Long-term vision needed to improve access to child development services

Dr Stephen Oo
AMA (WA) Paediatrics Representative

Figures revealed in the WA Parliament show the median time it takes to get to see a developmental paediatrician in Perth has increased to 23.9 months. This is deeply concerning, as it means at least 50% of patients will be waiting much longer than the two-year period.

For many families, this wait will be just the start of a journey and does not account for further long waits for autism assessments. For the families currently waiting, it means stress and uncertainty, associated with a lack of diagnosis; and it may also mean years without access to therapy and school support that are often tied to a diagnosis.

The wait-time figures continue to grow. Concerningly, it was reported in September 2025 that nearly 12,000 children were waiting to see a paediatrician. A two-year wait to see a paediatrician for these children is far too long. There is overwhelming evidence that early intervention makes a major difference, and we know there is a very tight window in early life when therapy is more effective. This translates into better long-term outcomes, not just in developmental domains but also in educational, social and mental health outcomes. There is a life-long cost to these kids if they're not seen soon enough.

PAEDIATRIC FACTS

- **Children with developmental difficulties are waiting almost two years to see a paediatrician in Perth, seven months longer than they were last year.**
- **The wait time to see a clinical psychologist is now 11.4 months, 8.4 for an occupational therapist, 5.4 for a speech pathologist, 4.1 for an audiologist, and 1.4 for a physiotherapist.**
- **A 2023 parliamentary select committee report on child development services said there had been a 52% increase in referrals to child development services over the previous decade.**

The waits for children with developmental issues extend beyond just the initial wait for paediatrician review. The parliamentary figures also show long wait times to see other developmental allied health staff. The wait time to see a clinical psychologist is now 11.4 months (fortunately down by half from 23.5 a year ago); 8.4 months for an occupational therapist; 5.4 months for a speech pathologist; 4.1 months for an audiologist, and 1.4 months for a physiotherapist.

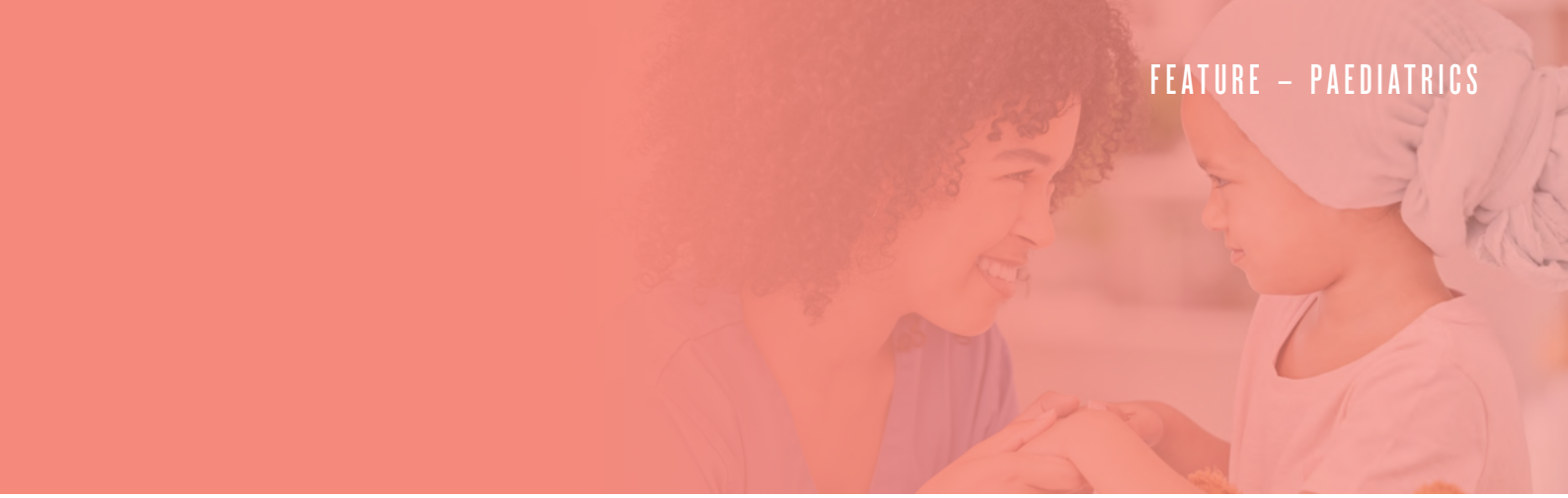
The human costs for these kids and families of delayed diagnosis, and therefore support, should not be underestimated. These are families that already experience financial strain due to limited ability to work, or missed work, due to the care needs of their kids. Daycare may not be an option for many if their child has significant regulation and behavioural issues. These issues will only rise with the current cost of living pressures, and will only add to already high rates of carer burnout and social isolation.

