Aboriginal Health Council of Western Australia

Submission to the Select Committee into Child Development Services

Inquiry into Child Development Services

7 November 2022

The Aboriginal Health Council Western Australia (AHCWA) welcomes the opportunity to provide a submission to the Select Committee into Child Development Services regarding the Inquiry into Child Development Services (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 (2)(d) of the inquiry's Terms of Reference, "opportunities to increase engagement in the primary care sector including improved collaboration across both government and non-government child development services including Aboriginal Community Controlled Organisations", and includes feedback provided by AHCWA's Member Services. The submission highlights the importance of early childhood development, factors that may negatively influence development and the early childhood developmental delays some Aboriginal children are experiencing as they enter school. It also discusses the detrimental impact of undiagnosed and untreated developmental delays. The submission outlines the challenges Aboriginal clients face – in metropolitan, regional and remote areas across WA – when trying to access paediatric care, allied health services, and developmental assessments and supports. Difficulties accessing these services negatively impacts Aboriginal children's ability to have prosperous and healthy lives. Finally, the submission makes recommendations to improve access to child development services for Aboriginal children in WA.

(2)(a) The importance of early childhood development

The first five years of a child's life are critical for positive life outcomes. It is during this time that children build the foundation for lifelong learning, health, and wellbeing. Children experience the greatest rate of development during their early years, which are a critically important time in brain development.[2] While connections in the brain are made throughout life, the rapid pace at which our brains develop in these first five years is never repeated.[3] Given the critical development that occurs during early childhood, this is the

[1] Throughout this submission, AHCWA uses the term 'Aboriginal' to respectfully refer to all Aboriginal and Torres Strait Islander people across WA.

[2] https://raisingchildren.net.au/guides/first-1000-days/development/development-first-five-years#about-early-child-development-nav-title

[3] https://harvardcenter.wpenginepowered.com/wp-content/uploads/2007/03/InBrief-The-Science-of-Early-Childhood-Development2.pdf

most effective time to support the wellbeing of children to prevent or lessen problems in later childhood, adolescence and adulthood. If a child is identified as having a potential developmental issue, it is critical they are referred for further diagnosis and, if necessary, receive appropriate treatment and services.

Biological and environmental factors impact on a child's development and include prematurity and low birth weight, birth injury, vision and hearing impairment, or chronic illness. Environmental risk factors can also include parental trauma, social isolation, poverty, poor housing, poor quality services and lack of access to services. Often risk factors cluster together, for example, poverty and its frequent associations with family and environmental risk factors, which represents the highest identifiable association with mild to moderate developmental delay.[4] Social determinants, and the impact of political and historical factors, can put Aboriginal children at a higher risk of experiencing developmental issues in childhood and into adulthood.[5] As such, a critical component of improving Aboriginal people's health and wellbeing is to ensure Aboriginal children are assessed for health and development issues and, where necessary, referred to high quality, culturally safe services as early as possible.

However, Aboriginal children are slipping between widening gaps. Recent data released by the Productivity Commission reflects the shortfall in the 10-year Closing the Gap target of having 55 per cent of Aboriginal and Torres Strait Islander children meeting national early development goals, with just 34.3 per cent of Aboriginal children meeting the threshold in 2021, down from 35.2 per cent in 2018.[6] 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 form 2018.[7] 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[8] and 25.9 per cent[9] 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.

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. Poor life outcomes associated with poverty are social determinants of crime.[10] In 2021, the Australian Institute of Health and Welfare reported that 79 per cent of WA youth in detention aged 10–17 were Aboriginal or Torres Strait Islander[11] and in the June 2021 quarter, WA Aboriginal children were 54 times more likely to be detained than non-Aboriginal children.[12] Despite steady improvements in reducing the Aboriginal 'rate per 10,000 young people' in

[4] is my child normal? Milestones and red flags for referral (racgp.org.au)

[5] Wise S 2013, *Improving the early life outcomes of Indigenous children: implementing early childhood development at the local level*, Closing the Gap Clearing House, Australian Institute of Health and Welfare (AIHW).

[6] Backwards step on Closing the Gap action as early childhood development for Indigenous Australians falls short | Indigenous Australians | The Guardian

[7] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4

[8] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4, Table CtG4A.3

[9] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area4 Table CtG4A.4

[10] https://www.socialreinvestmentwa.org.au/justice-reinvestment

[11] 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

[12] 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).

detention, as per Closing the Gap Target 11, substantial work remains to achieve the target of reducing Aboriginal youth in detention by 30 per cent.[13]

It is widely reported that children with neurodevelopmental disorders are disproportionately represented in youth justice systems.[14] 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)'.[15] The study concluded with a recommendation to enhance diagnostic pathways to improve rehabilitative processes[16], and also identifies intervention strategies as having a positive influence on children in detention and the potential to reduce recidivism.[17] 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'.[18]

The WA Government should 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, 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.

