



MDAA submission on assessment and support services for people with ADHD- 2023

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About this submission

This submission is produced by the Multicultural Disability Advocacy Association of NSW Inc. (MDAA) in response to 'assessment and support services for people with ADHD'. The submission will discuss the barriers to consistent, timely and best practice assessment of ADHD and support services for people with ADHD, within the Terms of Reference. It will also draw attention to how people with ADHD from CALD communities and their specific needs.

Assessment and support services for people with ADHD

The Multicultural Disability Advocacy Association of NSW (MDAA) is the leading organisation representing individuals with disability, their families, and carers in NSW. With a dedicated emphasis on individuals from culturally and linguistically diverse (CALD) or non-English speaking (NES) backgrounds, MDAA has been tirelessly advocating for the rights of this specific demographic since its establishment in 1995.

MDAA's primary mission revolves around creating positive change and enhancing the lives of people with disability from CALD/NES backgrounds. Through persistent advocacy efforts, MDAA endeavours to secure improved outcomes, equitable access to services, and enhanced opportunities for individuals and their families. Furthermore, MDAA actively works towards fostering increased participation and inclusivity within the disability sector, ensuring that all individuals, regardless of their cultural or linguistic background, can fully engage in society and enjoy their rights.

As MDAA exists to represent *all* people with disability in NSW from CALD communities, this certainly includes those diagnosed with Attention-deficit/hyperactivity disorder (ADHD). However, the people for whom MDAA advocates face specific barriers that need to be highlighted and properly addressed otherwise assessment and support services will invariably fall short.

Adequacy of access to ADHD diagnosis and of access to supports after an ADHD assessment

Access to diagnosis and supports are dependent on various factors. Cultural issues can influence access to diagnosis and supports from the very start. The person with ADHD, especially a child, can be subject to treatment based on particular assumptions. In some cultures, parents regard what has been identified as ADHD in children as not so much a medical condition but an individual deficit (Ghosh, 2015, p. 20). This confirmed by more recent research (Slobodin & Masalha, 2020, p.470). If the family are sceptical of ADHD as a concept, obtaining supports will be challenging. This is especially the case if ADHD is stigmatised.

If a family from a CALD community does agree with the ADHD diagnosis, there are still barriers to treatment. There is research indicating that the first information source

on ADHD for parents is usually a discussion with the treating health professional (Ahmed et al., 2014, p. 664). This is not always informative and is often brief. This is related to a paucity of adequately trained medical professionals who can accurately and efficiently diagnose ADHD.

People of moderate means rely on public health services and there can be long waiting times before obtaining a diagnosis. The sheer volume of requests for assessments mean tertiary level health care organisations cannot handle them and people miss out on that level of expertise.

Diagnosis is dependent on functional impairment in two settings (Centers for Disease Control and Prevention, 2022) such as home and work. If someone from a CALD community cannot obtain employment, then there is only one reference point – which hampers any diagnosis.

CALD patients who have difficulty with English may have problems when it comes to a neuropsychological assessment. Interpretation of cognitive tests may not be accurate. Moreover, diagnosis in part consists of questionnaires and to what extent they have been translated into different languages is a matter of conjecture. The whole process does not appear to be inclusive.

The Australian health system as a whole is not as inclusive of CALD communities as it could be (Australian Institute of Health and Welfare [AIHW], 2022). It is complex and especially so for those with language barriers. Knowing who to approach in the health system for appropriate treatment is not always easy for those whose first language is English – let alone anyone else.

The system can also be costly. Access to ADHD diagnosis is often made difficult by the outlays involved. GPs do not tend to diagnose ADHD. Instead, clinical neuropsychologists, clinical psychologists, or psychiatrists do so and there is no Medicare rebate for clinical neuropsychologists. This can make the costs prohibitive to many and that of course does not apply only to CALD patients (the rough estimate of an ADHD assessment by a clinical neuropsychologist is \$2000 but cheaper in university clinics). Psychiatrists who are not in the public health system will charge

consultation rates. A full neuropsychological (cognitive) assessment is not required for a diagnosis of ADHD, but it can assist. Furthermore, some psychiatrists and other health professionals may request a second opinion on ADHD (thus increasing costs to the patient).

Access to supports is not always available. If ADHD is picked up in school age years, there are supports in school, but they are dependent on the school the child attends. Some schools have the relevant resources while others do not. There is little access to supports for adults. Support that does exist comes in the forms of advocacy organisations.

The availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services

In NSW, this is dependent on Local Health Districts. In regard to ADHD, there has been historically a focus on the paediatric population but more recently, a rise in adult diagnoses. As mentioned previously, support services for adults have not been as prevalent as they should be and for adults from CALD communities, they would be even more scarce.

