

Submission to the Parliamentary Enquiry on Child Development Services – Puntukurnu Aboriginal Medical Service

by

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Background

Puntukurnu Aboriginal Medical Service (PAMS) is an Aboriginal Community Controlled Health Service (ACCHS) that provides primary health care to the Martu and Nyiyaparli people of the Western Desert. The population characteristics of the PAMS clients are notable for a high proportion of young people characterised by lower life expectancy and relatively high fertility. Ages 0-4, 5-9, 10-14 and 14 – 19 each make up around 8.5% of our current patients, making young Aboriginal people approximately one third of our patients. This adds up to just under 1000 individuals, although perhaps one third of these are patients regularly seen at PAMS. Spread across five communities including the township of Newman, and the four remote communities of Jigalong, Parnngurr, Punmu and Kunawarritji, PAMS reach covers approximately 50,000 sq kilometres.

Highly prevalent conditions relevant to developmental paediatrics

The Aboriginal children cared for and treated at PAMS clinically present with high rates of a number of developmental concerns, most notably fetal alcohol spectrum disorder (FASD). A brief search of our clinical software identified 68 children and young people who have a diagnosis of FASD listed in their summary. Although this may not be entirely accurate due to issues with data input, it reflects the high rates of behavioural issues and alcohol consumption in pregnancy which are identified in our children. Additionally developmental delays frequently observed by clinicians include language, speech, gross and fine motor delays as well as behavioural issues with 59 children whose names appeared in the clinical software when searching by keyword “delayed development”. Up to 36 children have been identified with additional allied health needs, despite PAMS limited capacity to provide such allied health services such as occupational therapy (OT). The Occupational Therapist currently providing services at PAMS believes that 80 to 90 per cent of the referrals she has received are for children who may be diagnosed with FASD. Nineteen children were found by a keyword search for Attention Deficit Hyperactivity Disorder (ADHD). These numbers are all likely to be grossly under-representative of the true prevalence of all these conditions due to lack of early screening and the requirement that these conditions be diagnosed by a paediatrician. Our clinical software system indicates PAMS has 85 children currently referred to a Paediatrician and awaiting appointments, assessments, diagnosis and/or treatment (although this includes referrals for medical as well as developmental issues).

The cohort of Aboriginal children seen by PAMS are born with a number of risk factors for developmental issues (in addition to antenatal alcohol use) such as maternal smoking, low birth weight, poor nutritional status and higher rates of preterm birth. At a young age, these children are also then frequently exposed to a number of traumatic events such as domestic violence, which then results in a complex interplay of neurological, developmental and psychological factors manifesting as significant behavioural issues. When this is not addressed early enough, it results in a number of

social and emotional adverse outcomes such as poor school attendance and low educational achievement, high rates of juvenile offending, substance use and mental health problems.

Current Paediatric and Child Development Services

PAMS paediatric services are at present in a state of flux following the disruption of our previous charter plane service from Port Hedland to Jigalong. In the past, this service enabled a paediatric registrar to visit and see children once a month. As a result, we have had no visiting paediatrician since early 2022. We may have a return of service to Jigalong before the end of this year. The situation in the other remote Aboriginal communities we service is even more dire where there has been no visiting paediatrician since the end of 2020. This has been due to a complex interplay of inadequate funding and workforce issues, including due to COVID and border closures.

There is a paediatric clinic run out of WA Country Health (WACHS) in Newman. Child development services may be accessed via referrals to the paediatric clinic Port Hedland, but this is not an ideal situation with long travel times over distances ranging from 600km to 800km from our communities to Port Hedland. I am actually not really able to differentiate regular paediatric services from the developmental clinic in Port Hedland, as Griffiths assessments etc are all done by the regular paediatric clinic. They are only able to do one Griffiths assessment per day, so we have been unable to transport a larger group of children or send siblings together for this purpose. As far as I am aware, the Port Hedland paediatric clinic lacks a neuropsychologist and as a result, the clinic is unable to make official diagnoses of FASD. The Department of Communities may be moving into that space towards the end of this year however.

At this time, PAMS has limited workforce and capacity to provide allied health services to meet the needs of young children in the region. We currently employ one Occupational Therapist (OT) employed through the Jiji Program (grant funded for 2 years). We also have funding for one Speech Pathologist; however, PAMS 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; however, this has been infrequent and interrupted due to COVID restrictions and WACHS travel policies in 2022. There are visiting allied health services from Port Hedland to the more remote communities; however, these are more aligned to meet the needs of adults rather than paediatric developmental needs. Previously, PAMS was able to utilise PATCHES to provide diagnostic assessments for FASD in particular, but PATCHES has not visited our communities in the last two years and it appears that there are no future plans to do so.

In addition to the current lack of diagnostic services, there is limited access to ongoing therapy services in the remote communities. PAMS has one OT working across six sites with a brief to enrol five children at each site so she has essentially already met her quota without further consideration of new patients. As previously stated, the WACHS allied health services at present are quite minimal, and even when they were visiting regularly, one visit per month is simply not enough. WACHS allied health in Newman (although they mainly focus on Children in Care), and some private providers may provide care, but this often relies on a child having a NDIS package to access therapy; however, the travel costs for therapists or patients are often prohibitive.

