NACCHO
National Aboriginal Community Controlled Health Organisation
Aboriginal health in Aboriginal hands
www.naccho.org.au

Barriers to assessment and support services for people with ADHD

Submission to the Senate Standing Committees on Community Affairs

June 2023

ABOUT NACCHO

NACCHO is the national peak body representing 145 Aboriginal Community Controlled Health Organisations (ACCHOs). We also assist a number of other community-controlled organisations.

The first Aboriginal medical service was established at Redfern in 1971 as a response to the urgent need to provide decent, accessible health services for the largely medically uninsured Aboriginal population of Redfern. The mainstream was not working. So it was, that over fifty years ago, Aboriginal people took control and designed and delivered their own model of health care. Similar Aboriginal medical services quickly sprung up around the country. In 1974, a national representative body was formed to represent these Aboriginal medical services at the national level. This has grown into what NACCHO is today. All this predated Medibank in 1975.

NACCHO liaises with its membership, and the eight state/territory affiliates, governments, and other organisations on Aboriginal and Torres Strait Islander health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs.

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal health practitioners and/or nurses to provide the bulk of primary health care services. Our 145 members provide services from about 550 clinics. Our sector provides over 3.1 million episodes of care per year for over 410,000 people across Australia, which includes about one million episodes of care in very remote regions.

ACCHOs contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive primary health care, and by integrating and coordinating care and services. Many provide home and site visits; medical, public health and health promotion services; allied health; nursing services; assistance with making appointments and transport; help accessing childcare or dealing with the justice system; drug and alcohol services; and help with income support. Our services build ongoing relationships to give continuity of care so that chronic conditions are managed, and preventative health care is targeted. Through local engagement and a proven service delivery model, our clients 'stick'. Clearly, the cultural safety in which we provide our services is a key factor of our success.

ACCHOs are also closing the employment gap. Collectively, we employ about 7,000 staff – 54 per cent of whom are Aboriginal or Torres Strait Islanders – which makes us the third largest employer of Aboriginal or Torres Strait people in the country.

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Recommendations

NACCHO recommends:

1. any interventions to improve access to diagnosis and support for people with ADHD be implemented in accordance with the four Priority Reforms of the National Agreement.
2. build the capacity of the ACCHO sector to ensure adequate and culturally safe diagnosis, management and support for Aboriginal and Torres Strait Islander children and adults with ADHD and other neurodiverse conditions.
3. investment in the development of culturally appropriate ADHD diagnostic tools for Aboriginal and Torres Strait Islander people.
4. the development of culturally appropriate supports and interventions for Aboriginal and Torres Strait Islander people in partnership with Aboriginal and Torres Strait Islander people and organisations.
5. alignment of medicines regulations across jurisdictions to allow for cross-border dispensing and improve accessibility to medicines.
6. the introduction of shared care models in remote and border regions.
7. ADHD be recognised as a primary disability under the NDIS.
8. in line with other List B Conditions under the NDIS Act, ADHD is assessed on both diagnosis and functional impairments, recognising that the severity of ADHD symptoms and characteristics is varied.
9. the *Australian Evidence-Based Clinical Practice Guideline for ADHD* be added to the HealthPathways information portal to support their wider use in general practice.

Acknowledgements

NACCHO welcomes the opportunity to provide a submission to the inquiry into *Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD*.

NACCHO would like to acknowledge the valuable input received from the Aboriginal Health Council of Western Australia (AHCWA), the Aboriginal Health and Medical Research Council (AH&MRC) of NSW, Queensland Aboriginal and Islander Health Council (QAIHC) and the Aboriginal Medical Services Alliance of the Northern Territory (AMSANT) in this submission.

National Agreement on Closing the Gap

At the meeting of National Cabinet in early February 2023, First Ministers agreed to renew their commitment to Closing the Gap by re-signing the National Agreement, first signed in July 2020. The reforms and targets outlined in the National Agreement seek to overcome the inequality experienced by Aboriginal and Torres Strait Islander people, and achieve life outcomes equal to all Australians.

