

SUBMISSION

Assessment and support services for people with ADHD

Submission Title:	Assessment and support services for people with ADHD
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CARERS QUEENSLAND

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship, or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with disability, people who identify as culturally and linguistically diverse, First Nations Australians, people with diverse bodies, genders, relationships, and sexualities and those living in rural and remote Queensland provide care to family members or friends daily. For some caring is a short-term commitment whilst for others, it is a role that literally lasts a lifetime.

Family and friend carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged. Carers come from all walks of life.

Carers Queensland is the peak body representing the diverse concerns, needs and interests of caring families in Queensland. Carers Queensland believes that all carers regardless of their age, disability, gender or gender expression, sexual orientation, religion, socioeconomic status, geographical location, or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment, and education like other citizens. Carers Queensland's mission is to improve the quality of life of all carers throughout Queensland.

We aspire to provide an independent platform from which to advance the issues and concerns of the 533,200 carers in Queensland and believe our knowledge and expertise in carer issues means we can provide the Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected, and acted on.

Our submission is informed by national and international peer reviewed data, our own experience as a service provider and the personal and often difficult admissions of carers, those people who provide unpaid care and support.

Introduction

ADHD is a common condition in both children and adults, and has a significant, often limiting impact, on their daily lives. The lack of available and accessible assessments, supports and treatments has a significant impact on the entire family and has several repercussions for family unity and wellbeing, individual wellbeing, and financial and employment pressures and success.

Carers Queensland believes more education for medical and education professionals and the wider community is required to effectively ensure the social inclusion of individuals with ADHD fully into our society, enabling them to be engaged economically and socially active citizens.

Discussion

Diagnosis

The assessment process for an ADHD diagnosis can be expensive, challenging and disheartening for many families. Parents and carers seeking a clinical assessment and diagnosis for their child, have told Carers Queensland of being unable to access an assessment by an appropriately qualified practitioner in the public healthcare system, for 12 months or more in metropolitan areas and 18 months or more in regional Queensland. This leaves many families with two, often untenable options - to wait for an assessment or to access private healthcare professionals.

An assessment purchased from a private provider can range from \$1200 to \$4000 which is prohibitive¹ for many caring families. In desperation some caring families are being pushed into financial stress to gain access to a diagnosis and appropriate treatments. Caring families on public healthcare waiting lists, often find themselves being priced out of an ADHD assessment with out-of-pocket costs ranging from \$500-\$2000. This is only made worse in regional areas, where families often have to travel to urban areas in order to access the appropriate professional, increasing out of pocket costs for accommodation, petrol, time off work etc. We believe that every child and adult in Queensland with suspected ADHD should be able to access a clinical assessment without incurring significant financial penalties.

Prior to assessment and diagnosis, there is a need for education for medical and educational professionals in the full range of ADHD symptoms and how these present and impact on each gender. The widely recognised symptoms of ADHD are from a male perspective and as such the female presentation is not widely understood nor recognised. ²Girls are far less likely to receive an ADHD diagnosis and instead be mis-diagnosed or have their symptoms reduced to simply 'problems at home.' One carer we have spoken with advised that when seeking an ADHD assessment for her daughter, who displays multiple symptoms and has immediate family members already diagnosed with ADHD, several General Practitioners refused to provide a referral and stated that her daughter is just simply an emotional girl. This family, is therefore, left with no advice or supports to care for their daughter.

Unlike the (usually) more hyperactive and impulsive behaviour of boys diagnosed with ADHD, girls present with ADHD with much more subtle symptoms which are often overlooked, meaning that these

¹ ACOSS data suggests that those population groups facing the highest risks of poverty in 2019-2020 included people in households relying on income support payments including the Disability Support Pension and Carer Payment, sole parent families and households where the primary income earner is of working age and not workforce connected. Accessed from: <https://povertyandinequality.acoss.org.au/poverty-in-australia-2023-who-is-affected/>

² *Under-diagnosed and under treated, girls with ADHD face distinct risks*, The Knowable Magazine, 2020

girls are not assessed nor treated for their condition. This has a severe ramification for that child both in the immediate and long term. Not only does that mean that girls, and their families, are not receiving the correct, if any, treatment, or support, they are also growing up without an understanding of themselves. Children who grow up without an understanding or knowledge of their ADHD are more likely to internalise their behaviour, leading to feelings of worthlessness and other mental health conditions (e.g., depression, anxiety etc.). The lack of diagnosis has a long-lasting impact upon the child but also upon the family who are unable to access any supports or funding to support their child and the family relationships. Better health and educational practitioner education about the female experience of this condition will result in timely assessment and access to appropriate treatments, facilitating better outcomes for the individual including long-term wellness of girls with ADHD.

The first step following a diagnosis is securing the correct and effective treatment is an emotionally and financially costly endeavour. Medication is usually the first form of treatment for ADHD, potentially coupled with therapy to be able to learn appropriate coping techniques. There are a multitude of blockages individuals are encountering in this journey. Firstly, the required ongoing medical appointments to receive prescriptions is financially burdensome. This, combined with the cost of medication, is a significant barrier for many. Families with one person diagnosed with ADHD are spending upwards of \$100 per month for prescription medication. This is unaffordable and is leading to the decision to ration medication for some. We have had reports from families who have decided to not medicate their child over the weekend due to the exorbitant cost, leading to significant pressures and stress within the family when dealing with the unmedicated child's ADHD symptoms.

