Disability Advocacy

Submission to the Senate Standing Committee on Community Affairs

Assessment and support services for people with ADHD

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About Disability Advocacy NSW (DA)

DA has over 35 years of experience providing individual advocacy to people with disability (PWD) of any age. The organisation services over two thirds of NSW, making it the largest individual disability advocacy organisation within NSW.

While DA has a presence in Sydney, it has a strong commitment to regional, rural and remote (RRR) areas in NSW. With local disability advocates – on the ground - in Western Sydney, Armidale, Bathurst, Broken Hill, Ballina, the Blue Mountains, Coffs Harbour, Dubbo, Newcastle, Central Coast, Port Macquarie, Tamworth, Gosford, Taree, Ballina – DA has firsthand insights and observations of the lived experiences of PWD and their families living in these areas.

DA's systemic advocacy draws on coalface information from clients, disability advocates, and the disability sector more broadly to identify and address emerging policy issues. In this submission, we focus on issues relate to ADHD, assessments and the NDIS. In addition to this submission, we invite members of the Senate Standing Committee on Community Affairs to conduct site visits to our RRR offices alongside our policy and communications lead (contact details below) to hear more about the experiences of PWD living in RRR areas.

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Introduction

ADHD, the NDIS and community-based supports in RRR areas

DA welcomes the opportunity to make this submission regarding assessment and support services for people with ADHD. In previous submissions[1][2], DA has discussed how PWD living in RRR areas are double disadvantaged. This occurs when a person's disability intersects with their RRR location to impinge on their quality of life.

In this submission, we highlight how people with ADHD experience difficulties with accessing supports and services both because of the difficulties of living with ADHD and because of their location. In doing so, we highlight the inadequacy of service systems in supporting people with ADHD with particular regard to gaps that exist with the NDIS and community-based supports.

To do this, we address the following criteria of the terms of reference (TOR):

(a) adequacy of access to ADHD diagnosis;

(b) adequacy of access to supports after an ADHD assessment;

(c) the availability, training and attitudes of treating practitioners, including workforce development options for increasing access to ADHD assessment and support services;

(d) impact of gender bias in ADHD assessment, support services and research;

(f) 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;

Our responses to these TORs are based on a workshop conducted with DA advocates (*N*=27) who have experience providing individual advocacy support to people with ADHD who experience unfair treatment with service systems. These include the NDIS, educational

[1] NDIS Joint Standing Committee's Inquiry into NDIS' Implementation and Performance (submission number 79).
[2] NDIS Joint Standing Committee's Inquiry into the NDIS' implementation and forecasting (submission number, 81).

settings, and healthcare. Within this group of advocates were self-identified advocates (*n* =3) who also live with ADHD, and were able to offer both their professional and personal insights.

Adequacy of access to ADHD diagnosis

Accessing an ADHD diagnosis in RRR areas is difficult due to costs, and limited amount of allied health services/clinicians with the appropriate expertise and knowledge needed to conduct assessments. These issues can make obtaining a diagnosis prohibitive particularly if people are financially disadvantaged and live in a RRR area. There can also be significant time delays in getting assessments due to long waitlist which can be up to twelve months or more, even outside the public health system.

Costly reports

- An ADHD diagnosis is costly (e.g., $2.5 to $3.5k for a functional capacity assessment). While bulk billing may be available in public hospitals, there is often lengthy waitlists, and hospitals in RRR areas often do not have the resources and or capacity to provide assessments. As one advocate described, getting a diagnosis in a public hospital is an option that 'is non-existent' in their regional town.
- For families on low incomes, where other conditions and disabilities may exist, there may already be financial pressure and restraints associated with the costs of living with a disability (e.g., medication, travel and fees to see specialists) in a RRR area.

The high costs associated with obtaining a formal diagnosis of ADHD is a significant barrier for many low socio-economic families, which raises concerns that ADHD may be under diagnosed across this cohort.

Limited allied health services and lengthy wait lists

- In RRR areas people often need to travel vast distances to attend medical and or specialist appointments. For PWD on low incomes, travelling vast distances may not be an option due to limited and unreliable public transport, the cost of travel, and the need for support workers to assist with travel.

- The NDIA might fund an ADHD assessment if there is another primary diagnosis that has enabled an individual to access the NDIS. However, the quality of reports can be problematic (discussed in further detail below).
- Outside of the public system in RRR areas, there are issues of thin markets where there is limited availability of service providers, which contributes to lengthy waitlists and sometimes, closed books. In New England, for instance, the wait list has been up to 2 years.

The long wait times and the difficulties associated with getting an assessment, can result in people with undiagnosed ADHD being declined access to services, or having to self-fund the supports that they need for years at a time. This is a serious concern, particularly for children who remain undiagnosed for lengthy periods of time.