This Government's first Closing the Gap Implementation Plan commits to achieving Closing the Gap targets *through implementation of the Priority Reforms*. This represents a shift away from focussing on the Targets, towards the structural changes that the Priority Reforms require, and which are more likely to achieve meaningful outcomes for our people in the long term:

Priority Reform Area 1 – Formal partnerships and shared decision-making
This Priority Reform commits to building and strengthening structures that empower Aboriginal and Torres Strait Islander people to share decision-making authority with governments to accelerate policy and place-based progress against Closing the Gap.

Priority Reform Area 2 – Building the community-controlled sector
This Priority Reform commits to building Aboriginal and Torres Strait Islander community-controlled sectors to deliver services to support Closing the Gap. In recognition that Aboriginal and Torres Strait Islander community-controlled services are better for Aboriginal and Torres Strait Islander people, achieve better results, employ more Aboriginal and Torres Strait Islander people and are often preferred over mainstream services.

Priority Reform Area 3 – Transformation of mainstream institutions
This Priority Reform commits to systemic and structural transformation of mainstream government organisations to improve to identify and eliminate racism, embed and practice cultural safety, deliver services in partnership with Aboriginal and Torres Strait Islander people, support truth telling about agencies' history with Aboriginal and Torres Strait Islander people, and engage fully and transparently with Aboriginal and Torres Strait Islander people when programs are being changed.

Priority Reform 4 – Sharing data and information to support decision making
This Priority Reform commits to shared access to location-specific data and information (data sovereignty) to inform local-decision making and support Aboriginal and Torres Strait Islander communities and organisations to support the achievement of the first three Priority Reforms.

NACCHO recommends any interventions to improve access to diagnosis and support for people with ADHD be implemented in accordance with the four Priority Reforms of the National Agreement.

Introduction

It is estimated that around 1 in every 20 Australians has ADHD. It is more prevalent in boys but is believed to be under diagnosed in girls and adults.

The *Australian Evidence-Based Clinical Practice Guideline for ADHD* (the Guideline) outlines a number of groups at increased risk of ADHD. Aboriginal and Torres Strait Islander people are overrepresented in a number, including: children born pre-term, with a low birth weight, or with prenatal exposure to substance including alcohol, children in out of home care, people who are imprisoned or in the correction system and people of all ages with neurodevelopmental disorders.

In 2021, Aboriginal and Torres Strait Islander adults were imprisoned at a rate 14 times that of other Australians.[1]

At 30 June 2021, 1 in 17 Aboriginal and Torres Strait Islander children (around 19,500) were in out-of-home care, around 11 times the rate for non-Indigenous children. Aboriginal and Torres Strait Islander children on care and protection orders at 30 June increased from about 19,700 in 2017 to about 24,200 in 2021.[2] Aboriginal and Torres Strait Islander children in out of home care (OOHC) are known to have poorer educational engagement, emotional and behavioural issues arising from trauma, placement instability and disconnection to their culture and kin.

A 2018 study found 89% of 10-17 year-olds in youth detention had at least one form of severe neurodevelopmental impairment, with 36% having Fetal Alcohol Spectrum Disorder (FASD).[3] People with FASD are likely to have impaired motor skills, cognition, language, attention, memory and a variety of co-morbid conditions which may include ADHD, visual impairment, chronic otitis media, hearing loss, expressive and receptive language disorders and conduct disorders.

The 2005 Western Australian Aboriginal Child Health Survey found that compared to non-Indigenous children, Indigenous children reported a higher risk (15.8% vs. 9.7%) of hyperactivity problems associated with ADHD.[4] There also appears to be an increased risk of ADHD in people living with FASD[5], which disproportionately affects Aboriginal and Torres Strait Islander children[6]. A study in the Fitzroy Crossing region of WA focusing on the prevalence of neurodevelopmental disorders and FASD amongst Aboriginal children living in remote communities, found as many as 26% of children assessed had ADHD and/or sensory problems[7].