How did we end up here?

The core problem is longstanding workforce shortages. There have been two parliamentary inquiries over the last two decades that document how WA Health's Child Development Service (CDS) has continued to struggle. The most recent parliamentary select committee into child development services released their report in November 2023, and it makes clear that CDS has experienced an unprecedented surge in demand, with a 52% increase in referrals since 2013-14.

Despite this, there has not been a meaningful staffing increase for the last 14 years from 2010-2023. In 2010 there was a significant $49 million injection of funding, which did result in the halving of wait times. Following the recent 2023 inquiry report, the Government announced in 2024 an additional $38 million funding for CDS. While this funding is welcome, when considered relative to 2010, and with inflation and significantly larger waitlists, its impact is unlikely to be as large as required.

Even with that additional funding, it has not been easy to fill workforce gaps after 14 years of underfunding. Paediatric training pathways are generally longer, with most paediatricians being in training for 10 years before finally qualifying. It is part of the reason why workforce shortages cannot be fixed quickly, even following funding uplift.



“The core problem is workforce shortages, not just in developmental paediatrics, but for a lot of the other sub-specialist paediatricians and paediatric surgeons as well. Fixing it needs a coordinated plan. We need to train more clinicians, and we need to put concerted effort into retaining more people than we train.

The current struggles in CDS are the consequence of successive governments’ poor long-term planning and a health funding model that waits to react to the next crisis. WA kids cannot afford another 14 years to pass before CDS receives another meaningful staffing increase.

What are the possible solutions?

What we need is a long-term vision to tackle this problem. Obviously, we need more training positions, particularly in areas where the wait times are longest. Specifically, we need more developmental paediatricians. We also need to keep in mind that clinicians are currently carrying heavy caseloads, and there remains a risk of burnout – this can exacerbate the problem if people leave the health system altogether, or leave for other jurisdictions. Some thought must be given to rationalising people’s caseloads.

Recruiting more International Medical Graduates (IMGs) could help to boost our numbers, but that is not necessarily an easy solution to implement. We have to acknowledge, as Health Minister Meredith Hammat has articulated when talking about wait times, that WA is competing with every other state as well as internationally for a very small pool of specialists. And demand is growing faster across the country, and the training pipelines are too small.

The other issue is that when we’re parachuting in a person trained overseas, specialties like child development require knowledge of local systems and resources. So, IMGs need significant supervision and training as well, in a system where training is already limited due to already high workloads.

I believe the level of workforce pressure in paediatrics is not unique to WA, but is added to by our geographic isolation and spread which makes workforce distribution challenging. Telehealth has helped improve access for families in rural and regional areas. Workforce mobility for paediatric specialties both to urban and rural areas is required to ease geographic disparity in services and to deliver care closer to home.

While there is an investment in older adult community hubs by the Government, it would be good to see similar thought put to the paediatric community hubs to help with mobility of paediatric services in general. The fact remains that almost any solution to create better efficiency cannot be implemented without a larger workforce, and a need for a greater number of paediatric clinicians on the ground.

Looking to the long-term future, a lot of thought still needs to be given to support integration of services. This includes making funding available to pilot novel team-based care models that bridge between the silos of child development services, child and adolescent mental health services, and hospital services. We also need integration into the schools, where kids spend a significant portion of their lives.

I would hope that at some point we could embed OTs and speech pathologists into early education pathways, and start early in kindergarten and pre-kindergarten, where they reach out to identify children with difficulties as early as possible and provide support.

Early educators already do an amazing job of providing support to many vulnerable children, and often want and need guidance from developmental therapists to better help those with developmental differences. When we recognise that not all children learn in the same way, in school environments where accommodations and support are more universal, we often find all children benefit – not just those with the most need.

