

# Response to Australian Government Senate Standing Committee on Community Affairs Inquiry into Assessment and Support Services for People with ADHD

9 June 2023

Carers Australia welcomes the opportunity to respond to the Australian Government Senate Standing Committee on Community Affairs [Inquiry into the Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder \(ADHD\) and support services for people with ADHD.](#)

Adequate access to attention deficit hyperactivity disorder (ADHD) assessments and support services is of great importance to not only the estimated 1 million Australians who have been diagnosed with ADHD, but also to those facing barriers in accessing a diagnosis, and the carers<sup>1</sup> of those navigating the system. Excessive wait times, high out-of-pocket costs, lack of available practitioners, prejudice in assessments and the absence of necessary supports are a few of the issues facing Australian's who interact with the health system as a result of ADHD. The impact of these issues is far reaching and can be detrimental to the lives of people with ADHD, their families and their carers.

Carers Australia represents the 2.65 million people who provide unpaid care and support to family members and friends who have a disability, mental ill health, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. For many of these carers the individual they provide care for has ADHD as a primary or secondary disability, or they themselves have it. As such, this inquiry, and subsequent efforts to improve the coordination and delivery of ADHD support and services is significant.

The [Carer Recognition Act 2010](#) (Cth) aims to increase recognition and awareness of carers and acknowledge the valuable contribution they make to society. The cornerstone of the Act is the Statement for Australia's Carers which sets out ten principles that articulate how carers should be treated and considered, including:

- The relationship between carers and the persons for whom they care should be recognised and respected, and
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

Our primary focus for this response is to ensure accessible and inclusive access to ADHD assessment, diagnosis and support services for both people with ADHD and their carers. Our response will discuss three key issues pertinent to many of the carers we represent:

- Accessibility, cost, and prejudice as barriers to assessment, diagnosis, and support
- Absence of coordination and accountability for ADHD within Commonwealth government
- The integral role of carers in ADHD management and support

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<sup>1</sup> Carers Australia uses the term 'carer' as defined by the Commonwealth [Carer Recognition Act 2010](#) (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

## The current state of ADHD assessment, diagnosis and support, and its impact on carers

The publication of the [Australian Evidence-Based Clinical Practice Guideline for ADHD](#) alongside other new research and guidance in relation to ADHD has highlighted the seemingly increasing inaccessibility and inefficiency of current system interactions and clinical practice regarding ADHD.

When exploring and examining the interactions that exist currently when accessing support or services for ADHD, it is necessary to assess the impact of these interactions not only on individuals with ADHD but all their informal supports and carers throughout this process. As 'partners in care', carers are often involved in, or coordinating, the management of diagnosis, assessment and treatment associated with ADHD and this has become increasingly evident.

### Accessibility

The absence of qualified practitioners coupled with excessive wait times is an additional barrier that many have reported. This inaccessibility is making it hard for individuals to obtain diagnosis or adequately manage their symptoms which in turn, make it harder to stay on top of other things within their lives such as employment, personal wellbeing, relationships, or families.

The 2022 Carer Wellbeing Survey found that the largest barriers experienced by all carers when seeking access to services for the care recipient related to the accessibility of service delivery. Amongst the most reported barriers were difficulty finding high quality services (69.3%), long waiting times to access services (66.9%), lack of local service availability (64.0%), difficulty affording services (64.2%), and poor coordination between services (61.9%).<sup>2</sup> Feedback provided to Carers Australia from the National Carer Network, gives us reason to believe these barriers are also experienced by carers of people with ADHD. We have been made aware of ADHD assessment wait times for new patients were 12-18 months long and, in some instances, even being waitlisted was denied due to extreme demand.

It must be understood that these delays and barriers in accessing support have widespread impacts for individuals seeking services and their carers. Not only does it delay necessary support needed to maintain or improve their quality of life, but the barriers can also adversely impact the financial and employment outcomes for carers. The 2022 Carer Wellbeing Survey revealed that of those carers who were working or who wanted to be in paid work, 44.8% were doing less paid work than desired, compared to only 23.1% of Australians more generally. Of the carers who reported less paid work than desired 70.8% also reported poor wellbeing.<sup>3</sup>

*"It's all too much. I have my own physical and mental disabilities and injuries that I have no help with, including ADHD, while needing to provide care for other people. I am on robot mode, my mental health has plummeted, my skills and masking abilities are deteriorating, and I'm experiencing more shutdowns than ever before in my life. This is not sustainable." – Carer Wellbeing Survey 2022 respondent*

**Carers Australia urges the Committee to recognise that 'adequate access' to diagnosis services or ADHD supports, cannot be achieved without recognition of the integral role carers and informal supports have in the facilitation and management of this access.**

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<sup>2</sup> The 2022 Carer Wellbeing Survey - a collaboration between Carers Australia and University of Canberra, and funded by the Australian Department of Social Services [\[accessed online\]](#)

<sup>3</sup> Ibid.