Due to the hereditary nature of ADHD and the increase of awareness of the condition, many adults are now seeking diagnosis. In seeking treatment, adults are experiencing long wait times for an appropriate clinical professional, disbelief from the medical professional and suspicion about their motives behind requesting a diagnosis and treatment. Adults with ADHD have told us that they felt like they were committing a wrongdoing by requesting treatment for their condition. Adults have reported feeling stigmatised by pharmacists as either an addict or not really needing medication, despite the medication allowing them to maintain full time employment and participate fully in their life. Carers also advised there is a significant stigma within the medical community about the impact of medication, that it will cause an individual to lose their personality. This is concerning, because it actively stigmatises prescription medication and will result in some individuals choosing not to take it based on fear, despite requiring the medication to fully function. Effective medical treatment is predicated on treating practitioners being fully informed about the disorder, its manifestations and potential impact on the individual and their networks including learning institutions and employers. For families with multiple members diagnosed with ADHD the cost of pharmaceutical treatment is prohibitive.

Once an assessment and diagnosis has been obtained, there are no specific supports for families caring for a loved one with ADHD. Often, the only source of support and advice families can access is informal peer support. One family has informed us that their child was diagnosed over five years ago, and they have been unable to find any support for themselves. While other families have been advised by medical practitioners to take a Triple P Parenting class as their only form of support. This advice is not appropriate nor is it supportive of the caring family who require locally based supports in place to enable them to appropriately respond to the needs of their family. The lack of supports and resources for families can further lead to relationship strain, stress, and emotional turmoil.

Education

Education is a particularly complex issue for children with ADHD. Following from the assessment and diagnosis process, schools are not equipped to adequately support and effectively educate these children. Children with ADHD and other co-morbid conditions can engage in behaviours which are deemed to be unacceptable by schools. Carers have reported to us that they will receive several calls per week to collect their child early because they have been removed from the classroom or are only allowed to attend for a limited number of hours. In some cases, parents have been advised by their child's school to always be within a fifteen-minute radius so they can collect their child with very little notice. Families have requested adjustments for their children, such as teacher aides, movement breaks etc and they have all been refused with schools stating that they do not receive funding for ADHD supports. Not only does this mean that the child is missing out on social and academic outcomes and achievements, it is also untenable for the family who are potentially being pushed into financial difficulty as they are regularly required to leave work to attend to their child or disengage from the workforce, having a detrimental impact on the social and emotional wellbeing of the family.

The system has become so unmanageable for some families they have chosen to home-school their child. The consistent removal from the classroom effectively becomes a punishment for the child for behaviour they can neither understand nor control, furthering them from the experiences of their peers and potentially damaging their ability to create connections as they move from childhood into adulthood.

The inability of the education system to provide adequate supports for children with ADHD is not new. We have heard several reports from adults with ADHD that they had a similar experience in schools. Ranging from a lack of supports, being labelled as difficult or lazy, being isolated and segregated from their peers, has all had a detrimental impact not only on educational achievements, but also mental health. School experiences were so bad for some, the very thought of continuing their education causes too much stress and anxiety to be a realistic option, therefore limiting their educational outcomes and future carer advancement. It is essential that the education system develops effective long-term strategies to enable children to remain in school, learning alongside their peers, with adequate supports in place.

Transitioning into Adulthood

The lack of available assessments, diagnosis, and support services for adults with ADHD has a severely detrimental impact on the emotional wellbeing, social and financial participation of the individual. Securing and maintaining employment can be difficult for those diagnosed with ADHD as workplaces may not have a robust understanding of the condition or know how to adequately support employees in managing their work in line with any reasonable adjustments. Many individuals with this condition have relied on the kindness of their work colleagues to assist and support them to fulfil their employment responsibilities rather than formal reasonable adjustments. Furthermore, due to societal attitudes towards neurodiversity, many feel unable to inform their employer of their condition due to the fear of stigma and discrimination, leaving them without support in the workplace. When this is combined with a later in life diagnosis, or a restricted education as a child, this engenders a greater dependency between the individual with ADHD and their family who are providing emotional and financial support, which potentially creates a further strain on family dynamics. It is essential there is greater education and support made available for adults with ADHD. Community awareness, education and acceptance are essential to enable the full participation of all individuals in our society.

Recommendation

Carers Queensland makes several recommendations:

- ADHD assessments should not be only for those with financial means. More affordable and accessible options must be made available through the Medicare rebate system.
- Greater education into the symptoms and different presentations of ADHD for educational, medical professionals and support services to ensure all genders are being given the correct and adequate diagnosis and treatment. Community awareness, understanding and acceptance is essential.
- Children with ADHD deserve the same access to education as their peers. More supports in the education system to keep children in school are essential.
- Increased ADHD support services for individuals with ADHD and their families, enabling families to remain socially connected and thus reducing the number of people who may 'fall through the cracks.'
- Government and support services need to build communities of lived experience to evidence inform policy and program evaluation and future service delivery.