Aboriginal Health Council of Western Australia

Submission to the Senate Community Affairs Reference Committee

Inquiry into the Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD

21 June 2023

The Aboriginal Health Council Western Australia (AHCWA) welcomes the opportunity to provide a submission to the Senate Standing Committee regarding the Inquiry into the Barriers to consistent, timely and best practice assessment of attention deficit hyperactivity disorder (ADHD) and support services for people with ADHD (the inquiry).

AHCWA is the peak body for 23 Aboriginal Community Controlled Health Services (ACCHS) in Western Australia (WA). WA ACCHS are located across geographically diverse metropolitan, regional and remote locations. They deliver the most effective model of comprehensive primary health care for Aboriginal people[1] and are in a unique position to identify and respond to the local, cultural and health needs of Aboriginal people and their communities. AHCWA exists to support and act on behalf of its 23 Member ACCHS, actively representing and responding to their individual and collective needs.

This submission responds primarily to (a) "adequacy of access to ADHD diagnosis" and (b) "adequacy of access to supports after an ADHD assessment" of the inquiry's Terms of Reference, more specifically for Aboriginal children, as this was the feedback provided by AHCWA's Member Services. The submission highlights the challenges Aboriginal clients face – in metropolitan, regional and remote areas across WA – when trying to access ADHD assessments and diagnosis. In addition to long waitlists and, in some places, a complete absence of access to assessment, there appears to be a lack of support services across the state and obstacles and barriers for Aboriginal people to access those that do exist. Finally, AHCWA would like to draw attention to the Considerations pertaining to Aboriginal and Torres Strait Islander people in the 2022 Australian ADHD Professional Association (AADPA) Guidelines and make recommendations to improve access to ADHD assessment and diagnosis, as well as culturally safe and appropriate support services for Aboriginal people in WA.

Background

Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental condition, typically diagnosed in childhood, by observable symptoms such as trouble paying attention, controlling impulsive behaviours, or be overly active.[2] ADHD often lasts into adulthood, but can be managed through behavioural strategies and/or medication so that individuals with the condition are able to live productive, healthy lives. ADHD is present in almost all regions of the world,[3] indicating it is not a culturally specific phenomenon; however, it

[1] Throughout this submission, AHCWA uses the term 'Aboriginal' to respectfully refer to all Aboriginal and Torres Strait Islander people across WA.
[2] The worldwide prevalence of ADHD: a systematic review and metaregression analysis - PubMed (nih.gov)
[3] IBID

is perceived differently across cultures with some viewing mental health holistically beyond the notion of symptoms and functional impairment. This is the case for Aboriginal people, who view mental health through the lens of connection to spirituality, environment, community, Country, social-emotional and physical health.[4]

AHCWA Member Services expressed agreement with this holistic view of mental health as ACCHS' health professionals discussed cultural elements where certain behaviours may be interpreted differently due to cultural (and even generational) context. For example, some of the behaviours that are expected of children (especially at school such as sitting quietly, mat time, etc.) are perhaps not in line with cultural differences in parenting techniques and expectations. Additionally, one ACCHS said there may be a difference in reaction for the diagnosis of ADHD depending on a number of cultural and socio-economic factors with some parents seeking diagnosis, where others may be concerned with an assessment of children that might result in an ADHD diagnosis, perhaps a remnant of colonisation or fear of child removal and/or protection interventions.

The critical importance of developmental assessments and supports

ACCHS recognise a critical component of improving health and wellbeing is to ensure Aboriginal children are assessed for health, development and behavioural issues and, where necessary, referred to high quality, culturally safe services as early as possible. This includes the recommended universal schedule of childhood health and development checks; a school health check at school entry; and screenings through visits to General Practitioners and child health nurses. AHCWA Member Services acknowledged the importance of child health checks and screenings, and highlighted workforce gaps and the need for further training as factors contributing to challenges and barriers impacting ACCHS ability to effectively screen for developmental and behavioural issues, including ADHD.

One ACCHS in the Pilbara commented that it is highly unlikely a child in community would be diagnosed with ADHD prior to attending school. This was based on the fact that behaviours often triggering assessment are not likely to be identified by family members as particularly abnormal. Moreover, even if they were, the assessment process is somewhat dependent on information from teachers' observations of children. As a result, if attendance at school is irregular or inconsistent, or a child does not attend school for whatever reason, then the amount of necessary information to support assessment and diagnosis is likely to be missing or incomplete. Further, a lack of culturally appropriate screening and diagnostic tools often prohibits parents, and children, from fully engaging in the assessment process. For instance, the completion of a Connors questionnaire requires a baseline level of parental education and literacy, which may not be present, thus inciting shame or embarrassment and a lack of engagement in the process.

