



Submission to the Senate Community Affairs Reference Committee

Inquiry into the Assessment and Support Services for People with ADHD.

June 2023

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Ms Pothida Youhorn
Committee Secretary,
Community Affairs Reference Committee
The Senate, Parliament House, Canberra ACT 2600

9th June 2023

Dear Ms Youhorn,

The Learning Difficulties Coalition of NSW Inc. (LDC) is a peak body educational and advocacy group providing support and information to parents, teachers and health professionals regarding children and adolescents with learning and attention difficulties, including ADHD. The LDC, which has been in existence since 1989, operates a Parent Helpline during school terms. In addition we provide seminars, resources and, most importantly, a voice for parents to government and other partner organisations. The LDC is supported by a Grant-in-Aid from the NSW Department of Education. Further information can be found on our website: www ldc org au

The Management Committee of the LDC welcomes the opportunity to make a submission to the *Senate Inquiry into the Assessment and Support Services for People with ADHD*. We are consistently aware of the support needs of the number of students in all primary and secondary schools experiencing this neurodevelopmental disorder, and take any and every opportunity to advocate on their behalf.

Our submission highlights areas of particular on-going concern, as they relate to the Terms of Reference for this inquiry. In particular we will be highlighting issues relating to the access to diagnostic and support services, the high costs involved, and the need for relevant and community-accessible resources.

Thank you for receiving our submission, and we look forward to viewing the report when it is published later in 2023.

With regards,

Julia Starling, PhD
President, LDC Management Committee

Senate Inquiry into the Assessment and Support Services for People with ADHD
Submitted by the Learning Difficulties Coalition of NSW Inc (LDC) on 9th June 2023

***Please note that statements in italics have been provided by LDC members (mainly parents and teachers) who responded to a survey sent out to all members requesting comments for this submission.**

Primary and Secondary School Students with diagnosed or undiagnosed ADHD.

Attention DeficitHyperactivity Disorder (ADHD) is a complex neurodevelopmental disorder that is defined by “persistent, impairing and developmentally inappropriate inattentive/disorganised and /or hyperactive/impulsive behaviours” (Coghill et al, 2021, p.1). ADHD is the most common neurodevelopmental disorder in children and adolescents, with the prevalence in Australia estimated to be between 6% and 10% (Rege, 2021).

The following are some common difficulties associated with ADHD:

- Mental health issues
- Disorganisation
- Variability of moods
- Social awkwardness
- Poor co-ordination
- Poor self-esteem
- Associated Specific Learning Disorders

As a result, ADHD has a significant detrimental effect on a young person’s personal development. Research highlights the following as being of particular concern in populations of children and adolescents. Long term issues associated with a lack of identification and treatment are well documented. For example, Coghill(2018) states: ‘Between one in three and one in four children are being treated in Australia [for ADHD]. Those who are diagnosed with ADHD in adulthood, where it hasn’t been diagnosed in childhood, have a four times higher rate of mortality than those without ADHD’.

There is a high correlation between ADHD and antisocial behaviour as well as risk of harm to selves through risk taking behaviour. A high percentage of individuals with ADHD who are not supported effectively go on to develop mental health issues such as conduct disorder, depression, anxiety, eating disorders, and, in the worst case, suicide. A high correlation has been reported between incarcerated adolescent males with ADHD and attempted and completed suicide (Ruchkin et al, 2017).

It is therefore essential that children and adolescents with suspected ADHD are able to access relevant health and education services for both diagnosis and appropriate supportive interventions in a timely fashion. The situation across Australia is, however, falling alarmingly short of responding to this need.

1. Access to services

1.1 Access to assessment and diagnostic services

Because of the complexities of ADHD and possible associated health, mental health and learning difficulties, the assessment and diagnosis of ADHD needs to be carried out by a specialist health practitioner, such as a psychiatrist, paediatrician or psychologist. This raises two main issues, long waiting lists, and the high costs of specialist services.

The adequacy of access to ADHD diagnosis is variable and is often dependent on socio-economic background, an understanding of the referral system, and a parent or carer's advocacy skills. Access to assessment services is impacted by delays in identification, long wait lists, financial constraints, and a complex system that is difficult to navigate.

With specialists' costs often running to between \$2500 and \$3000, there is a lack of affordable services, factors that escalate for families in regional, rural and remote areas due to a paucity of services and additional travel times. According to a recent ABC news report, parents in Perth say they are facing an 18-month wait to see a public paediatrician due to a huge demand, with wait times estimated to be even longer in regional and remote areas (ABC South West WA, Loney and Moussali, March 2023).