Within the realm of treating practitioners, there exists an observable inclination towards reluctance when it comes to diagnosing Attention-Deficit/Hyperactivity Disorder (ADHD) in adults. Individuals in adulthood who seek a diagnosis encounter additional barriers, including General Practitioners (GPs) withholding referrals to specialists who possess the expertise required for accurate diagnoses, predominantly due to factors such as the individual's ability to maintain employment. Furthermore, specialists may stipulate the need for further costly assessments or seek second opinions to corroborate an initial diagnosis prior to commencing treatment.

Impact of gender bias in ADHD assessment, support services and research

ADHD affects both males and females, but research suggests a greater prevalence in males (Rucklidge, 2014). However, this should be viewed with caution. There may be gender differences in how ADHD manifests itself, referral bias, co-morbidities, delays in diagnosis and misdiagnosis.

The underdiagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) in women persists as a significant concern within the clinical landscape. This disparity can be attributed, at least in part, to the presence of gender bias and the distinct presentation of ADHD symptoms in women.

Historically, ADHD has been predominantly studied and understood through the lens of its manifestation in males, leading to a lack of recognition and awareness of the disorder in females. The symptoms of ADHD often differ in their outward presentation between genders, with women commonly exhibiting less overtly disruptive or hyperactive behaviours. Instead, women with ADHD may present with internal struggles such as chronic disorganization, difficulties with executive functioning, emotional dysregulation, and a high prevalence of comorbid mental health conditions such as anxiety and depression.

Due to this, women with ADHD often go undiagnosed or are misdiagnosed with other conditions, leading to delayed intervention and appropriate treatment. Anecdotally, the underdiagnosis of ADHD in women is believed to stem from the perception that their outward presentation has less impact on those around them, masking the significant impairments and challenges they experience internally.

In addition to the traits associated with Attention-Deficit/Hyperactivity Disorder (ADHD), it is worth noting that individuals with ADHD may also experience comorbidities such as Borderline Personality Disorder (BPD) and Rejection Sensitivity Dysphoria (RSD). These comorbid conditions can further influence an individual's experiences and challenges.

Addressing these issues necessitates increased awareness among healthcare professionals and a paradigm shift in understanding the gender-specific manifestations of ADHD. By recognising and appropriately evaluating the unique symptomatology exhibited by women, healthcare providers can facilitate early diagnoses and tailored interventions. This inclusive approach is crucial for ensuring equitable access to the necessary support and interventions for women with ADHD, ultimately improving their overall well-being and quality of life.

Access to and cost of ADHD medication, including Medicare and Pharmaceutical Benefits Scheme coverage and options to improve access to ADHD medications

Medication for ADHD in Australia is covered by the PBS which obviously assists with costs. However, it should be noted that only specialists such as a psychiatrist can prescribe such medications and a consultation would add to the overall expense.

A critical aspect of Attention-Deficit/Hyperactivity Disorder (ADHD) is the presence of poor executive functioning, which encompasses difficulties in areas such as planning, organising, and sustaining attention. However, the requirement of medication scripts that are only valid for six months, poses a significant barrier to accessing uninterrupted treatment for individuals with ADHD.

Individuals with ADHD often rely on medication as an essential component of their treatment plan to manage their symptoms and improve their executive functioning abilities. However, the restriction to prescribing ADHD medications with limited script validity periods introduces challenges for individuals seeking ongoing treatment. The necessity to renew medication scripts every six months imposes additional administrative burdens on patients, and significant cost. This may lead to disruptions in medication continuity, as individuals may experience lapses in access to their prescribed medication while awaiting script renewals, which can have detrimental effects on their executive functioning and overall well-being.

Furthermore, the requirement for frequent script renewals may lead to delays in treatment initiation for individuals who are newly diagnosed or seeking medication adjustments. These delays hinder timely access to the appropriate medication regimen, potentially prolonging the negative impact of ADHD symptoms on an individual's functioning, academic or occupational performance, and quality of life.

To improve access to treatment for individuals with ADHD, it is essential to reassess the limitations imposed by short-term medication scripts. Implementing measures such as extending the validity period of medication scripts or adopting alternative prescription practices could alleviate the burden on patients and healthcare providers,

ensuring a smoother continuity of treatment and better management of executive functioning impairments associated with ADHD.

By addressing this barrier, individuals with ADHD can benefit from uninterrupted access to medication, supporting their executive functioning needs and enabling them to thrive in various aspects of their lives, including academics, work, and personal relationships.