(2)(d) Opportunities to increase engagement in the primary care sector including improved collaboration across both government and non-government child development services including Aboriginal Community Controlled Organisations

Initial early childhood screening

In WA, the recommended universal schedule of childhood health and development checks consists of five visits to a child health nurse between birth and two years of age (the "purple book") and a school health check at school entry. In metropolitan Perth, this service is provided by Child and Adolescent Health Service (CAHS) Community Child Health. In regional WA the service is provided primarily by WA Country Health Service (WACHS). Some ACCHS , particularly in remote areas, provide the service under contract to WACHS.

Additionally, WACHS offers a more comprehensive Enhanced Child Health Schedule (ECHS), particularly for Aboriginal families. This schedule includes the six universal child health contacts plus a further ten contacts to provide extra support and monitoring. Whereas the universal schedule is designed to be provided by a

[13] https://www.pc.gov.au/closing-the-gap-data/dashboard/socioeconomic/outcome-area11
[14] 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).
[15] 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).
[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. http://dx.doi.org/10.1136/bmjopen-2017-019605 (pg. 8).
[17] 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).
[18] 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).

trained child health nurse, the additional ECHS contacts can be provided by an Aboriginal Health Worker/Practitioner (AHW/P) or a general nurse. WACHS encourages ACCHS to provide these extra services in recognition of the sector's holistic model of care and closer engagement with Aboriginal families. However, only some ACCHS are funded to do this work.

ACCHS are well placed to provide initial primary care-level developmental screening for Aboriginal children. The model of care is comprehensive, community-centered, collaborative and culturally safe. Screening does not rely solely on attendance at scheduled visits but can be done opportunistically when families attend for other reasons. Perhaps most importantly, children and their families feel safe in an environment where they have trusted and established relationships with the staff (particularly AHW/Ps).

ACCHS' child health service provision is, however, patchy across the state due to inadequate funding (particularly where there is no WACHS child health nurse contract). Child health screening is time-consuming and services need adequate resources to do it well. There is also a need for increased training/upskilling in child development for AHW/Ps, clinic nurses and remote area nurses to support the work of scarce specialist child health nurses.

One potential solution includes providing AHW/Ps with additional skills to support early childhood development and further respond to the needs of children in their communities. In this way, every encounter a child has with the service is an opportunity to track that child's developmental progress. This would involve providing training to AHW/Ps to develop the necessary skills and capabilities to make and record developmental observations. While AHCWA has partnered with WACHS to deliver child health education in the past, there is need for additional investment and support to recommence this kind of training. AHW/Ps are integral to ACCHS in light of their cultural understanding, clinical expertise, and their relationships with clients and community – for these reasons, they play an essential role in providing remote health services. Hence, AHW/Ps are perfectly placed to support the expansion of access to culturally safe child health and development services in remote locations.

Lack of access to services, long wait times and poor referral pathways

AHCWA's Member Services discussed various obstacles and barriers to accessing support when health checks identified children with additional needs. It is clear from feedback provided by lead clinicians in the ACCHS sector that access to child development 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 including for FASD and Autism Spectrum Disorder (ASD).

Member Services discussed the challenge of accessing paediatricians to assess developmental delays, as well as developmental paediatricians to provide assessments for more complex disorders. Some Member Services in regional and remote areas said that they receive funding from Rural Health West to secure a visiting paediatrician anywhere from three to six times per year. In other regions, such as the Ngaanyatjarra Lands, a paediatrician visits three times per year for one week, traveling to various communities to see children. 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.

Prior to the COVID-19 pandemic, clinicians in remote Pilbara communities said there was a fly-in-fly-out (FIFO) paediatrician from WACHS visiting Jigalong once a month. When regional borders closed, services were disrupted for an extended period of time and COVID-19 exacerbated conditions and caused delays in access. A FIFO paediatric service to Jigalong recommenced in January 2022; however, the sale of the Charter Company, logistical challenges and workforce shortages have again disrupted that service. Another regionally-based ACCHS said that they had secured a private paediatrician on a regular basis for a half day each week. However, this is only possible because it was drawn from their core funding, at a costly annual expense.