Due to the lack of clear and consistent community-accessible guidelines, there is a variable understanding of ADHD and the diagnostic criteria. Many GPs, allied health professionals, and teachers do not know the reasons for, and the specifics of how to refer a child for, a diagnostic assessment. *The system is even more complex for families to navigate if English is not their first language, or literacy skills are low.* In addition, ADHD is typically not identified until a child reaches school age, meaning that they are already in the school learning environment and missing valuable learning opportunities from the start of school.

All of these issues may add to the time it takes for a child to be identified as having a possible ADHD, with an escalation in the damaging impact to that child's psycho-social and academic progress.

1.2 Access to post-diagnosis supports

High-quality care is recognised as being essential for children and adolescents with ADHD. This may involve pharmacological interventions, and/or non- pharmacological interventions such as occupational therapy, speech pathology, counselling and classroom management strategies. *The entire team around the individual (e.g. parent, paediatrician, GP, teacher, therapists) need to understand ADHD and work collaboratively to communicate essential interventions, supports, and adjustments.* There are similar issues of availability of services, public and private waiting list times and service delivery costs.

Access to supports at school requires persistent advocacy from parents and teachers. Supports available within a school setting vary based on teacher experience and school leadership. External therapists often recommend adjustments in the classroom, to the curriculum, and examination process, however it can be challenging for teachers to provide all the recommended adjustments. The team around the individual needs to have understanding, empathy, and motivation to provide meaningful, and evidence-based support. Supports and adjustments need to be implemented across curriculum and by all school staff. Within the

school setting ADHD intervention, adjustments and supports need to be included in Individual Education Plans and registered with the NCCD.

Additional costs are incurred when a child is prescribed medication. According to the survey of LDC parent members, medications costs under the PBS are “manageable, however still very expensive”. Individuals and their families accept the cost of medication as an essential part of the ADHD management program. *Access to medication is impacted by time and costs associated with getting scripts repeated. 6 monthly reviews by specialist paediatricians, the need for parents to take time off work as well as travel time to appointments. The cost to see the Paediatrician for 15 minutes is subsidised by Medicare, however there is still an out of pocket expense of \$200 per visit.* One parent stated that it is frustrating to have scripts kept at one pharmacy and that only one month’s supply can be purchased at a time. Another parent suggests that GPs, under the support and supervision of paediatrician, should be able to manage repeat scripts.

Adults with ADHD: Adults with ADHD: ADHD affects approximately 533,000 adults in Australia (aged 20+) (Australian Government Productivity Commission, 2023)

Unfortunately, knowledge, understanding, and adjustments for ADHD do not often carry across into the community and workplace. The responsibility shifts to the individual to adjust their behaviours, and without access to quality intervention in the school years, skills such as developing strategies to support concentrating, organising, and completing tasks, these continue to be challenging. Without providing quality intervention we are setting up these individuals to fail. Additionally, the costs associated with accessing medication is very challenging for young adults who have moved out of the family home, are trying to manage the cost of independent living and have to self-fund their medication and support services.

In summary:

- Access to essential services for assessment and diagnosis of ADHD is very challenging due to a scarcity of specialists, long waiting lists and costs that are beyond the reach of many parents and carers.
- There are similar barriers to accessing recommended support services.

2. Costs to Australian society of underdiagnosed and undertreated ADHD

Without the right level and type of supports from early childhood onwards, the cost to the broader community are substantial. Individuals with ADHD are at risk of poor mental health, low academic achievement, disengagement, reduced success in the workforce, challenging behaviour, and in some cases criminal or violent behaviour.

In the school setting, children are being set up to fail. If they miss vital skills in primary school, they will always be behind. Lack of support within schools has a huge impact. If individuals are not supported, they find classroom learning to be challenging, become disengaged, and end up not finishing school. Students with untreated ADHD often disrupt others, impacting both their learning, and the learning of their peers. Disengagement and barriers to learning for students with ADHD needs to be support and are mandatory under the Disability Discrimination Act (1992). When young children, their parents, and teachers are not given access to specialist help to equip them with strategies to manage ADHD they miss learning opportunities and miss learning basic skills. Too often individuals are being blamed for their challenges associated with ADHD. Individuals with ADHD can develop pervasive and persistent

negative and hopeless self-concepts. They may have limited opportunities to learn at their "true" ability levels. Children miss out on building meaningful relationships with peers and miss the opportunity to see themselves as capable. There is also stress in families trying to cope with challenging behaviours associated with ADHD.