Several clinicians from AHCWA Member Services recognised that ADHD is correlated with an array of socioeconomic difficulties that impact adversely on health, including impaired school performance, difficulty in sustaining healthy relationships, challenges in self-managing concurrent illness or chronic disease, and a propensity for risk-taking behaviour and misadventure. These obstacles and barriers result in Aboriginal children potentially slipping between widening gaps. Recent data released by the Productivity Commission reflects the shortfall in the socio-economic target 4 of the National Agreement on Closing the Gap of having 55 per cent of Aboriginal and Torres Strait Islander children meeting national early

[4] Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (Dudgeon et al., 2014) https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/working-together-aboriginal-and-wellbeing-2014.pdf

development goals, with just 34.3 per cent of Aboriginal children meeting the threshold in 2021, down from 35.2 per cent in 2018.[5] In WA, only 31.3 per cent of Aboriginal children were assessed as developmentally on track across all five domains in 2021, a decrease of 0.1 per cent from 2018.[6] According to the 2021 Australian Early Development Census (AEDC), Aboriginal children in very remote areas across WA, as well as Aboriginal children living in the most disadvantaged socio-economic areas, were least likely to be developmentally on track across all five domains (18.6 per cent[7] and 25.9 per cent[8] respectively). Declines against the five AEDC domains were recorded for Aboriginal children across very remote, remote and regional areas with major cities only improving by 0.1 per cent.[9]

Historical and contemporary injustices have deeply impacted Aboriginal people in WA – socially, emotionally and economically – and inter-generational trauma and entrenched disadvantage are experienced at significantly higher rates than for the non-Indigenous population.[10] Poor life outcomes associated with poverty are social determinants of crime.[11] In 2021, the Australian Institute of Health and Welfare reported that 79 per cent of WA youth in detention aged 10 to 17 years were Aboriginal or Torres Strait Islander[12] and in the June 2021 quarter, WA Aboriginal children were 54 times more likely to be detained than non-Aboriginal children.[13] Despite steady improvements in reducing the Aboriginal 'rate per 10,000 young people' in detention, as per Target 11 of the National Agreement on Closing the Gap, substantial work remains to achieve the target of reducing Aboriginal youth in detention by 30 per cent.[14]

Moreover, it is widely reported that children with neurodevelopmental disorders are disproportionately represented in youth justice systems.[15] A 2018 publication assessing the prevalence of youth neurodevelopmental impairment in Banksia Hill Detention Centre revealed 89 per cent of the detained youth 'had at least one domain of severe neurodevelopmental impairment, [and 36 per cent] were diagnosed with Fetal Alcohol Spectrum Disorder (FASD)'.[16] The study concluded with a recommendation to enhance diagnostic pathways to improve rehabilitative processes[17], and also identifies intervention strategies as having a positive influence on children in detention and the potential to reduce recidivism.[18]

[5] Backwards step on Closing the Gap action as early childhood development for Indigenous Australians falls short | Indigenous Australians | The Guardian
[6] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4
[7] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4, Table CtG4A.3
[8] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4 Table CtG4A.4
[9] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4
[10] https://www.socialreinvestmentwa.org.au/justice-reinvestment
[11] https://www.socialreinvestmentwa.org.au/justice-reinvestment
[12] Figure: Number of young people in detention on an average night in Western Australia, June quarter 2021. https://www.aihw.gov.au/reports/youth-justice/youth-detention-population-in-australia-2021/contents/data-visualisation/number-of-young-people-in-detention
[13] AIHW. Youth detention population in Australia 2021. (2021). https://www.aihw.gov.au/getmedia/63a1f495-fbce-4571-bcea-aae07827afa0/aihw-juv-136.pdf.aspx?inline=true (pg. 18).
[14] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area11
[15] Holland, L., Reid, N. & Smirnov, A. Neurodevelopmental disorders in youth justice: a systematic review of screening, assessment and interventions. (2021). https://doi.org/10.1007/s11292-021-09475-w (pg. 1).
[16] Bower, C., Watkins, R.E., Mutch, R.C., et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. (2018). http://dx.doi.org/10.1136/bmjopen-2017-019605 (pg. 1).
[17] Bower, C., Watkins, R.E., Mutch, R.C., et al. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. http://dx.doi.org/10.1136/bmjopen-2017-019605 (pg. 8).
[18] Holland, L., Reid, N. & Smirnov, A. Neurodevelopmental disorders in youth justice: a systematic review of screening, assessment and interventions. (2021). https://doi.org/10.1007/s11292-021-09475-w (pg. 30).