I write this final comment with awareness that our health system is under enormous pressure from an ageing population, with discourse being dominated by significant adult bed and ED pressures. I worry that in doing so, we forget about the littlest members of society and that their healthcare needs are equally urgent and important. The latest waitlist data represents their tiny cries for help. ■

Paradigm shift needed to improve the detection of children with treatable genetic condition

Dr Andrew Martin, Consultant Paediatrician

Paediatricians are pushing for a universal childhood screening program to help detect and manage the estimated 20,000 children with inherited high cholesterol across Australia, to prevent their risk of future heart disease.

Children with familial hypercholesterolaemia, known as FH, are born with very high levels of low-density lipoprotein (LDL), or "bad" cholesterol. The common genetic condition, affecting one in every 250 of the general population, predisposes affected individuals to cardiovascular disease (CVD) in early adult life.

Untreated, 50% of men and 20% of women with FH will suffer a fatal or non-fatal coronary event by age 50. However, when diagnosed and managed from childhood, future CVD is completely preventable and individuals can expect a normal life expectancy, emphasising the importance of early detection and management.

Consultant paediatrician Dr Andrew Martin, the medical lead at Perth Children's Hospital (PCH) paediatric Centre for High Impact Lipid Disorders (CHILD), says the case for universal screening for FH is gaining traction nationally and internationally, supported by over three decades of evidence demonstrating that early detection and treatment prevent premature CVD.

"There is a real push across the world to try and change the narrative, so we think about FH and other high-impact inherited lipid disorders as treatable paediatric conditions, allowing us to focus on maintaining the heart health of these children," Dr Martin explains.

"We can manage FH very effectively if it is diagnosed in childhood, as opposed to the current situation where adults with FH are identified for the first time in a coronary care unit with established CVD, after having suffered a heart attack, requiring coronary artery stents or bypass surgery.

"Diagnosing and managing inherited high cholesterol from childhood is true prevention, and it means we can stop history repeating itself generation after generation for families with FH."

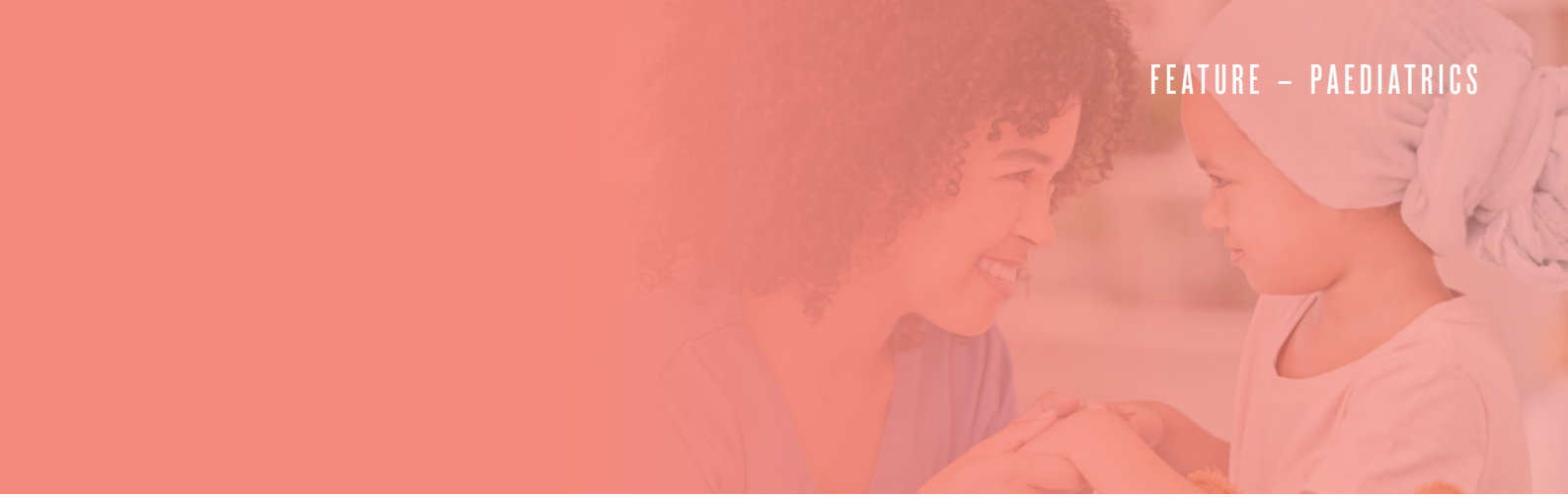
Dr Martin says the most effective way to screen for FH is in childhood, with various options being considered nationally. Screening children with a total or LDL-cholesterol level between the ages of one and nine best discriminates between those with and without FH in the general population.

