FASD: Pathways to diagnosis

A guide for permanent and adoptive carers

What is a FASD diagnosis?

FASD (Fetal Alcohol Spectrum Disorder) is a lifelong neurodevelopmental disability caused by exposure to alcohol before birth. A diagnosis is based on clinical assessment, not a single test. It can be made at any age.

Diagnosis requires four things:

- Confirmed prenatal alcohol exposure (PAE)
- Clinically significant impairment in at least three of nine domains of brain function
- Functional impact – the impairments affect daily life at home and at school or work
- No better explanation for the difficulties

> *A diagnosis does not determine a child's potential or predict their future. It provides a framework for understanding how they function and what supports they need.*

The nine domains of brain function

Assessors look for significant impairment in at least three of these areas:

Motor skills
- Balance, coordination, fine motor

Communication
- Understanding and using language

Academic skills
- Reading, writing, maths

Memory
- Holding and using information

Attention
- Sustaining focus; filtering distractions

Executive function
- Planning, organising, flexible thinking

Adaptive functioning
- Managing daily life tasks independently

Emotional and behavioural regulation
- Managing reactions and impulses

Intellectual abilities
- General cognitive ability (IQ)

> *A child does not need a low IQ to be diagnosed with FASD. Many children with FASD have average or above-average intellectual abilities but significant difficulties in other domains.*

Prenatal alcohol exposure (PAE)

Confirmation of prenatal alcohol exposure is required for a FASD diagnosis. This can be challenging for carers to obtain if it is not clearly written in medical or other records, and if they don't have first hand knowledge.

If PAE is known

- Write down what you remember, including amounts, timing, and how you know
- Ask others who have information to document it – a DFFH case note, an email from a family member, or a note from something you were told
- Pass this information on to the paediatrician or GP

If PAE is suspected but not confirmed

- Ask professionals for help to locate records – birth records, antenatal records, child protection records
- The CISS scheme in Victoria allows medical providers to request records without parental consent – this includes information about birth parents of children who have been adopted.
- FASDConnect can assist paediatricians to find and assess this information

> *If PAE cannot be confirmed, a FASD diagnosis may not be possible – but a developmental assessment is still worthwhile. The child may be eligible for supports regardless of diagnosis.*

Who does the assessment?

Assessment can be completed by a multidisciplinary team or by a paediatrician, psychiatrist or psychologist working with input from others.

Paediatrician

- Physical examination, including facial features and other dysmorphology
- Other health issues that may contribute to or complicate the picture
- ADHD assessment and global developmental assessment for children under 7
- Referral to psychology, speech pathology, and occupational therapy
- Referral to the Monash Children's Hospital VicFAS clinic

Psychologist or neuropsychologist

- Intellectual abilities (IQ)
- Attention, memory, and academic skills
- Executive function
- Adaptive functioning (Vineland)
- Emotional and behavioural regulation

Speech pathologist

- Language comprehension and expression
- Social communication (contributes to adaptive functioning)

Occupational therapist or physiotherapist

- Motor skills, balance, and coordination

Where to start

A paediatrician is usually the starting point for a FASD assessment. Options include:

- Community paediatric clinics
- Hospital outpatient clinics
- Aboriginal children's clinics, including Wadja and Healthy Koori Kids
- Private paediatricians
- Paediatricians in schools
- Children's Health and Wellbeing Locals (Brimbank Melton, Loddon, Southern Metro Melbourne)

If you are waiting for a paediatrician, a GP can also support referrals for allied health assessments, help locate low-cost or free options, and refer children aged 0–3 directly to Monash Health.

Allied health assessments

Allied health assessments can be completed through:

- NDIS providers
- Community health clinics
- Private providers
- University clinics
- Department of Education
- Child and adolescent mental health services (CAMHS)

Clinicians are encouraged to refer to the FASD Guidelines for information and guidance for conducting assessments.

> *Clinicians assess both a child's natural abilities (what they are capable of) and their functional performance (what they can actually do in daily life). Information from home and school is important – not just clinic performance.*

When the picture is complicated

When scores don't reflect daily functioning

Some children perform well in a clinic setting – with support, scaffolding, and a calm environment – but can't reproduce this in everyday life. A child might have average test scores but be unable to manage independently at home. Or the carer might report much greater challenges at home, while the school might not report the same concerns.

