmania that provides specific support for people with ADHD. 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 the Medicare Benefits Scheme.

Although support can be delivered by psychologists and other allied health professionals, due to workforce issues, it is difficult to access this support. Even more limited is access to appropriate resources for family and friend carers. Some businesses and consulting services provide information sessions and workshops for parents, carers, and other family members, but as there is no financial support available to assist people who aren't in a financial position to pay, therefore people are often not able to access these resources.

It can also be difficult to access medication for ADHD, particularly for those with a recent diagnosis, as Tasmania has strict prescribing regulations. For example, in Tasmania, ADHD medication is prescribed by a psychiatrist or paediatrician, and they must be a prescriber with Tasmanian residency. Many people are not able to access a psychiatrist or

[5] https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf
[6] Holden, S. E., Jenkins-Jones, S., Poole, C. D., Morgan, C. L., Coghill, D., & Currie, C. J. (2013). The prevalence and incidence, resource use and financial costs of treating people with attention deficit/hyperactivity disorder (ADHD) in the United Kingdom (1998 to 2010). Child and adolescent psychiatry and mental health, 7(1), 34
[7] Banaschewski T., Rohde L.A. Phenomenology. In: Banaschewski T., Zuddas A., Asherson P., Buitelaar J., Coghill D., Danckaerts M., et al., editors. ADHD and Hyperkinetic Disorder. 2nd ed. Oxford: Oxford University Press; 2015. p. 5 -17
[8] Larson, K., Russ, S. A., Kahn, R. S., & Halfon, N. (2011). Patterns of comorbidity, functioning, and service use for US children with ADHD, 2007. Pediatrics, 127;462
[9] Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a populationderived sample. Journal of the American Academy of Child & Adolescent Psychiatry, 47(8), 921-929

paediatrician in Tasmania, and although these services can be accessed interstate and via telehealth, prescriptions from health professionals residing outside the state are not valid for dispensing in Tasmania. This is an issue that has recently been reported on by the ABC.[10]

The latter part of this submission touches more directly on how the NDIS could support people with ADHD, but currently, if the person does not have a diagnosis of a comorbid condition, they are currently not supported under the scheme, although it could be argued that ADHD is a lifelong condition that has the potential to significantly impact many areas of a person's life.

People who have ADHD often go without other wrap-around supports that may be available such as behavioural therapy, (which has been shown to be an effective early intervention support), as it is simply unaffordable. Often behavioural support can be covered under the scope of NDIS plans, but for people with only a diagnosis of ADHD, they would not be deemed eligible for NDIS, therefore they would be required to pay full fee to access this support. The prices for support such as behavioural therapy plans, behavioural management strategies, and specialist behavioural intervention support are usually charged privately at the NDIS rates, which for Tasmania the price ranges from $193.99 to 234.83 per hour.[11] The cost also increases with remoteness.

Behavioural therapy, as well as coaching are often valuable resources for parents and other carers as it can equip them with additional skills and understanding specific to ADHD to help support the needs of the person they care for. Some people may be able to obtain a Chronic Disease Management plan through their GP which provides a Medicare rebate for some services such as occupational therapy, but as previously mentioned there is a shortage of allied health professionals available within Tasmania, and whilst telehealth is an option, it is not appropriate for everyone. To access this type of plan, a person must also be able to access a GP to create the plan, which is currently another huge issue in Tasmania.

If the person is also accessing medication for their ADHD, particularly in the case of children, their parent or carer may be further out of pocket. places a greater level of emotional and financial stress on the carer if they are responsible for funding this.

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

The social and economic costs of failing to provide adequate and appropriate ADHD services are significant and alarming. Deloitte Access Economics reported that in Australia, the social and economic costs of ADHD in 2019 were estimated to cost $20.42 billion, which equates to $25,071 per person with ADHD.[12] This included costs to the health system, education, crime and justice, productivity, and wellbeing. Overall, the report found that ADHD imposed significant economic and wellbeing costs to the Australian population. Despite being from 2019, this particular report provides a significant baseline level of research that answers many questions posed in the ToR. It would be interesting to observe more up-to-date findings based on the structure of this report.