Long wait lists for paediatric appointments are a serious concern for ACCHS across WA. Clinicians in Perth said referral pathways through Kooliny Moordt, CAHS Aboriginal team, often result in wait times of more than 12 months to access a paediatrician. This is confirmed 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".[19] 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.[20] A news article discussing the launch of this inquiry stated that 5944 children in metropolitan Perth and 1025 children in country WA are said to be waiting to see a paediatrician in the public health system.[21] Despite CAHS funding additional temporary CDS paediatrician positions, as well as paediatric training positions, wait times across metropolitan Perth continue to increase.

In the Kimberley, clinicians discussed children aged six or seven years old waiting up to 12 months to see a developmental paediatrician. Additionally, at one regionally-based ACCHS, lead clinicians described the pathway for supporting children with developmental delays as one characterised by a lack of access to a developmental paediatrician, delayed assessments and diagnoses, and long wait lists that push children further behind, impacting their social and emotional wellbeing. The same service said that after their regular developmental paediatrician retired in 2021, they were left to engage with WACHS services at the hospital, with wait times of up to 12 months leaving children without diagnoses that might allow access to NDIS packages and support.

Another remote ACCHS discussed challenges with referrals being sent back from the regional hospital. The ACCHS clinician said a lack of capacity at the hospital was resulting in children only being seen when presenting with acute conditions. The ACCHS clinician spent a great deal of time trying to clarify the services WACHS is responsible for delivering, as well as advocating on behalf of specific clients with high levels of need. For example, one child with developmental delays, including significant speech delays, and gross and fine motor delays, was said to have been waiting for two years without any provision of services or support.

Lack of access to formal diagnoses impacting on treatment options

Due to a lack of initial assessments, ACCHS clinicians report that a large proportion of children are missing out on support services for undiagnosed developmental delays. A Pilbara-based ACCHS discussed a population of children in Newman and Jigalong who are "massively underserved". The lead clinician pointed to a backlog of children with undiagnosed behavioural and developmental issues, with more than 44

[19] Wait times for child development services still too high - Opposition Alliance (loop.wa.gov.au)
[20] RACGP - Paediatricians float solutions for deteriorating access problems
[21] Inquiry launched into WA's exploding wait times for child development services (watoday.com.au)

referrals currently on the books. In this particular area, children in need of assessment must travel to Port Hedland to access a WACHS child development paediatrician, which is a vast distance from some of the remote communities needing support.

Pilbara clinicians also said that there are a number of children who would be eligible for NDIS packages, but are not enrolled because they have not been properly assessed. Earlier access to assessments and potential diagnosis of developmental delays in these children may increase NDIS accessibility, creating a greater incentive for NDIS providers to deliver services in remote communities. There could also be pooling of NDIS funding between children to pay for the travel costs of allied health services. Clinicians report that they see a number of young adults who clearly have had developmental delays from childhood, but have never been properly assessed and therefore are ineligible for services and payment. One young adult only received a formal diagnosis of FASD in his early twenties. Evidence shows this is not uncommon.[22]

One of the most concerning issues raised by several Member ACCHS was the increasing need for FASD assessments. Because the accurate diagnosis of FASD requires assessment by a range of clinicians, this presents a challenge in an environment of health workforce shortages and vast distances between ACCHS and specialist services. The gold standard entails the assessment and diagnosis being conducted by a specialist multi-disciplinary team, including a paediatrician or adolescent physician and psychologist with any combination of a speech pathologist, occupational therapist, social worker and physiotherapist.[23] As such, access to screening and diagnostic services in rural and remote locations is often limited.

Many of the ACCHS said that, prior to the COVID-19 pandemic, FASD assessments were completed by Patches Paediatric Outreach. However, those services were disrupted when border closures and regional lockdowns began and they have not recommenced. When inquiring with Patches about when those services would begin again, AHCWA was told Patches does not currently have the capacity to conduct outreach assessments due to workforce issues, and that they were hoping to be able to provide such services again in early 2023. Until that time, FASD assessments can only be performed in Perth, with patients responsible for the cost of travel, which is a major barrier for families.

Additionally, some clinicians said that ASD assessments with the Department of Communities often entail a wait time of 12 months. Moreover, one Member ACCHS said the service pathway to support adolescents with ASD to transition into adult psychiatry is unclear. Private psychiatry is costly, which presents challenges for young people and their families when trying to access necessary and appropriate services.

Inadequate allied health services

Many of ACHWA's Member Services noted the lack of allied health services for children, long wait times for services that are available and a need for greater access to multi-disciplinary teams of child allied health professionals, preferably embedded in their ACCHS. In an article discussing the launch of this inquiry, it was said that more than 17,000 children are currently waiting to access services such as speech pathology, physiotherapy and occupational therapy, with wait lists for children to see audiologists, clinical psychologists, OTs and speech pathologists just as high.[24]

[22] https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf

[23] Bower C, Elliott E (2016), on behalf of the Steering Group. Report to the Australian Government Department of Health: Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder (FASD).