When carers are completing assessment questionnaires, it's important to describe what the child actually does, not what they could do in an ideal moment.

Clinicians assessing children with FASD need to be able recognise why a child might be able to demonstrate self regulation skills at school, but have significant behaviour challenges at home. Increased scaffolding and routine at school, the effects of medication, and fatigue all play a role in the varying behaviour children show in different settings. They can use their clinical judgement and draw on test scores as well as real-world observations when assessing if a child has an impairment.

If a child has clear impairments

If a child has a few areas of clear impairment in areas most commonly assessed – intellectual abilities, adaptive function, language, motor skills and/or ADHD, this might be enough to progress a FASD diagnosis. Paediatricians can review this information using the FASD Guidelines and seek support from services like FASDConnect to consider a diagnosis.

If impairments are not obvious

Some children do not have obvious delays in these areas but still have significant difficulties in executive function, attention, memory, or emotional regulation. These children are more likely to need additional assessments – these may be an option through the school or their current providers, or they might need a referral to a neuropsychologist.

Assessments that don't directly contribute to diagnosis

Not all assessments by allied health providers contribute to a FASD diagnosis.

- Sensory assessments – useful for planning support but do not contribute to the diagnostic domains
- Autism assessments – if autism is ruled out, the results may contribute to the social communication domain
- Screening tools – can indicate where further assessment is needed, but not sufficient alone
- Trauma assessments – helpful for understanding the child, but do not tell us about neurodevelopment

> *It is important to understand a child's cognitive and language abilities before implementing trauma-informed or therapeutic strategies. Strategies that rely on verbal reasoning or abstract thinking may not be accessible to children with FASD.*

If a child doesn't meet diagnostic criteria

Not meeting criteria at one point in time does not mean FASD is ruled out. Some domains, including executive function and adaptive skills, develop over time and may not show significant impairment until later.

- If the gap between the child and their peers widens over time, reassessment may be needed
- Reassessment before the end of primary school is often helpful
- Continue gathering information about what the child struggles with in daily life

If PAE cannot be confirmed, a FASD diagnosis may not be possible even where impairments are clear. NDIS eligibility is moving towards functional impairment as a criterion for support, which may provide a pathway regardless of diagnosis.

What carers can do

- Keep advocating – document what you observe and share it with clinicians
- Collect information: what does the child struggle with, and in which settings?
- Use FASD-informed strategies even without a diagnosis – they benefit all children
- Work with allied health providers and use supports like PCAF to find good options
- Learn about FASD and brain-based behaviour to help reframe how you understand the child's actions

> *A diagnosis can provide a pathway forward, but it is not the only pathway to getting support. The work of understanding a child's needs – and advocating for them – matters regardless of where things land diagnostically.*

Services and resources

FASD services in Victoria

FASD services at Monash Children's hospital include:

- VicFAS - Specialist FASD assessment service for children aged 3-10 - referral from a paediatrician or psychiatrist is required. Long wait times apply, but there are options for Aboriginal children, and the secondary consultation service is available.
- Jacana – assessments for children aged 0-3 – referral from a paediatrician or GP
- FASDConnect – secondary consultation for children aged 0-18 in Out of Home Care (primarily children under DFFH care, but can provide advice to paediatricians of children in permanent care.
- https://monashchildrenshospital.org/developmental-paediatrics/
- Other hospitals are developing capacity to assess FASD.

Allied health assessment options

University clinics at Victoria university, Australian Catholic University, Melbourne University, La Trobe Uni and others can provide free or low cost assessment. If you google **"developmental assessments in Victorian universities**" you will find options – check the detail for what they can provide, the age range, and costs/waiting times.

Some community health providers have child development clinics – if you seach online for "**paediatric clinic community health**" you will find a list of providers.

Children's Health and Wellbeing Locals can be found at: https://www.medicarementalhealth.gov.au/finding-help/kids-hubs#find-your-nearest-location

FASD guidelines

Information about the FASD Diagnostic Guidelines can be found at the University of Queensland or the FASDHub.

UQ is developing resources to support families and those with lived experience understand the FASD guidelines – you can join the mailing list for updates.