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[1] Indigenous Health Performance Framework, https://www.indigenoushpf.gov.au/measures/2-11-contact-criminal-justice-system

[2] AIHW, Child protection Australia (2020–21). Retrieved from: https://www.aihw.gov.au/reports/child-protection/child-protection-australia-2020-21/contents/about

[3] Bower, et al (2018) *Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia* BMJ Open: UK

[4] Zubrick SR, Silburn SR, Lawrence DM, Mitrou FG, Dalby RB, Blair EM, Griffin J, Milroy H, De Maio JA, Cox A, Li J. The Western Australian Aboriginal Child Health Survey: The Social and Emotional Wellbeing of Aboriginal Children and Young People. Perth: Curtin University of Technology and Telethon Institute for Child Health Research, 2005.

5 Burd L. FASD and ADHD: Are they related and How?. Bmc Psychiatry. 2016 Dec;16:1-3.

[6] Telethon Kids Institute. Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (2nd edition) – chapter 20: Addressing Fetal Alcohol Spectrum Disorder in Aboriginal Communities. [Internet]. Perth: Telethon Kids Institute. 2014. Available from: wt-part-5-chapt-20-final.pdf (telethonkids.org.au)

However, the prevalence of ADHD for Aboriginal and Torres Strait Islander people is largely unknown and suspected to be underdiagnosed. This may be due to barriers to accessing diagnostic services or misdiagnosis. It is known that Aboriginal and Torres Strait Islander people are twice as likely to experience a disability than other Australians[8], and that they are less likely to access services than other Australians. There are several reasons for this, including limited availability of culturally safe services, marginalisation and lack of trust in government. The impact of disability exacerbates the divide in health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples and other Australians.[9] These disparities warrant innovation and policy reform.

Aboriginal and Torres Strait Islander perceptions of disability

Disability is a socially constructed concept arising from western culture and society. People from Aboriginal or Torres Strait Islander backgrounds may have a very different understanding or concept of disability, and in many Aboriginal and Torres Strait Islander languages there is no word for disability.

Aboriginal and Torres Strait Islander people often focus on a person's holistic health, social and emotional wellbeing, and celebrate the strengths and differences of an individual rather than focusing on deficit. This can often result in under-recognising and responding to specialist needs of people in Aboriginal and Torres Strait Islander communities, particularly those with less visible disabilities such as ADHD.

Service providers must acknowledge differences in the awareness and understanding of disability in Aboriginal and Torres Strait Islander communities. According to one study:

> 'In contrast to the Western perspective which emphasises impairment and the need for remediation, some Indigenous Australians view disability as a characteristic of the individual, something to be supported by the broader community rather than ameliorated. Indeed, labelling, and categorising individuals with regard to their abilities or impairments is considered disrespectful in some Aboriginal and Torres Strait Islander communities.'

However, this does not mean that Aboriginal and Torres Strait Islander people with ADHD and their families do not want or require support. It does mean that an appreciation of these perceptions play an integral part in providing support to Aboriginal and Torres Strait Islander people.

Improved outcomes for Aboriginal and Torres Strait Islander people requires consideration of cultural differences in perceptions of disability and ADHD by Aboriginal and Torres Strait Islander people. We know the provision of culturally safe care to Aboriginal and Torres Strait Islander people delivers better health outcomes.[10]

Importance of an ACCHO-led approach

ACCHOs play a central role in the provision of culturally safe, trauma-informed care primary health care for Aboriginal and Torres Strait Islander communities. Rooted in self-determination, ACCHOs help overcome many of the barriers to access experienced by Aboriginal and Torres Strait Islander people.

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[8] AIHW (2017) 'The Aboriginal and Torres Strait Islander Health Performance Framework Report' AIHW: Canberra.

[9] Bailey et al (2020) 'Indigenous Australians with Autism a scoping study' *Autism, 24*(5).