## Cost

In developing the newly published guideline for ADHD, Deloitte Access Economics was commissioned to estimate the socioeconomic cost of ADHD in Australia. The findings demonstrate not only the burden ADHD has on the healthcare system and individuals' quality of life, but also the associated productivity and financial costs for both individuals and carers.

The total productivity cost of ADHD was estimated to be \$10.19 billion in 2019, of which, informal carer costs were estimated to make up \$210.4 million.<sup>4</sup> For informal carers, costs were attributed to time forfeited to undertake caring responsibilities that could have been spent on paid work or undertaking leisure time activities.

It is also important to note that for most carers' decreased productivity and its associated costs such as limited employment opportunities and outcomes, are not the only impact. Many carers report having to cover the costs of medication and health services for the person they care for. The 2020 National Carer Survey found that a key contributing factor to carer financial distress is expenditure on the costs of care. Almost two thirds of carers reported contributing financially to the costs of medicine for the person they cared for, with half contributing to their transport costs. Just over one in five (22.2%) carers did not incur any additional costs relating to their caring role.<sup>5</sup> For carers of children or young people this becomes increasingly relevant. As the prevalence of ADHD is highest during childhood, it is only logical that those incurring the financial costs of assessment, diagnosis and management of ADHD are carers or family members.

**Limited availability of mainstream services throughout the public health system only increases the financial costs borne by individuals and carers.** Many carers and families are forced to seek a formal assessment privately, in which they are still facing extensive wait times but are also faced with high out-of-pocket costs. This only becomes more impactful when these costs are in addition to those required to manage other disabilities or mental ill health, such as developmental delay or behavioral issues.

## Prejudice

Unfortunately, the barriers to adequate access and support are not limited to availability of services, instead for many people who manage to undergo assessment or treatment, they face prejudice and bias in achieving or maintaining care.

Feedback provided to Carers Australia by the National Carer Network identified several instances where behavioural issues experienced by a child were dismissed, as they were assumed to be in response to environmental factors such as disability or mental ill health of the carer. One carer shared their experience caring for their child who had been labelled as having substantial behavioural difficulties from toddler age onwards. She was regularly told that the issues were due to environmental issues related to the carer's (and mother of the child) mental ill health. This stigma stuck around for several years until she could finally afford to see a child psychologist, with the hope of getting support and intervention guidance. After being a patient for two years with minimal improvement, the psychologist suggested further exploration. However, they were told formal assessments through the public system were a two-year wait. After making the decision to cover the high out-of-pocket cost for a private assessment, the child finally received a diagnosis and is now managing their ADHD with both medication and non-pharmaceutical interventions.

*"A wasted 7 years that brought struggle to my family unit, made the life miserable for my child and further aggravated my mental illness." – Carer and mother of child*

<sup>4</sup> Deloitte Access Economics, *The social and economic costs of ADHD in Australia* (2019), [\[accessed online\]](#).

<sup>5</sup> Carers NSW, *2020 National Carer Survey* (2020), [\[accessed online\]](#)

The reality is this is not an uncommon occurrence. Data from the 2018 Survey of Disability, Ageing and Carers found that over one-third of primary carers (those providing the most amount of care) also live with disability, this is over twice the rate of non-carers.<sup>6</sup> For some of these carers who provide care for a family member their diagnosis can often limit the assessments of their children, delay adequate treatment and support and negatively impact the wellbeing outcomes of the individual with ADHD, their carers and the broader family unit.

These negative impacts on carers are clearly evident in research. Findings from 2022 Carer Wellbeing Survey remained consistent with previous years in reporting that carers are three times less likely to have high levels of wellbeing compared to the average Australian. More so, wellbeing was poorer amongst carers who were unemployed, caring for children or grandchildren, caring for multiple people, providing more than 40 hours of caring a week, and those caring for a person with autism spectrum disorder, drug/alcohol dependency, or mental illness/psychosocial disability.<sup>7</sup>

For individuals, carers and families who face prejudice that impacts the ADHD assessment or service provision, they are forced to incur additional stress, financial burden and illbeing as their needs cannot be otherwise met. These instances can lead to or increase existing mental ill health and impact the outcomes of all individuals involved – most prominently, the individual with ADHD. Effective management, including access to medication and support services for both individuals and their carers, can drastically improve individual wellbeing. However, **efforts to address prejudice in early diagnosis and treatment must be addressed. Without this, we strip individuals with ADHD of their right to fulfil their potential which can result in an increased reliance on care and health services.**

## Lack of accountability for ADHD

In assessing the adequacy of, and interaction between, Commonwealth, state and local government services in meeting the needs of people with ADHD at all life stages, Carers Australia is dismayed by the absence of accountability and coordination within government to address its impacts.

