



WACSSO

Partnering with P&Cs to
advance public education

WACSSO SUBMISSION

Senate Inquiry:

*Assessment and support
services for people with*

ADHD

June 2023

Acknowledgments

Acknowledgement of Country

The Western Australian Council of State School Organisations pays respect to First Nations and Traditional Custodians throughout Australia, recognising their connection to land, waters and sky.

We acknowledge parents, families, Elders and communities as sharers of culture and knowledge; and recognise the value this learning holds for children and young people.

Acknowledging Parents

WACSSO acknowledges parents* as the first educators in their child's life. We celebrate and honour the diversity of families and recognise the vital role they play in supporting children and young people throughout their learning journeys.

* WACSSO recognises the term "parent" to also include a child's primary carer.

Who is WACSSO

The Western Australian Council of State School Organisations Inc. (WACSSO) is the peak body representing parents of public school students in Western Australia. For over 100 years, WACSSO has provided services and representation at State and National levels to more than 660 Parents and Citizens Associations (P&Cs). WACSSO is primarily a volunteer organisation made up of a President and State Councillors (representatives) from geographically based electorates. As such, the Organisation has a wide representative reach across the state. WACSSO uses our strong networks with parents, carers and stakeholders in public education to inform our advocacy efforts.

Contact

Pania Turner

WACSSO President

0477 644 000 | president@wacssso.wa.edu.au | PO Box 6295 East Perth, WA 6892

Introduction

In preparing this paper, WACSSO highlights the role of parents, teachers, principals, and health professionals in supporting children with an Attention Deficit Hyperactivity Disorder (ADHD) diagnosis. We also highlight the role of all in supporting those children and young people awaiting formal diagnosis. In most cases, parents and teachers are the first to notice challenges in the school environment for children which may lead to an ADHD diagnosis. Parents are also the first and, in most cases, the strongest advocates for their children as they navigate both diagnosis and treatment for ADHD.

The worldwide pooled prevalence of ADHD is just above 5% (with significant variability) ([The worldwide prevalence of ADHD: a systematic review and meta-regression analysis - PubMed \(nih.gov\)](#)), meaning that on average one child in a class will be diagnosed with ADHD. This prevalence means that the number of children, families and schools navigating treatment and support for this condition is significant and the impact of access to diagnosis, treatment and support for these children is topical and relevant to many.

Our responses consider some of the experiences of public school parents and our affiliates from across WA. WACSSO has chosen to respond to 5 of the 12 Terms of Reference of this Inquiry.

Responses to Terms of Reference

Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD, with particular reference to:

(A) adequacy of access to ADHD diagnosis

ADHD is present from childhood and is usually most identifiable when children start school, meaning this is when diagnosis generally occurs. Parents report that identification of children with ADHD, and an understanding of common behavioural markers, is getting better but support is lagging as is access to specialists who can provide a formal diagnosis.

We have received reports of families waiting over 18 months to see specialists, even when the family and the school are proactive about seeking help. Access to specialists is intensified by the lack of school psychologists in public schools, meaning the flagging of a potential diagnosis is also delayed. Recent [media coverage](#) reports two-year wait times in WA for paediatricians diagnosing and treating ADHD, and the reporting requirements themselves for this diagnosis are complex. These wait times are deplorable and impact essential support being provided to the student in a timely manner. Delays affect student learning outcomes and school experience, which is both frustrating and heartbreaking for parents.

An urgent review is required in terms of funding. Families express their desire for funding to be granted based on need, not a diagnosis. For example, we note that ADHD is not currently covered by the NDIS, and it is not considered a funded disability within the WA Department of Education. Other similar and frequently co-existing conditions such as Autism incur immediate NDIS support with one professional diagnosis. Given the extraordinary wait times previously mentioned we strongly advocate for the same model in schools if a model based on needs versus diagnosis is not supported.

Further, an ADHD diagnosis is based on the criteria being met in more than one environment, most commonly school and home. Unfortunately, parents report that not all teachers have the knowledge required to identify the challenges associated with ADHD, particularly the inattentive type where outward signs of challenges and associated behaviours may not be apparent. This results in some children failing to meet the diagnostic test despite challenges in many areas of their life. One parent reported paying \$3,500 for an ADHD and Autism assessment, but as her son did not exhibit the behaviours in the school setting, he failed to receive a diagnosis and continues to struggle with extreme school anxiety.