"We performed a WA pilot study in 2018 to 2020, funded by the PCH Foundation and Telethon, where we screened children aged 12 to 18 months for FH at the time of an immunisation, with a point-of-care cholesterol test.

"We screened 448 children and diagnosed three with FH. Importantly, with reverse cascade testing, each child with FH led to the detection of previously unaware family members with FH, resulting in an additional five adult relatives who were at more imminent risk of an acute coronary event being diagnosed and able to start treatment without delay.

"Our universal screening approach to detect FH in childhood was not only feasible, but also acceptable, with 90% of families reporting they would choose to screen their next child, and it is highly cost-effective."

Dr Martin says a national universal childhood FH screening program remains a key advocacy priority, but there is much GPs can do now to improve the detection of children with FH. CHILD is encouraging GPs to think about screening for FH as part of any routine blood tests, and to follow up with cascade screening of the extended family if the initial results proved positive.



FH is one of the most common and serious genetic disorders in childhood, yet remains profoundly underdiagnosed and undertreated in Australia.

"If a child is having a blood test for any reason, there is an opportunity to add on a non-fasting lipid profile, especially if there is a family history of high cholesterol or premature CVD," he says.

"This is a simple step with the potential not only to identify a child with FH who can commence management to prevent future CVD, but with reverse cascade testing to diagnose their affected parent with FH and other family members."

A clinical diagnosis of probable FH can be made in a child with a non-fasting LDL-cholesterol >5 mmol/L, or LDL-cholesterol >4 mmol/L, if there is a parental history of hypercholesterolaemia or premature CVD. Children with probable FH should be referred to the PCH lipid clinic for confirmatory genetic testing and to plan management.

Once an individual is found to have a pathogenic FH variant, GPs can request genetic cascade testing of any first- or second-degree relatives, using MBS Item 73353. CHILD will support cascade testing of any first or second degree relatives of an FH proband under 18.

Once the FH diagnosis is confirmed in a child, management is relatively straightforward and highly effective. A heart-healthy lifestyle should be introduced, with a diet low in saturated and trans-fats, encouraging physical activity and maintaining a healthy body weight.

LDL-cholesterol goals for children are less stringent than for adults: <4 mmol/L for children under 10 years and <3.5 mmol/L for children aged 10-18. This can be achieved in most children with lipid-lowering medication, most often a low-dose statin, which is well tolerated and has an excellent long-term safety profile in childhood.

Despite major advances in knowledge of FH, and national and international guidelines, Dr Martin says FH remains largely undetected and untreated worldwide, with more than 90% of adults and 95% of children unaware they have the condition.

In response to this persistent under-detection of FH in the general population, the 2022 Prague Declaration was a call to action, endorsed by European national governments and policymakers, to commit to implementing FH universal childhood screening – this has been commenced by several European countries including Slovenia, Germany and Luxembourg.

Dr Martin says a PCH Foundation-funded, three-year program, 'FH in Kids', has helped increase the detection of children with FH in WA. Working in collaboration with the adult tertiary hospitals and GPs, FH in Kids supported the co-ordinated cascade testing of children under 18, and has demonstrated a three-fold increase in rates of FH detection over the first two years of the program.

"There were adults who had been diagnosed with FH, but cascade testing of their children or grandchildren had not occurred," he says. "FH in Kids helped us achieve that, but having screened through all of these patients, we are now left waiting for adults to present with a clinical event before their children can be screened."