Despite it being the most common neurodevelopmental disorder, affecting over 800,00 Australians, and the estimated \$20.42 billion in social and economic costs that burden all Australians<sup>8</sup>, there has been minimal effort to recognise or support those who suffer most. The [National Children's Mental Health and Wellbeing Strategy](#) successfully recognises ADHD and the need for collaborative care as a preventative and management measure, yet most other national strategies neglect it. In fact, there is no mention of ADHD within the [National Mental Health and Suicide Prevention Strategy](#), [Australian Disability Strategy](#), [National Preventative Health Strategy](#) or [National Action Plan for the Health of Children and Young People](#).

Treatment and service options for people with ADHD are extremely limited within the public health system, and of those available most require you to have received a diagnosis. As highlighted earlier, various accessibility issues exist in accessing services for ADHD and these issues, coupled with widespread increases to health care across the system, increase demand for mental health services<sup>9</sup>, and general cost of living pressures, people are reporting having pay between \$200 and \$500 to receive an ADHD diagnosis<sup>10</sup>.

<sup>6</sup> Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, (2018). [\[accessed online\]](#)

<sup>7</sup> *Op.cit*(2)

<sup>8</sup> *Op.cit*(4)

<sup>9</sup> Australian Government, *Strengthening Medicare Taskforce Report* (2022). [\[accessed online\]](#).

<sup>10</sup> Australian Broadcast Corporation, *ADHD clinics capitalise on diagnosis explosion, with some charging up to \$3,000 and paying doctors up to \$900,000 a year* (2023). [\[accessed online\]](#).

The Australian Government's funding for a new clinical practice guideline for ADHD in 2022 was a welcomed step in the right direction.<sup>11</sup> However, **Carers Australia urges government to embed access to diagnosis and supports for individuals with ADHD, their families and their carers into broader system policy to ensure accountability and coordination across Commonwealth, state and local government.**

## **Moving forward – acknowledging the role of informal supports in ADHD management**

In the Committee's assessment of the Inquiry topic and development of recommendations, specifically how they relate to the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD, Carers Australia strongly supports the considerations for Parent/family training that have been included within the guideline.

We highlight two principal recommendations that came out of the guidelines evidence review:

1. Parent/family training should be offered to parents/carers/families of children and adolescents with ADHD, and
2. Any parent/family training interventions should be specific to the needs of the person with ADHD and their parents/carers/families, be strengths-based, and foster hope and personal empowerment.<sup>12</sup>

It has become increasingly evident that early identification of people with ADHD is needed to allow for intervention to occur as early in life as possible to reduce impacts on functioning and maximise positive outcomes. Although this belief is consistent amongst health care professionals, community organisations and government policy, there is still a distinct lack of support for a key cohort of stakeholders that are a requirement to enable early intervention – carers.

Increased focus on the early years and the role of both prevention and intervention in childhood is needed to adequately address many of the health issues facing Australian children. However, despite clear messaging within the National Action Plan for the health of children and young people, the Australian Disability Strategy, and several of Carers Australia's submissions<sup>13</sup>, very little has been done to adequately support carers, parents, and families to maximise healthy development.

**Thus, Carers Australia recommends that all measures recommended by the Committee to improve access and adequacy of ADHD diagnosis and services, explicitly recognise the role carers play in ADHD treatment, managing and individual support.**

**This recognition should be coupled with increased, equitable access to support services specifically for carers.**

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<sup>11</sup> Australian Government Department of Health and Aged Care, *Better diagnosis, treatment and care for ADHD* (2022), [\[accessed online\]](#).

<sup>12</sup> Australian Professionals Association, *Australian evidence-based clinical practice guideline for ADHD* (2023), [\[accessed online\]](#).

<sup>13</sup> Carers Australia, [Response to Australian Government Early Years Strategy Discussion Paper](#) (2023), [Response to Australian Government Inquiry into School Refusal and related matters](#) (2023), [Submission to Australian Government Inquiry into Work and Care](#) (2022).

## About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

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