[10] Aboriginal community controlled health services: leading the way in primary care. Kathryn S Panaretto, Mark Wenitong, Selwyn Button and Ian T Ring, Med J Aust 2014; 200 (11): 649-652, doi: 10.5694/mja13.00005

ACCHOs provide a holistic, multidisciplinary model of care that encompasses primary health as well as social and emotional wellbeing and are well placed to provide services for Aboriginal and Torres Strait Islander people.[11]

The beneficial health outcomes for Aboriginal and Torres Strait Islander patients who are cared for by Aboriginal and Torres Strait Islander health staff are well documented and recognised in key policy documents, including the *National Aboriginal and Torres Strait Islander Health Plan*, and the *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework*. Indeed, ACCHOs are the preferred model for delivery of Aboriginal and Torres Strait Islander primary health care. Over 50% of Aboriginal and Torres Strait Islander people prefer to attend an ACCHO over a non-Indigenous practice and this number is growing.

The Child and Youth Assessment and Treatment Service (CYATS) delivered by the Central Australian Aboriginal Congress (Congress), in Alice Springs provides free diagnostic assessments and therapeutic interventions to Aboriginal children who may have neurodevelopmental delays or disorders such as FASD, Autism Spectrum Disorder (ASD), and ADHD.[12]

In keeping with ACCHO models of holistic care, CYATS also ensures that appropriate health, educational and wellbeing services are in place to support the family and the child which may include early learning services, NDIS access, social and emotional wellbeing programs, allied health services, and appropriate schools.[13]

ACCHOs are well suited to provide services for Aboriginal and Torres Strait Islander people with ADHD, given the likely prevalence, risk factors and burden of disease across Aboriginal and Torres Strait Islander communities. However, the current responsivity of ACCHOs to screen for and diagnose ADHD impacts on already stretched services – a focus on increasing their capacity and capability to do so is critical.

NACCHO recommends Government build the capacity of the ACCHO sector to ensure adequate and culturally safe diagnosis and support for Aboriginal and Torres Strait Islander children and adults with ADHD and other neurodiverse conditions.

Barriers to diagnosis

It is unknown if screening and diagnostic services are more readily available in settings for high-risk groups, and more importantly if services are culturally accessible to Aboriginal and Torres Strait Islander people.

ADHD is diagnosed based on Western concepts of health. Like psychological assessment tools used in child and adolescent behavioural assessments, tools used to screen for and diagnose ADHD are not validated for Aboriginal and Torres Strait Islander people.[14,15] The Australian Evidence-Based Clinical

[11] Bell et al (2000) 'Aboriginal community-controlled health service'. In 'General Practice in Australia' Department of Health and Aged Care: Canberra.

[12] SNAICC National Voice for our Children, Early intervention profile, https://www.snaicc.org.au/wp-content/uploads/2022/02/SNAICC-Early-Intervention-Profile-CAAC-CYATS.pdf

[13] SNAICC National Voice for our Children, Early intervention profile, https://www.snaicc.org.au/wp-content/uploads/2022/02/SNAICC-Early-Intervention-Profile-CAAC-CYATS.pdf

[14] Loh P, Hayden G, Vicary D, Mancini V, Martin N, Piek J. Australian Aboriginal perspectives of attention deficit hyperactivity disorder. Australian & New Zealand Journal of Psychiatry. 2016;50(4):309-10.

[15] Chau T, Tiego J, Brown L, Coghill D, Jobson L, Montgomery A, Murrup-Stewart C, Sciberras E, Silk TJ, Spencer-Smith M, Stefanac N. Against the use of the Strengths and Difficulties Questionnaire for Aboriginal and Torres Strait Islander children aged 2–15 years. Australian & New Zealand Journal of Psychiatry. 2023 Mar

Practice Guideline For ADHD notes that the identification of ADHD in Aboriginal and Torres Strait Islander peoples can be difficult, due to the lack of valid screening tools, and that the validity of rating scales used for screening and assessment of ADHD is generally not well established in most Aboriginal and Torres Strait Islander groups.[16] It further notes that it is likely that ADHD is commonly overlooked in Aboriginal and Torres Strait Islander peoples when presenting for other difficulties.

This may lead to both underdiagnosis, but also, overdiagnosis if culturally and clinically appropriate specialist assessment is not performed. What we do know is that considering the over representation and risk factors of ADHD, Aboriginal health and wellbeing services are more likely to experience presentations of ADHD in their clients and communities, and therefore will need more targeted supports and interventions.