Building upon these results, a 2022 study noted that youth in WA detention had 'high rates of unrecognised and unmet health and wellbeing requirements, including undiagnosed FASD'.[19]

AHCWA urges the WA Government to acknowledge the high likelihood that there are many Aboriginal youth in detention that have undiagnosed developmental, physical and mental health conditions that require culturally appropriate diagnoses and treatment. Alongside other health professionals, ACCHS will be a key component of any comprehensive and culturally secure health service for youth in detention. This aligns with Priority Reform Two of the National Agreement on Closing the Gap, which focuses on building Aboriginal community-controlled sectors to deliver high quality services that meet the needs of Aboriginal people, and Priority Reform Three, which aims to make mainstream services culturally safe and delivered in partnership with Aboriginal people.

Challenges and barriers to ADHD assessments, diagnosis, medication and support services

AHCWA's Member Services discussed various obstacles and barriers to accessing assessments and diagnosis related to neurodevelopmental conditions, including ADHD, as well as supports after an assessment. It is evident from feedback provided by lead clinicians in the ACCHS sector that access to services and support varies by region. However, there are challenges shared by Member ACCHS, including inconsistent or inadequate access to paediatricians and allied health services, long wait times or poor referral pathways, and delayed diagnoses or no access to diagnostic services. Many AHCWA Members also mentioned the lack of developmental paediatric assessments for any neurodevelopmental conditions.

Member Services discussed the challenge of accessing paediatricians to assess developmental delays, as well as developmental paediatricians to provide assessments for more complex disorders, such as ADHD. In addition, it was recognised that many other diagnoses or factors affect behaviour and teasing that out requires a great deal of expertise, time and services that ACCHS often cannot access. For instance, neurocognitive aspects of FASD and other conditions could all present as inattention, but may or may not be improved by the use of stimulants and their efficacy is reliant on a number of baseline variables including, but not limited to - food security, environmental health and nutrition, iron deficiency and sleep – any of which might not be optimised.

Some Member Services in regional and remote areas highlighted that they receive limited funding to secure a visiting paediatrician anywhere from three to six times per year, while in other regions a paediatrician visits three times per year for one week, traveling to various communities to see children. The quality of service offered is very high, though the waitlist is generally long making access difficult. These paediatricians work with local GPs as co-prescribers and often collaborate cooperatively in partnership. While some ACCHS discussed how highly transient Aboriginal populations find it difficult to access prescriptions when moving between towns, solutions can usually be found through communication between ACCHS as needed. While ACCHS appreciate that there is at least some availability of services in their communities, they stressed that there is a clear need for more. Furthermore, Member ACCHS mentioned the service pathway to support adolescents with neurodevelopmental conditions, such as ADHD, to transition into adult support services is unclear, as private costly services are not viable, presenting challenges for young people and their families when trying to access necessary and appropriate services.

[19] Mutch, R., Freeman, J., Kippin, N., Safe, B., Pestell, C., Passmore, H., ... & Marriot, R. Comprehensive Clinical Paediatric Assessment of Children and Adolescents Sentenced to Detention in Western Australia. (2022). http://www.jfasrp.com/index.php/JFASRP/article/view/22/9 (pg. e27).

Long wait lists for paediatric appointments were also discussed as a serious concern for ACCHS across WA. Clinicians in Perth said referral pathways through Kooliny Moordt, Child and Adolescent Health Service (CAHS) Aboriginal team, often result in wait times of more than 12 months to access a paediatrician. This is further supported by data provided by the Shadow Minister for Early Childhood Learning, the Hon Donna Faragher MLC, who recently said "the median wait time to access a paediatrician through the metropolitan Child Development Service is now 16.4 months".[20] Moreover, in an August 2022 article, the Royal Australian College of General Practitioners highlighted the crisis of inaccessibility of paediatricians across Australia and referred to "exploding wait times" for child development services in the metropolitan Perth area.[21] Despite CAHS funding additional temporary CDS paediatrician positions, as well as paediatric training positions, wait times across metropolitan Perth continue to increase.

Where assessments are accessible and may result in diagnosis, one ACCHS discussed challenges associated with stimulant prescribing for young people, highlighting the need for children to regularly attend school. In order to safely and effectively prescribe stimulants for children in community, it is essential that the paediatrician knows the child is attending school, where the stimulant is stored and given to the child, as the purpose of stimulants is to foster academic achievement such as literacy. As such, stimulants are often not administered over weekends. However, if a child is not regularly attending school, they are not receiving their medication and teachers are unable to monitor its efficacy. Most importantly, children with ADHD are not benefiting from the necessary medication to regulate behaviour and support learning. One Member ACCHS discussed the need for increased access to non-pharmacological treatment and less dependency on medication as the sole treatment.