In adulthood, individuals who have accessed intervention can develop the skills to take personal responsibility and self advocate for the ADHD needs. Individuals who have not accessed appropriate intervention may experience social and economic costs. They may have difficulties with self-regulation in the workforce resulting in loss of income and reliance on benefits. In the workplace an individual with ADHD may experience poor focus and low motivation which impacts their success at work and limits their employment opportunities. Too frequently individuals with ADHD develop anxiety and depression which affects their employment and their social life. They are more likely to engage in self-medication which brings with it a raft of medical, social, and economic harms. There is also the cost of lost productivity and the loss of potential employees for the workforce who may not be able to reach their full potential.

Productivity losses in Australia due to ADHD are substantial (\$10.19 billion). The total social and economic costs of ADHD in Australia in 2019 were estimated to be \$20.42 billion (Deloitte, 2019).

3. The role of NDIS in supporting children and adolescents with ADHD.

There are arguments both for and against the access to NDIS funding for those diagnosed with ADHD. Currently an ADHD diagnosis is not recognised as a primary disability, and when an application is made there needs to be a link with a primary disability that is recognised by the NDIA. It is possible to get NDIS funding when there is a 'Neurological-Other' diagnosis, however this needs provision of a substantive report from a Neuropsychologist as well as a Psychiatrist, which puts it out of reach financially for most families.

To be eligible for NDIS funding, the condition must cause permanent impairment (physical, intellectual, cognitive, neurological, visual, hearing or psychosocial), resulting in significant disability. **The debate, and subsequent decision-making, should therefore be focused on the degree to which the attention disorder impacts an individual's functioning in all aspects of current life, and in the long term.** This will be the case for some, but not all, individuals.

The following are some responses provided by the LDC membership:

- Access to interventions help the individual develop essential skills and strategies to be able to live independently and reach their potential. Interventions are self funded with little rebate through Medicare. Many families cannot afford these essential interventions. Barriers to accessing intervention leads to individuals with ADHD missing out.

- ADHD is a life-long disability that impacts academic, social, communication, and self esteem development. It is very unfortunate the ADHD is not included in the NDIS. It is essentially saying that medication is the only government support for families. Access to intervention can stop individuals from falling behind academically and support their mental health. When individuals fall behind this can impact on their mental health and increase challenging behaviours. Individuals may become disengaged and unmotivated if they fail to access all that schools can offer, and drop out.

- Intervention teaches important capacity building strategies and how to use those strategies at school and in the community to learn and develop.....Schools do not have the resources or skills to support individuals with complex learning difficulties associated the ADHD.

- Some feel that due to the high number of individuals with ADHD, this means that it is not possible to support them all through the NDIS. While some individuals with ADHD can manage without supports, many do need high levels of support to learn and develop. As the NDIS is needs based, access to funds would be dependent on an individual's need. Some also feel that individuals with ADHD can learn and develop with quality differentiated teaching practices however many need more support.

4. Access to guidelines and resources.

There is an evident need for the development and provision of holistic, systemic resources, and for these resources to be made widely available. The Australian ADHD Professional Association's Australian clinical practice guidelines are a case in point. These guidelines are relevant and adequate for ADHD informed professionals, and exemplify a large volume of work by a team with significant knowledge and expertise in the field of ADHD. However, on a recent (informal) survey of medical colleagues in the field of ADHD, none of them were aware of the existence of this document. Ensuring a wide dissemination of such resources is key, rather than creating further publications.

Such guidelines available in modified and summarised form could be made available to the wider community, such as GPs, teachers and parents.

Awareness raising can take many forms: for instance it could be drawing attention to the under-identification of girls, who present differently to boys in many instances, and can 'fly under the radar' with their inattentive and withdrawn behaviours. Males with negative behaviour tend to be diagnosed quicker than females who are quiet and causing no trouble.

Improvements have occurred in young males being diagnosed and their differences being better understood. In the past the attitude may have been "boys will be boys" and a male's tendency to be more active and less interested in sitting and learning may have led to many males who are now adults not being diagnosed. If ADHD characteristics are not accurately identified and felt to be "typical boy behaviour", these individuals will not get the supports they need to reach their potential.

Since understanding and active support across the whole school community is key to a child and adolescent's positive development, the development and provision of up-to-date awareness-raising professional development resources is also highly recommended.

5. Summary of recommendations

- **Improved and earlier access to specialist services and interventions**
- **More accessible and affordable support for assessments and ongoing management**
- **Better dissemination of key resources such as the AADPA guidelines, with**
- **A modified, readily accessible version of these guidelines for the wider community e.g. GPs, counsellors, teachers, parents**

- **Additional community resources e.g. evidence-based online training**
- **NDIS: recognition of ADHD as a primary disability for those with significant, long-term conditions.**

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