The report also touches on the cost to informal carers of someone who has ADHD. It estimated that in 2019, the cost to informal carers, of people with ADHD in Australia in 2019

[10] https://www.abc.net.au/news/2023-04-24/adhd-diagnosis-and-treatment-difficult-to-access/102233340

[11] file:///C:/Users/JulieRyanCare2Serve%E2%80%93/Downloads/PB%20NDIS%20Pricing%20Arrangements%20and%20Price%20Limits%202022-23%20pdf.pdf

[12] https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf

was $210.4 million. We highlight that there are limitations around this estimate because to estimate the proportion of people with ADHD receiving support from an informal carer, it was assumed only children and adolescents who used health services (63% of children aged 6-8 years, which was applied to all children and adolescents due to a lack of evidence) would have received informal care from a carer. It was assumed that no adults received support from a carer to try and balance the effect of the children who did not have ADHD.[13]

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.[14] Whilst this report doesn't specifically focus on carers of people with ADHD, primary carers supporting someone with ADHD are covered under the broad banner of these carers.

The NDIS and supporting people with ADHD

Currently, a diagnosis of ADHD on its own is not an eligible condition covered by the NDIS, despite the challenges it can cause for a person across many areas of life, but it can sometimes be supported if the person does have another eligible co-morbid condition which is their primary disability.

ADHD can create a number of challenges that can be caused by an impairment as listed under the NDIS disability requirements. For example, NDIA literature states:

> *"When we consider your disability, we think about whether any reduction or loss in your ability to do things, across all life domains, is because of an impairment.*
>
> *An impairment is a loss or significant change in at least one of:*
>
> - *your body's functions*
> - *your body structure*
> - *how you think and learn*
>
> *To meet the disability requirements, we must have evidence your disability is caused by at least one of the impairments below:*
>
> - *intellectual – such as how you speak and listen, read and write, solve problems, and process and remember information*
> - *cognitive – such as how you think, learn new things, use judgment to make decisions, and pay attention*
> - *neurological – such as how your body functions*
> - *sensory – such as how you see or hear*
> - *physical – such as the ability to move parts of your body"*[15]

Furthermore, although ADHD is considered to be a neurodevelopmental disorder, it can have significant impacts on the life domains that are required to have a proven impact upon to be eligible to receive support under the psychosocial disability eligibility criteria.

[13] https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-social-costs-adhd-australia-270819.pdf
[14] https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf
[15] https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/do-you-meet-disability-requirements#permanent

Having access to NDIS support would be a way to more equitably assist people with ADHD to increase their functional capacity, independence, ability to work, study and participate in social life, which are aims of the NDIS.[16] By not including ADHD as an eligible diagnosis, discrimination towards this cohort will remain, as the cost of support is currently an enormous barrier to accessing available support.

We also highlight that many people who care for someone with ADHD have told us that they believe medication is not appropriate for every person who has ADHD and that they believe requiring people to have tried all of the 'available medical interventions' to meet NDIS eligibility requirements can, in fact, be harmful and cause physical issues, along with mental and emotional distress. Medication is not appropriate for everyone, nor is it appropriate to enforce this. This is something that carers strongly feel must be appropriately addressed if ADHD becomes an eligible diagnosis under the NDIS.

Caring for someone who has ADHD

Proving care to someone with ADHD can be both challenging and rewarding. Some of the additional things that are often required by a carer in these circumstances include:

- Carrying an additional 'mental load' by needing to be extra organised, especially when planning days and scheduling appointments
- Sometimes additional cleaning support is required
- Reminding and prompting for certain tasks
- Emotional, behavioural, and regulatory support
- Supporting the person to manage their finances
- Accompanying the person to appointments
- Children may be more prone to being sent home from school, or refuse to attend school
- Advocacy, especially at school
- Preparation of different foods, or being extra cautious about the types of food or food additives
- Support to help the person stay on track with tasks
- Support for the often-co-morbid conditions that occur such as OCD, pathological demand avoidance, autism, anxiety, depression, learning disabilities
- Provision of social support and stimulation

How does this impact carers?