Lack of knowledge

- There appears to be a fundamental lack of understanding and knowledge of what ADHD is among many general practitioners (GPs), psychologists, psychiatrists and other allied health professionals who conduct assessments. Advocates report that some practitioners retain older, outdated notions of ADHD that do not align with modern diagnostic criteria.
- Common community perceptions of ADHD are based on the dated idea[3] of a hyperactive presentation among young white boys – something that many people believe that children grow out of. Such false perceptions can lead to misdiagnoses, particularly among females, Aboriginal and Torres Straight Islanders peoples and culturally and linguistically diverse peoples[4].

The quality of reports

Accessing supports and services for ADHD via the NDIS requires the Vineland - a functional capacity assessment for ADHD. However, many specialists and/or clinicians do not

[3] In 2013 that the DSM was updated to have an understanding, a better understanding of what ADHD was, and 2009 that adults were included in an ADHD diagnosis.
[4] See ADHD Guideline Development Group. (2022). *Australian evidence-based clinical practice guideline for Attention Deficit Hyperactivity*. Melbourne: Australian ADHD Professionals Association; 2022.

understand how to write these reports. Advocates explain that allied health professionals, such as Occupational Therapists (OTs), are trained to write reports from a recovery-based model, and the Vineland is based on a deficit model.

Therefore, allied health professional can struggle to conceptualise their client's condition in the manner required for diagnosis and access to support services, even when their patient experiences significant impairment because of their ADHD. This ultimately leads to assessments that inadequately demonstrate that a person with ADHD meets the access requirements to access supports and services for ADHD via the NDIS.

Recommendation:

NSW government to provide funding for:

- Increased access to diagnosis and assessment within public hospitals. People need to have access to low cost, timely, assessments within a reasonable distance from where they are located.
- Increased subsidies for ADHD assessments conducted by allied health professionals.

Adequacy of access to supports after an ADHD assessment

Supports and services for ADHD after obtaining a diagnosis is limited, particularly for adults if they are unable to access supports and services through the NDIS. Most options revolve around medication with little psycho-education, and social and interpersonal skill development.

Limited services and support

Most people report using medication as a stand-alone intervention to manage symptoms of ADHD. One advocate noted that while access to medication may be useful:

> *'if they can't then get access to the supports and accommodations that they need to be successful in work and education and just in the community. You know there's only so far that medication is going to take them… studies*

> *showed very clearly that where there is extra supports of having... support in the workplace and school support with family…They had much greater quality of life outcomes, educational outcomes, employment outcomes, less loss of work, bad grades and you know, even the mental health side of things. So lower levels of suicidal ideation and ... criminal activity or borderline criminal activity.*

For better life outcomes, a more holistic biopsychosocial approach needs to be made more available for people with ADHD.

The role of schools

Advocates report that schools can play an integral role in supporting families to access the appropriate supports and services. However, there are vast inconsistencies among schools in their capacity to support students with ADHD.

In some fortunate cases, it is often teaching staff that recommend an assessment if they notice concerns with learning or behaviour. Some schools may have counsellor and/or a psychologist available and may be able to do some form of an assessment that can then be provided to a paediatrician to support a formal diagnosis. Additionally, classroom observation notes can also be shared with a paediatrician to support their assessment.

In other instances, advocates report that some schools can misrecognise symptoms of ADHD as belonging to 'naughty' children. This then leads to punitive and disciplinary approaches (e.g., exclusion, suspensions and expulsions) to manage behaviour[5]. As one advocate described, such misrecognition of behaviour does not 'illicit much sympathy' among teaching staff and can result in children being ostracised in classroom settings.

Limited options for adults

Support and treatment options are limited for adults ADHD. Outside of medication, support options can include psychology and ADHD coaches. While psychology can be accessed via a Mental Health Care Plan (MHCP), these are limited to 10 sessions. Coaching sessions are relatively new, and not accessible through MHCP, and are currently self-funded.

[5] See DA's education report, 'Falling behind: A need for inclusive education'.

Recommendations:

More support at a state level can help to relieve the pressure on the NDIS to allow access for people with ADHD. This can include state funding for:

- Research that needs to be conducted in the first instance to scope the extent to which the public and private sectors can meet demand for clinical assessments, particularly in RRR areas.
- Public schools to provide support and training for staff to recognise and respond to behaviours associated with ADHD.

At a Federal level, Medicare can offer subsidises for:

- Qualified ADHD coaching, as well as supports capacity building in social skills, daily living (e.g., executive functioning, budgeting, life admin). This is particularly important for people who may not meet the access requirements for the NDIS. Assessments for ADHD should be subsidised under Medicare, as a vital first step in receiving a diagnosis which then provides pathways for support.

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

As noted earlier, there appears to be a lack of understanding of a modern ADHD diagnosis and its relatively recent developments in the criteria in the DSM-5. Dated and false perceptions of ADHD are often gendered[6] (discussed in further detail below), with stereotypical understandings embodying a young hyper-active male. These misunderstandings can lead to misdiagnoses that in turn limit access to appropriate supports and services.