FH Australia, the consumer-led national voice for inherited high cholesterol, has called for Australia to follow Europe's lead and establish a universal childhood screening program for FH. Founded in 2023 by three Western Australians with a lived FH experience, FH Australia was established to raise awareness about this common inherited condition, to support individuals and families, and to advocate for solutions to the healthcare gaps that contribute to persistently low detection rates.

FH is a treatable paediatric disorder. With diagnosis and management from childhood, future cardiovascular disease is entirely preventable and a normal life expectancy is achievable.

"FH Australia is a key partner for CHILD, and we are incredibly lucky to have their leadership group based here in WA", Dr Martin says.

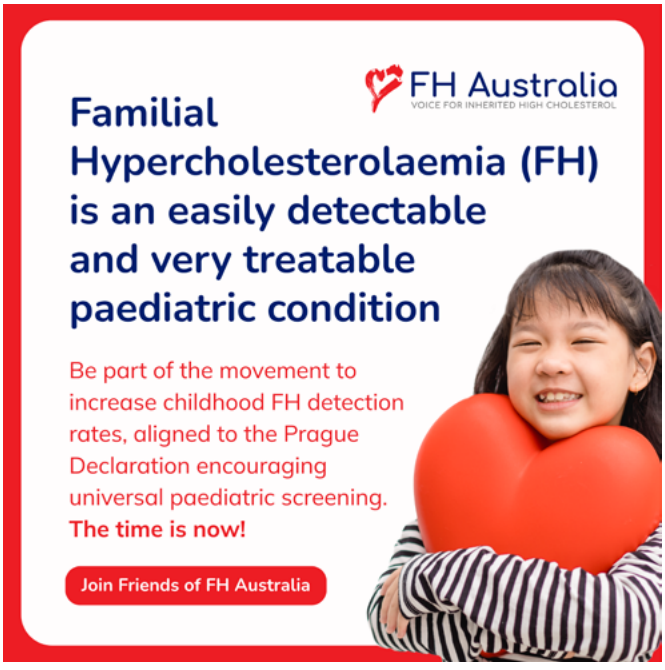
CHILD, established in July 2025 with a $3.2 million, five-year grant from the Stan Perron Charitable Foundation, is helping to provide world-class clinical care to children and adolescents with FH and other high-impact lipid disorders.

CHILD is the first of its kind in Australia, providing a multifunctional, multidisciplinary, cross-sector hub caring for children with FH, elevated Lp(a) and severe hypertriglyceridaemia in WA.

Dr Martin says FH is one of the most common and serious genetic disorders in childhood, yet it remains profoundly underdiagnosed and undertreated in Australia.

Three children are born with FH in Australia every day, and without a universal childhood screening program the overwhelming majority will not be diagnosed until they have already accumulated years of preventable CVD risk or, in too many cases, until a parent or they themselves suffer a premature CV event.

"Safe, effective and well-tolerated treatments are available. The evidence base for childhood detection, treatment and follow-up is robust. What is required now is the will from individual clinicians, health systems and government to find these children and treat them." ■



FH FACTS

- **Familial hypercholesterolaemia (FH) is inherited in an autosomal dominant manner, meaning that if a parent is affected, each child has a 50% chance of also inheriting the condition.**
- **The prevalence of FH is about 1 in 250 people, with an estimated 10,000 individuals affected in WA, of whom 2,000 are children under 16 years. There are three children born with FH every week in Western Australia.**
- **FH Australia, the consumer-led national voice for inherited high cholesterol, has called for Australia to follow Europe's lead and establish a universal childhood screening program for FH.**
- **FH in Kids, a PCH Foundation-funded three-year program, has demonstrated a three-fold increase in rates of FH detection over the first two years of the program.**
- **The paediatric Centre for High Impact Lipid Disorders (CHILD) at Perth Children's Hospital is the first of its kind in Australia, funded by a $3.2 million, five-year grant from the Stan Perron Charitable Foundation.**

> **"The evidence base for childhood detection, treatment and follow-up is robust. What is required now is the will from individual clinicians, health systems and government to find these children and treat them."**

More resources

- FH Australia: **fhaustralia.org.au**
- Referral guidelines for GPs: **pch.health.wa.gov.au/For-health-professionals/Referrals-to-PCH/Prereferral-guidelines/Lipid-disorders**