[24] Inquiry launched into WA's exploding wait times for child development services (watoday.com.au)

The majority of ACCHS who provided feedback for this submission said they did not have access to the full range of multi-disciplinary child allied health services, which further impacts developmental delays. In Perth, the ACCHS does not have an allied health team and is reliant on CDS to provide these services. Some services in remote areas said they did not have any visiting allied health services as it was difficult to secure travel for them, whereas others said that they were unable to fill positions that had been vacant for some time. Moreover, ACCHS in very remote areas said children rarely have the opportunity to travel to regional centres or Perth where services may be located given challenges such as vast distances and lack of transport. Other ACCHS said that they had no allied health services unless a child had secured NDIS funding; in those cases, it is sometimes possible to schedule allied health visits when a number of children require similar support.

In the Kimberley, access to the Commonwealth-funded National Disability Insurance Agency (NDIA) Remote Early Childhood Service (RECS) was said to be invaluable, providing funding for Early Childhood Early Intervention (ECEI) services and support for children under the age of seven if a potential developmental disability was observed by clinicians or parents who were able to refer children. While the grant-based parameters of this program allow for flexibility of use, the short-term nature of the funding is not sustainable. It does, however, provide access to developmental supports without diagnosis or assessment. Another regional ACCHS also utilises RECS to fund an OT and speech pathologist who are able to spend up to one day a week within the clinic seeing young children. Through RECS, NDIA bulk fund allied health services to children aged zero to seven; however, when children reach the age of seven, funding ceases. If the child continues to experience a developmental delay, and has not had an assessment resulting in an NDIS package, there are challenges with accessing services, the result of which is often long waitlists of up to 12 months to access a paediatrician through WACHS.

One Pilbara-based ACCHS discussed workforce challenges that make it difficult to provide allied health services to meet the high level of need among children and young people. The service currently employs one OT through a grant-based program; however, this is not sustainable and fails to meet the high level of need. The OT works across six sites and, at this time, is unable to take on new referrals as the need is so great with existing clients. The service also has funding for one speech pathologist, but has been unable to fill the role. WACHS previously provided allied health services from Newman to Jigalong (specifically physiotherapy, occupational therapy and occasionally speech pathology) about once a month. Unfortunately, this has been interrupted due to COVID-19 restrictions and WACHS travel policies in 2022.

Many ACCHS discussed how valuable it would be to have multi-disciplinary allied health services embedded in the clinic to facilitate an integrated model of care that acts as a ‘one stop shop’ for families accessing services for their children.

Working in partnership with the ACCHS sector and Aboriginal communities

If Aboriginal people are to enjoy long and healthy lives – Outcome 1 of the National Agreement – the WA Government must work in partnership with the ACCHS sector to improve equitable access to child health 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, 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 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".[25] Again, one of the guiding principles of the WA Aboriginal Health and Wellbeing Framework 2015-2030 includes: "Ongoing participation by Aboriginal people and organisations in decision-making to take back care, control and responsibility of their health and wellbeing"[26], 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.

(2)(e) Other government child development service models and programs operating outside of Western Australia and the applicability of those programs to the State

AHCWA suggests that the WA Government explores the following models of care that include child development components:

- Strengthening Care for Children
- The Australian Nurse-Family Partnership Program
- Aboriginal Maternal and Child Health: Aboriginal-led MCH services (Victoria)
- The Koori Maternity Strategy (Victoria)
- Aboriginal Family Birthing Program (SA)
- Anangu Bibi Family Birthing Program (SA)

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 complex disorders including FASD and ASD where the State does not have workforce capacity.

Recommendation Three: That the WA Government explore options to utilise telehealth as a supplementary service where there are workforce shortages and other barriers (such as level of remoteness). For this

[25] https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Sustainable-Health-Review/Final-report/sustainable-health-review-final-report.pdf
[26] https://ww2.health.wa.gov.au/~/media/Files/Corporate/general-documents/Aboriginal-health/PDF/12853_WA_Aboriginal_Health_and_Wellbeing_Framework.pdf p. 7

modality to reach its potential there is a need to provide training across the health sector. It also cannot completely replace in-person assessment and care.

Recommendation Four: That the WA Government advocate for the Commonwealth to raise the NDIA Remote Early Childhood Service eligibility age to nine and commit to longer-term funding of this program, with easier access for ACCHS to utilise this funding stream.

Recommendation Five: 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.

Recommendation Six: That the WA Government partners with the ACCHS sector to expand access to child development training for Aboriginal Health Workers and Practitioners.