In the New England area advocates report that there are issues with alleged fraudulence. There is a service provider that is overcharging for assessments and providing very poor-

[6] See Holthe, M. E. G., & Langvik, E. (2017). The Strives, Struggles, and Successes of Women Diagnosed With ADHD as Adults. *SAGE Open*, *7*(1).

quality reports, that the NDIA ultimately rejects, or the client does not use it 'because it is so bad', one advocate described.

Advocates also report that some assessors do not meet the person they are assessing. Additionally, advocates in this region have observed people conducting assessments with no relevant qualifications and experience, and billing people under an OT's license number. One advocate described one of these assessments as 'one of the most ridiculous reports I've seen in my career' and went on to explain that clients are also reluctant to make complaints. As there are few service providers in the area, they don't want to jeopardise access to a practitioner at a later stage should they need another assessment.

Recommendations:

- Better regulation and training of assessors to ensure that assessments are valid, and that the rights of those being assessed as consumers, are upheld. People seeking an assessment from a practitioner should be able to expect that the practitioner has appropriate understanding and qualification to conduct these assessments.
- Better regulation of costs and quality assessments – measures are needed to ensure that they are at the standard of quality that is needed for the NDIS and other support organisations to use.
- Ongoing training and professional development in assessing ADHD is mandated among any allied health professionals who conduct assessments (note this recommendation is also relevant to the section below).

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

Assigning a diagnosis of ADHD among young male children in the community appears easier compared to their female counterparts[7]. For females, ADHD presents differently, which can make it difficult to recognise if health professionals do not have a sound clinical understanding of its presentation.

[7] Furzer, J., Dhuey, E., & Laporte, A. (2022). ADHD misdiagnosis: Causes and mitigators. *Health Economics*, *31*(9), 1926-1953.

This means that females are often not diagnosed until later in life, in high school or even as an adult, when individuals start recognising the signs and symptoms of ADHD. An issue here is that when young adults or adults seek a referral from a GP to see a specialist for an assessment, some GPs may question a person's concerns of ADHD because their symptoms were not recognised as child and or adolescent[8]. Advocates report that the presumption here is that if it was not recognised earlier in life, then an ADHD diagnosis is unlikely. In this, there tends to be a disbelief and dismissiveness, with some GPs potentially misdiagnosing ADHD as a mood disorder. Additionally, some GPs might refuse to refer to a specialist because they do not believe that their patient might have ADHD as an adult.

A delayed diagnosis results in a delay of supports and treatments, which over the lifespan can have a cumulative effect on people. Not having appropriate supports and treatment can take a toll on people's emotional well-being and can impact and interact with other conditions and impairments[9]. For young people in school, it can also contribute to a decline in educational outcomes. It often not well understood that without early intervention and a diagnosis, there is an impact on functional capacity later in life that affects every day functioning.

Recommendation:

Greater education among allied health professionals around the different presentations of ADHD. In particular, training must highlight the intersections between children, women, Indigenous people, other health and mental health conditions, socioeconomic status etc. This can occur both in universities as well as ongoing professional development. Professional and registration bodies for allied health professionals could potentially be responsible for regulating this.

[8] Hansson Halleröd SL, Anckarsäter H, Råstam M, Hansson Scherman M. (2015). Experienced consequences of being diagnosed with ADHD as an adult - a qualitative study. *BMC Psychiatry.*
[9] Waite, R., & Ramsay, J. R. (2010). Adults with ADHD: Who are we missing?. *Issues in mental health nursing*, *31*(10), 670-678.

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

The NDIA does not recognise ADHD as a stand-alone primary diagnosis, nor does it have a mechanism to adequately assess the cumulative impacts of multiple diagnoses. Instead, the scheme tends to view a diagnosis in isolation - where conditions are viewed as separate from other diagnoses. Consequently, assessment results will often not reach the threshold needed to be considered as having a significant impairment. However, if the cumulative combined effects of multiple diagnosis were acknowledged, it is likely that they would be assessed as having a serious impairment.

As a stand-alone diagnosis, ADHD can be considered as a significant and permanent condition. Modern understandings of ADHD indicate that it is a lifelong impairment and is not 'curable' exclusively through medication. Additionally, recent research indicates that ADHD has significant negative impacts across a person's functional capacity, including the capacity to work, go to school, even when existing in isolation from other diagnoses.[10]

Recommendations:

- The NDIA add ADHD to List B: conditions that are likely to result in a permanent impairment.
- The NDIS stipulates clear guidelines for health professionals to write reports for the purpose of a functional assessment.
- The NDIA works with professional registration bodies to develop training and tools that can equip allied health professional with the skills needed to write reports.

[10] Sina Gerhand, Christopher W. N. Saville. (2022) ADHD prevalence in the psychiatric population. *International Journal of Psychiatry in Clinical Practice* 26:2, pages 165-177.