It is crucial that access to culturally sensitive identification, diagnosis and treatment of ADHD be improved to facilitate holistic primary care for Aboriginal people. AHCWA Member ACCHS recognise that, overall, primary health care is better served holistically, by comprehensive rather than disease-specific, referral services and that a strengthened and integrated mental health service would be more useful across the board than a service that addressed a single diagnosis. All of this should be explored, and delivered, in a culturally safe and appropriate way employing a strengths-based focus in local cultural contexts. If Aboriginal people are to enjoy long and healthy lives – as per Target 1 of the National Agreement on Closing the Gap – the WA Government needs to work in partnership with the ACCHS sector to improve equitable access to child health services, including neurodevelopmental assessments and support services, to support early childhood development. Optimal health and wellbeing outcomes for Aboriginal communities will only be achieved through Aboriginal community-led partnerships and locally based solutions. Community-specific circumstances and needs must determine the design and delivery of solutions.

As per Priority Reform One of the National Agreement on Closing the Gap, all governments have committed to partnering and sharing decision-making with Aboriginal organisations and communities. Under Priority Reform Two, governments have also committed to building Aboriginal community-controlled sectors to deliver services to support Closing the Gap. Similarly, Recommendation 3a of the WA Sustainable Health Review calls for "ongoing recognition and strengthening of the Aboriginal Community Controlled Health Services as leaders in Aboriginal primary health care including through sustainable funding for partnerships in prevention and early intervention."[22] Again, one of the guiding principles of the WA Aboriginal Health and Wellbeing Framework 2015-2030 includes: "Ongoing participation by Aboriginal people and organisations

[20] Wait times for child development services still too high - Opposition Alliance (loop.wa.gov.au)
[21] RACGP - Paediatricians float solutions for deteriorating access problems
[22] https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Sustainable-Health-Review/Final-report/sustainable-health-review-final-report.pdf

in decision-making to take back care, control and responsibility of their health and wellbeing"[23], which includes promoting health across the life course. The significant issues relating to child development services clearly require the WA Government to work with Aboriginal organisations and communities in a way that reflects these existing policy commitments.

RECOMMENDATIONS

Recommendation One: That the WA Government fund ACCHS to assist with the diagnosis and management of the many chronic developmental, physical and mental health conditions of the children detained in youth detention. Derbarl Yerrigan Health Service is ideally placed to assist with the management of the complex needs of youth detained at Banksia Hill Detention Centre.

Recommendation Two: That the WA Government increase its capacity to deliver child development services to meet the needs of Aboriginal children across WA, including:
(a) Increased access to paediatricians and allied health teams in ACCHS that do not currently have these services;
(b) Expanding access to paediatrician and allied health teams at ACCHS that already have some level of engagement; and
(c) Exploring options to support and fund other non-government providers who deliver assessments for neurodevelopmental conditions, and complex disorders, where the State does not have workforce capacity.

Recommendation Three: That Commonwealth Government supports AADPA 2022 ADHD Guidelines, considerations and recommendations that:
(a) Clinicians should conduct culturally appropriate screening assessment *and* assessment of ADHD in Aboriginal people, employing a strengths-based focus when possible, with the awareness that ADHD symptom questionnaires and other tools may not be valid and may require the use of an interpreter and/or Aboriginal Health Worker.
(b) Culturally and psychometrically validated symptom questionnaires should be developed for ADHD presenting in Aboriginal children, adolescents and adults.
(c) Interventions should include input from parents, families, community, and Elders as appropriate, to maximise treatment effectiveness given strong family values in Aboriginal cultures, with prioritisation given to the wishes of parents, families and individuals with ADHD regarding treatment options (e.g. cultural, pharmacological versus non-pharmacological treatments and their combination).
(d) Non-pharmacological interventions need to be culturally sensitive and appropriately tailored for Aboriginal people with consideration given to local cultural context.
(e) Pharmacological interventions should be explained carefully with an awareness of potential cultural issues and may be more acceptable if offered as part of a broader package aimed at helping a person reach their potential.

Recommendation Four: That the WA Government undertakes a study to determine the unmet need for child development services in Aboriginal communities, and commits to partnering with the ACCHS sector and Aboriginal people to design and deliver culturally secure, comprehensive programs to meet the need identified.

23 https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Aboriginal-health/PDF/12853_WA_Aboriginal_Health_and_Wellbeing_Framework.pdf p. 7