The role of the National Disability Insurance Scheme in supporting people with ADHD, with particular emphasis on the scheme's responsibility to recognise ADHD as a primary disability

There are approximately 800,000 people living with ADHD in Australia (Deloitte Access Economics, 2019, p. ii). This does not include projection of those undiagnosed. This figure represents many people for whom ADHD is disabling and causes loss of so-called functionality.

Evidence-based treatments should be funded by the NDIS for participants can prove that ADHD is the primary disability.

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

The interaction between the three levels of government when it comes to services for people with ADHD is fractured. Part of the problem stems from the NDIS and how it perceives its role.

The NDIS frequently tells people with mental health issues (including ADHD) that what they need is the responsibility of the mental health system ie: a state/territory responsibility. The mental health system certainly serves an essential purpose, but it is not interchangeable with the NDIS.

Governments try to avoid duplication including where there is shared responsibility for services for people with disability (Cook, 2019). Unfortunately, that can mean some NDIS applicants miss out on NDIS funding and have no other options available to

them. As for local government, they provide very little in the way of disability and mental health services.

Clearly, the interaction between the various levels of government needs considerable improvement.

The adequacy of Commonwealth funding allocated to ADHD research

Adequacy of funding for ADHD research should be assessed in line with what ADHD advocacy organisations are requesting in terms of financial outlay.

One outstanding issue seems to be the wealth of research in ADHD in the paediatric field in comparison to older age groups. Children with ADHD of course become adults and the ADHD does not disappear. Research deficits in this area require serious consideration.

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

The costs of ADHD by various measurements are formidable. Total productivity costs in 2019 were estimated to be in the range of US\$6.0 billion or US\$7.424 per Australian with ADHD (Sciberras et al., 2022, p. 79). Lack of adequate and appropriate services does and will have a social and economic cost.

The social cost of Attention-Deficit/Hyperactivity Disorder (ADHD) encompasses various challenges that individuals with ADHD face, including a phenomenon colloquially referred to as the "ADHD tax." This term reflects the additional costs incurred by individuals due to the impact of poor executive functioning on their daily lives.

ADHD is characterized by impairments in executive functioning skills, such as planning, organizing, time management, and task completion. These difficulties often result in increased time and effort required to accomplish tasks and meet responsibilities compared to individuals without ADHD. Consequently, individuals with ADHD may experience financial, emotional, and productivity-related repercussions.

Recognizing and addressing the social cost of ADHD is crucial for fostering inclusivity and supporting individuals with ADHD to thrive. By promoting awareness, understanding, and accommodations for executive functioning difficulties, society can help mitigate the financial, emotional, and productivity-related burdens faced by individuals with ADHD. This includes fostering an inclusive environment that embraces diverse learning and work styles, providing reasonable workplace accommodations, and ensuring access to support services that can assist with executive functioning challenges.

By addressing the social cost associated with ADHD and working towards, we can create a more equitable and supportive society, enabling individuals with ADHD to fully realize their potential and contribute meaningfully to various aspects of their lives.

The viability of recommendations from the Australian ADHD Professionals Association's Australian evidence-based clinical practice guideline for ADHD

The term 'viability' needs clarification here. The recommendations appear to be based on best practice. High risk groups have been identified in a report based on what appears to be sound scientific methodology (Australian ADHD Professionals Association, 2022). This is crucial because it demonstrates how ADHD is linked to other forms of disability including mental health issues. Therefore, it is logical to target these particular groups.

The report does acknowledge in the executive summary that services for First Nations people should be culturally safe. In cases where services are not delivered by First Nations providers, non-Indigenous professionals should ensure that all care is based on the principles set out in *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (Dudgeon, Milroy, & Walker, 2014).

International best practice for ADHD diagnosis, support services, practitioner education and cost

Clearly international best practice is the goal when it comes to ADHD diagnosis, support services, practitioner education and cost. The key question is how to get there. The issue of cost is crucial. Resources and training do not come cheaply.

However, that needs to be balanced with the economic and other costs of not doing anything.

MDAA also believes that international best practice needs to be inclusive of CALD communities. Expertise in ADHD needs to be communicated effectively to communities whose members may struggle with the English language. If not, a large number of Australians with ADHD will not obtain many benefits.

Any other related matters

ADHD is generally treatable through non-pharmacological or pharmacological means or a mix of both. MDAA wants to improve the lives of people with ADHD through:

Accurate and timely diagnosis and provide guidance on optimal and consistent assessment and treatment of ADHD. The guideline outlines a roadmap for ADHD clinical practice, research, and policy, now and in the future, with a focus on everyday functioning and quality of life for care based on age, gender, culture, setting and geography of people who are living with ADHD, and those who support them (Australian ADHD Professionals Association, 2022).

This can only lead to greater social, health and economic projections and gains as well as address the human rights of individuals with ADHD.

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