- If caring for a child, there is often a large amount of stress about how they are coping at school, or if the school is going to call and ask for the child to be picked up
- Missing time away from employment due to appointments, or a child needing to be picked up from school
- Emotional impacts such as stress, frustration, and confusion
- Financial difficulty or distress
- Social isolation and lack of time for self
- Poor health, lack of sleep, and tiredness

[16] https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/do-you-meet-disability-requirements

The following comments are provided with consent from several carers that we consulted with to inform this submission. We hope that these can illustrate what life can be like caring for different people with ADHD. We acknowledge that all situations are different, and we seek for all carers in this cohort to be better recognised and supported.

"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."

"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."

"My son really wants to be at school, but he is 'in the too-hard basket'. He is only 7 and had both Autism and ADHD and the school just don't have the skills and resources to support him. He is frequently sent home and even suspended, suspended at the age of 7! He really wants to be there and he deserves that opportunity. This is seriously affecting my mental health, I feel belittled, powerless, and so anxious. Not to mention how my son feels."

"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 learn skills to help them as well."

Nobody ever asked me, throughout any of the diagnosis process, or through accessing NDIS support what I needed as a carer. I'd love to have specialised tutoring for my son and even though it could probably be funded under his NDIS plan, I haven't been able to find anyone to provide the specialised tutoring he needs. I can't find tutoring for children who have dyslexia, dyscalculia, dysgraphia, and ADHD. The tutoring available is mostly suited to neurotypical children. This support could be so valuable in keeping my child engaged and doing well at school, so he has a better chance of opportunity as a teenager and adult."

"I'm a Mum of children aged 6 and 10 who both have ADHD. At school, in kinder and prep the teachers just brushed off my concerns saying that my child will grow out of it. Then after diagnosis, the school said there is nothing we can do. The ADHD is not supported by the NDIS.

There's a lot of eye-rolling from other parents at the park, pool, or shops when my children are running around, shouting and being impulsive as others assume by their age they should act otherwise. It can be a lonely journey as it's hard to find an understanding village.

As for community access, my 10 year old son got a complaint recently at football for shouting bad things at another child. It happens all the time between school and community activities. I feel like I'm forever apologising and explaining. He does not attend any community without an adult. So that's no playdates without parents, no social community activities without parents. It's hard to understand how tiring and non-stop it is unless you live with an ADHD child. They are so full of energy and creativity and so misunderstood by most."

"I'm in my 60s and my Husband, my daughter, three sons and 5 grandchildren all have ADHD. To be honest, the biggest thing that helped me survive was when my GP told my husband, when I was at breaking point many years ago that I should for at least one weekend every 6 months take a break and get away. We were able to afford it, and my husband agreed with this idea. Every time I came back it was complete chaos, but I really needed that time to recharge and make sure I was ok so that I could continue caring.

I home-schooled my children at various stages, because back then I was able to. It's not that easy these days with cost-of-living pressures. There needs to be more support for children who have ADHD and their families. These are the children who will be our future leaders, they'll be looking after us, and some even maybe running the country. There are more children now than ever before with ADHD. There must be better resources, especially within the education system. Within these resources, lived experience and a true understanding is just so important. Children with ADHD sometimes just need extra time, more moral support and mentoring, and creative and adaptive methods to support how they will learn best."

"My son is fifteen, I can't force him to take his meds or to go to school. People just don't understand that. All I can do is encourage him and be there for him and hope that he does the things that will help."

4. Future directions

We hope that this inquiry will influence the development of recommendations relevant to better support people in Australia who have ADHD, but we also seek for the recommendations to be explicitly inclusive of the needs of carers who support people with ADHD.

It is evident that there are significant workforce issues that must be addressed so that people can access appropriate, timely, and affordable diagnosis and support for ADHD. We strongly encourage consideration to be taken on whether ADHD should be included under the provisions of the NDIS and that barriers to accessing assessment, services, and treatments such as medication are reviewed.

A strong focus on further research would assist in developing a better understanding of the prevalence, experiences, and impact of ADHD on people who have ADHD, their families, and carers, and we acknowledge the importance of embedding lived experience into this.

We also highlight that a strong focus on education with an aim to reduce stigma and increase the understanding of ADHD for professionals and the wider community is needed.