Due to a lack of initial assessments, a large proportion of children who would be eligible for NDIS are not enrolled. Earlier access to assessments and potential diagnosis of developmental delays in these children may increase NDIS enrolment, creating a greater incentive for NDIS providers to come into community to provide services. There could also be pooling of NDIS funding between children to pay

for the travel costs of allied health. PATS funding is not applicable for allied health. In an attempt to explore alternate strategies to meet the needs of children with developmental delays PAMS has recently used NDIS money to access a FIFO model of care for allied health in Jigalong, which is starting soon. Diagnostic delays increase the risk of children being too old to receive NDIS without a diagnosis, and it has been the case that one patient who is under the age cut-off was refused a NDIS package due to a lack of diagnosis. We have 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 of our young adults (with an IQ of 53) only received a formal diagnosis of FASD in his early twenties.

There are also limitations in communication between organisations at present. For instance, recently a child who had been previously diagnosed with ADHD by a PATCHES assessment (and on the basis of this, met the diagnostic criteria for FASD with severe impairment in three neurodevelopmental domains) was seen in the Newman clinic. The paediatrician, who was new to the area, did not have access to the PATCHES report nor any collateral information from the school. This led to a consultation which did not address the primary issues and could be argued was not worth the 700km round trip.

PAMS has no private paediatricians servicing our communities. Over the last two years, our organisation did receive funding from Rural Health West to provide a paediatrician to the remote clinics; however, the amount granted was insufficient to employ a paediatrician and pay for travel costs. Funding did not cover paediatric services in Jigalong or Newman. With the breakdown of services in the region, we have been told that WACHS Karratha and Port Hedland will now be taking over the visiting paediatric service; however, this is still a work in progress. To give an idea of the cost of sending a visiting specialist to the remote communities, our fortnightly GP charter plane costs around \$12,000 to visit each of the three communities for one day.

When the visiting paediatrician from Port Hedland to Jigalong was unexpectedly cancelled, there was no move to offer a telehealth service in lieu. As far as I know the only paediatric telehealth services we have are the respiratory and endocrine clinics from PCH – nothing in the developmental sphere.

Specific Challenges

PAMS' patients do not fit nicely into a diagnostic box and often suffer from a number of co-morbidities. Many clients presenting with subtle or not so subtle brain damage from a number of intra-uterine and post-natal insults. These include, but are not limited to, fetal alcohol exposure, antenatal tobacco exposure, poor maternal nutrition, preterm delivery, exposure to psychological trauma, intergenerational trauma, cultural displacement, childhood malnutrition, hearing issues and many other conditions. Likewise, the therapy that is needed will not fit into a neat category, but needs to be outcomes and skills focussed.

One of the biggest issues facing this generation of young Aboriginal children is that their parents have also been exposed to the above issues and as a result, often lack well-developed emotional regulation skills to teach their children. In order for a child to meet their maximal developmental potential, they need parents who are able to teach and support them. Our OT at PAMS reports that one of her main areas of need that she has identified is helping the parents to better regulate their own emotions in order to pass on those skills to their children. This also manifests as a complex diagnostic interplay between mental health disorders and developmental disorders, where frequently the child does not fit neatly into either category and therefore does not receive the

necessary services. Lack of a clear diagnosis follows these children into adulthood when applying for the disability support pension as well.

Recommendations:

1. We were very happy with the diagnostic service provided by PATCHES, and we would be keen for that to be reinstated. Otherwise, a neuropsychologist regularly servicing at least Newman and Port Hedland, preferably in conjunction with a paediatrician with expertise in FASD.
2. We are keen for the Karratha / Port Hedland visiting paediatric service to be expedited.
3. When services are disrupted, we would appreciate a telehealth alternative. Clearly developmental assessments are not easy to do over telehealth, but it could help correctly triage the patients who need to travel to Port Hedland most urgently.
4. PATS funding for allied health would greatly improve service accessibility.
5. Multidisciplinary teams rather than individual clinicians.
6. A greater focus on community engagement and parental upskilling, as well as more inclusive relationships between WACHS services, our clinic, and other related parties such as the local schools, police and CPFS. For instance, a monthly or bimonthly case conference to identify gaps in service and high-risk kids would help immensely.
7. Assistance to upskill our existing primary healthcare providers. One of the common complaints from receiving services is that referrals lack enough information to properly triage and assess. If GPs and nurses at the coalface are given some additional skills then we can provide better referrals to help allocate resources more efficiently.
8. Better liaison between developmental paediatrics and CAMHS to manage complex behavioural issues.
9. A set of standardised referral assessments such as ADHD screening tools, Autism screening tools etc. which GPs can complete to facilitate easier triaging.
10. Aboriginal health workers or liaison officers inside the paediatric clinic at Port Hedland to help parents and relatives negotiate the system and to identify cultural factors which may be contributing to poor service engagement.
11. Basing the Newman paediatric clinic out of our facility for some of their time to improve access to our notes and to make use of our cultural brokerage. (Note this is currently being negotiated).
12. Building a closer relationship between existing WACHS allied health services and our Jiji program to reduce overlap and better facilitate care. (This will be included in an upcoming MOU between our organisation and WACHS Pilbara).

We hope that this submission helps bring to light the current dire situation in remote Aboriginal communities with regards to developmental paediatrics. We would also like to bring to your attention existing research in this area which demonstrated that a large proportion of young people in contact with the criminal justice system had underlying (and often undiagnosed) neurodevelopmental issues. If we wish to keep these children out of the criminal justice system, then we must invest in appropriate diagnosis and intensive therapy services from a young age.

[Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia | BMJ Open](#)

Bower C, Watkins RE, Mutch RC, *et al* Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia

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