Parents are also reporting that when the symptoms of ADHD are not recognised until later childhood, the referral process is often further delayed as a result of the overwhelmed Child and Adolescent Mental Health Services. This delayed diagnosis is the start of the compounding problem of a lower-quality educational experience for these children; families must wait for support, funding and the appointment of education assistants. Concerningly, delays can result in adverse mental health impacts for the child, including anxiety, depression and 'school refusal' (school can't). Additionally, our parents report that an ADHD diagnosis alone does not necessarily trigger the allocation of an education assistant; normally adjustments to teaching and strategies for learning are implemented first. These factors combined negatively impact the child, who is in most cases already at a disadvantage. In some cases, delayed diagnosis negatively impacts the classroom environment in which the child is placed. WACSSO hears from parents that their children are being labelled as naughty, lazy, or out of control and are placed on behaviour plans that fail to provide strategies that address the disorder. When children are labelled, especially when appointments take months or years to secure, these incorrect and unfair assumptions stay with children often throughout their schooling experience.

(B) adequacy of access to supports after an ADHD assessment

The initial diagnosis of ADHD is only the first step for children and families living with this disorder. Access to ongoing specialist support is necessary, particularly as the child grows and matures and the needs for therapy and medications change.

Parents are reporting extensive wait periods for specialists, even those whom the child already sees on a periodic basis, and these delays are negatively impacting treatment outcomes. Should a child need to change paediatrician, psychiatrist or psychologist for any reason, it is nearly impossible to make an appointment with a new provider.

In regional and remote areas, the situation is more challenging as there is often no continuity of care, with specialists operating on a fly-in basis which can often lead to medications not being able to be prescribed.

The experience of limited access to support means that children living with this disorder experience further disadvantages, particularly as they navigate the already difficult generic childhood milestones, such as moving from Primary to High School, starting puberty and so on.

(G) the adequacy of, and interaction between, Commonwealth, state and local government services to meet the needs of people with ADHD at all life stages

Parents report a lack of support as children transfer to the adult health system. This system can be difficult to navigate (for both new adults and their parents), and the transition process is often confusing. The notion that children diagnosed with ADHD grow out of it in childhood is a persistent myth; ADHD has life-long implications especially regarding lifestyle and planning for independence, navigating the transition to work and finding engaging employment, and mental health.

((i) the social and economic cost of failing to provide adequate and appropriate ADHD services

Failing to diagnose and treat ADHD early has significant negative impacts on a child's educational experience, as already mentioned. Parents report that children who cannot access the support they need are significantly disadvantaged and it is very difficult for them to participate fully in the classroom and school context. Participation in this context includes both in-class and extra-curricular activities.

Negative impacts are not limited to learning, with parents also reporting that their child experiences social exclusion and difficulty making and retaining friendships when their ADHD is not properly managed. Parents are not immune to these outcomes either, with some parents reporting feeling isolated from the school community, feeling judged, as well as experiencing significant impacts on their mental health, such as anxiety and depression. The long-term impacts of this situation without critical support put in place can limit future pathways and achievement of full potential for young people.

There is a gendered impact also, as mothers report working reduced hours or being unable to work in paid employment due to the complexity of their child's needs.

Allied Health supports such as Occupational Therapy and psychology have important benefits for children and adults with ADHD, including liaising with schools and developing solutions for their clients in the school environment. The lack of inclusion of ADHD diagnosis for NDIS funding means that critical Allied Health services are unavailable for children with an ADHD diagnosis. We call on the government to rectify this.

(l) any other related matters

WACSSO celebrates the diversity of children and young people. Thank you to the families who have shared their stories; thank you for your courage and continued advocacy for all children living with ADHD. It is our hope that the government's response to this important Inquiry will bring meaningful, positive change to Australian young people and their families.

WA Council of State School Organisations Inc.

151 Royal Street
East Perth
Western Australia 6004

PO Box 6295
East Perth
Western Australia 6892

p (08) 9264 4000
f (08) 9264 4948
e info@wacssso.wa.edu.au