Due to the paucity of community-controlled services delivering specialist services for neurodevelopmental disorders, many Aboriginal and Torres Strait Islander people will need to access mainstream services. Access to public ADHD diagnosis and treatment services is very limited for both children and adults, with wait times of up to two years.[17,18] Primary health care and early invention tells us is that significantly poorer outcomes arise when there are delays in diagnosis and intervention. A review of the accessibility issues relating to ADHD diagnosis is critical in further understanding and addressing the challenges, particularly for Aboriginal and Torres Strait Islander people.

NACCHO recommends a review relating to accessibility issues relating to ADHD diagnosis and investment in the development of culturally appropriate ADHD and neurodevelopmental diagnostic tools for Aboriginal and Torres Strait Islander people.

Barriers to accessing supports

In order to access support services, diagnosis is critical. Compounding poor outcomes due to diagnostic delays is the difficulty many Aboriginal and Torres Strait Islander people have in accessing supports. This might include a lack of local service providers which mean people need to travel off Country to access services, language and cultural barriers, lack of culturally appropriate services and a mistrust of institutional care due to personal and historical experiences, and experiences of systemic and interpersonal racism.

The availability and suitability of treatment and support for Aboriginal and Torres Strait Islander people with ADHD is limited and requires further research. Concerns such as a lack of trust, culturally inappropriate servicing, cost, remoteness and systemic discrimination and racism lead to access issues for Aboriginal and Torres Strait Islander people.

Developing specific strategies to address barriers to accessing support and to improve health literacy must be implemented. These must be based on Aboriginal and Torres Strait Islander concepts of health and social and emotional wellbeing in the broader context of their family and community. Interventions need to closely involve families and carers, and recommended services and support

[16] Australian Evidence-Based Clinical Practice Guideline For ADHD, ADHD Factsheet: ADHD in-Aboriginal and Torres Strait Islander Peoples https://adhdguideline.aadpa.com.au/wp-content/uploads/2022/12/ADHD-Factsheet-ADHD-in-Aboriginal-and-Torres-Strait-Islander-Peoples.pdf

[17] Whitehouse, A. Autism and ADHD assessment waits are up to two years. What can families do in the meantime? [Internet]. University of Western Australia. 2023. Available from: Autism and ADHD assessment waits are up to two years. What can families do in the meantime? (uwa.edu.au)

[18] Australian Broadcasting Association. ADHD diagnosis wait times are being blown out by the pandemic, experts say. [Internet]. ABC. 2022. Available from: ADHD diagnosis wait times are being blown out by the pandemic, experts say - ABC News

programs such as parenting programs, need to be sensitive of the reluctance Aboriginal people may have in disclosing, discussing, and managing challenging behaviours that can be associated with ADHD. Reasons for this can include fears of child removal as a result of the Stolen Generation and continued removal of children to out of home care.

NACCHO recommends the development of culturally appropriate supports and interventions for Aboriginal and Torres Strait Islander people led by Aboriginal and Torres Strait Islander community-controlled organisations.

In terms of treatments, best practice indicates that a combination of pharmaceutical and non-pharmaceutical inventions is recommended for people with ADHD. It is important to ensure that both forms of treatment are culturally accessible. Yet some evidence has suggested that Aboriginal children and adolescents are less likely to receive pharmacological treatment. One study also indicates that some pharmaceutical interventions may not be culturally supported.

> *Participants also saw the changes in a child's behaviour after medication as a loss of identity/self and this was reported to be the main contributor to treatment non-compliance. Overall, most participants recognised the detrimental effect of having ADHD. However, the current diagnostic process and treatment are not culturally appropriate to assist the Aboriginal community to effectively manage this disorder in their children.*[19]

ACCHOs are well placed to support culturally appropriate multimodal treatment models which integrate pharmaceutical and non-pharmaceutical inventions, which could enhance outcomes if adequately resourced. While the Closing the Gap Co-Payment Program has gone some way to improving access to pharmaceutical supports for Aboriginal and Torres Strait Islander people, it still presents administrative issues in client registration and prescription arrangements for practitioners.

Regulations regarding prescription of Section 8 medications used for ADHD varies across jurisdictions, further impacting access to treatments for ADHD. This requires both clients and practitioners to navigate multiple complex systems and laws, particularly in remote and border communities where movement of clients is common and where staff may provide locum services and visiting health services across borders. Access to medications can be further complicated by the fact that some jurisdictions do not honor prescriptions from other jurisdictions.

NACCHO recommends alignment of medicines regulations across jurisdictions to allow for cross-border dispensing and improve access to medications.

In addition, under current legislations, Section 8 medication can only be prescribed for a maximum of six months. The ability to fill or renew a prescription within this time can be hampered where access to visiting specialists is sporadic, where patients are often required to travel long distances to major centres for specialist health support and in regions often affected by severe weather events such as wet seasons and cyclones. Improved access to medications for ADHD could be better supported by shared care models which allow GPs to prescribe Section 8 medications as part of a comprehensive care team with a pediatrician or psychiatrist. The inclusion of pharmacists in ACCHOs to support is also required.

NACCHO recommends the introduction of shared care models in remote and border regions.

[19] Loh P, Hayden G, Vicary D, Mancini V, Martin N, Piek J. Australian Aboriginal perspectives of attention deficit hyperactivity disorder. Australian & New Zealand Journal of Psychiatry. 2016;50(4):309-10.

Role of the NDIS

The National Disability Insurance Scheme (NDIS) does not currently recognise ADHD as a primary disability. However, as with other neurodevelopmental disorders recognised under the NDIS, ADHD is a diagnosed and recognised neurodevelopmental disorder under the Diagnostic and Statistical Manual of Mental Disorders (DSM). The symptoms and characteristics of ADHD can have significant impacts on a person's ability to undertake activities of daily living, and in a range of environments such as home, school, work and community and support to manage these impacts is critical.

NACCHO recommends ADHD be recognised as a primary disability under the NDIS.

NACCHO recommends in line with other List B Conditions under the NDIS Act, ADHD is assessed on both diagnosis and functional impairments, recognising that the severity of ADHD symptoms and characteristics is varied.

Australian Evidence-Based Clinical Practice Guideline For ADHD

In principle, NACCHO supports the recommendations by the Australian Evidence-Based Clinical Practice Guideline For ADHD (the Guideline) and is encouraged to see the inclusion at 6.2 of recommendations to support access and care for Aboriginal and Torres Strait Islander people. However, other recommendations must be implemented in keeping with the Priority Reforms of the National Agreement. While Aboriginal and Torres Strait Islander people have a clear preference for using Aboriginal and Torres Strait Islander services, the reality is that the limited availability of ACCHO services and access to specialist supports will mean that many will need to access a mainstream service. Mainstream workforces and services must therefore be culturally competent to provide services to Aboriginal and Torres Strait Islander peoples.

NACCHO therefore highlight the need to ensure that any interventions are culturally appropriate and adequately resourced, particularly for Aboriginal and Torres Strait Islander community-controlled services. For example, integrating monitoring and screening as part of regular health checks may see reduced stigma and an increased in disclosure of concerns experienced however anecdotally, primary care practitioners are generally not well-versed in ADHD diagnosis and management.

It cannot be expected that Aboriginal and Torres Strait Islander health services and practitioners are expertly versed in recognising and responding to ADHD. Therefore, the appointment of specialist ADHD Care Coordinators in high-risk group settings (Recommendation 3.1.3) is strongly supported and aligns with existing ACCHO primary health care practices.

NACCHO supports recommendations around alignment of jurisdictional dispensing regulations, noting the issues raised above. We further note that the need to weigh the risk of misuse or stimulant diversion should not be a barrier to treatment. An approach which prioritises the needs and benefits of improved access for people with ADHD, over the risks of misuse, should be a strong consideration. Alternative approaches to accessing treatment and dispensing medication if risk factors present should be assessed on a case-by-case basis.

NACCHO recommends the Guidelines be added to the Health Pathways to support their wider use in general practice.