

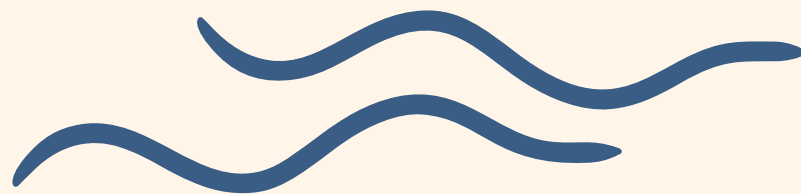
# Guide to the referral and diagnostic process

## What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the impacts of prenatal exposure to alcohol. Alcohol is a teratogen – a toxin that passes through the placenta and can cause damage to the brain and body of a developing embryo or fetus. FASD is a lifelong disability involving a spectrum of disorders depending on the frequency, quantity, and timing of alcohol exposure, as well as other comorbidities.

The Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) was published in 2016. It recommended an overarching diagnostic term of FASD with two organising categories - FASD with, and FASD without, the three characteristic facial features. Previously, a range of diagnostic terms such as Fetal Alcohol Syndrome and partial Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorder and Alcohol Related Birth Defects were used.

While there are no accurate prevalence rates of FASD in the general Australian population, estimates based on international data indicate that approximately 2% of the population may be affected – meaning as many as 6,000 babies could be born with FASD each year in Australia. This exceeds the prevalence of each of the following disorders: Autism Spectrum Disorder (ASD); Down's Syndrome; Spina Bifida; and Cerebral Palsy. FASD is sometimes referred to as a 'hidden harm' or 'invisible disability' as it is under-recognised and often goes undiagnosed. This is true in Australia, where there is limited awareness and knowledge of FASD, and specialist diagnostic services are rare.



## The purpose of this guide

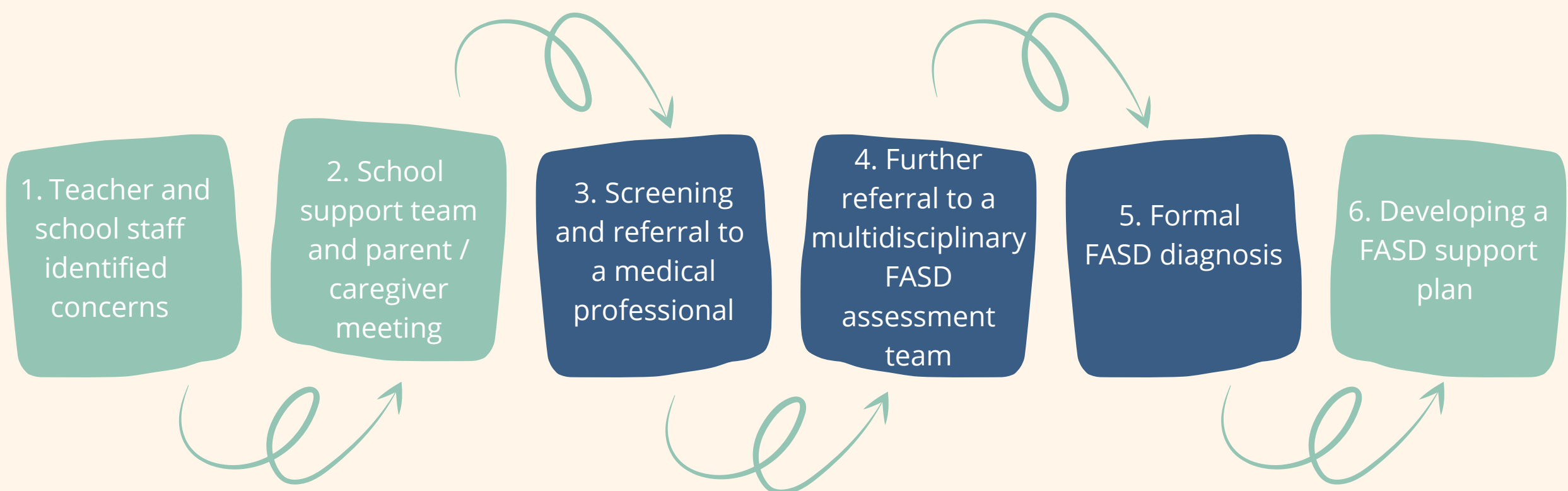
Research shows that timely diagnosis and early intervention is essential to ensure the best outcomes for people with FASD across a range of life goals, including mental health and education. Teachers and support staff can play a vital role in recognising neurodevelopmental concerns, connecting families and health services, and implementing supports in schools to ensure children with FASD are supported in their ongoing education.

This guide is intended to be useful for all primary school teachers and support staff and will outline the six stages in the referral process after concerns are identified at school. The referral process begins with the identification of concerns in an educational context and extends to the implementation of appropriate supports once a diagnosis has been made by a multidisciplinary team comprising medical and Allied Health professionals. The guide will provide more detail at the stages most relevant for primary school teachers and support staff, including identifying concerns in the classroom, arranging a school support team and parent meeting, and implementing supports in the classroom.

Approaches to the procedures, resources, and services required for the referral and diagnosis of FASD will vary between schools, regions, states, and territories. As such, for specific directions and steps, teachers and schools should refer to these local state and territory protocols as required. Instead, this guide will provide information on the importance of the referral and diagnosis process, clarification of the role of teachers and support staff, and guidance on how to discuss concerns with parents and caregivers.

## Steps in the FASD referral and diagnosis process

Select an area you are interested in to view or scroll down to view all in order. Please note that sections in green are those most relevant to primary school teachers and support staff, while those in blue are typically carried out by a multidisciplinary team of medical and Allied Health professionals.



### Step 1

#### Teacher and school staff identified concerns

Teaching and support staff are neither expected nor equipped to screen for or diagnose disability, including FASD. However, they are in an ideal position to recognise when a student is not learning or behaving neurotypically, and to raise concerns with school leaders, support teams, and the child's family. These discussions initiate the referral process when appropriate. Like all of us, each child with FASD will have their own strengths and challenges, however all are likely to have severe difficulty in at least three of the ten neurodevelopmental domains listed below:

##### 1. Academic achievement

Skills in reading, mathematics, and literacy (including written expression and spelling). Some children with FASD may have specific learning disorders.

##### 2. Attention

The ability to choose and concentrate on relevant information, including: selective attention (focusing on a particular stimuli), divided attention (focusing on two or more things at the same time), alternating attention (switching focus from one stimulus to another), and sustained attention (focusing for a long period of time and resisting distractions). Some children with FASD may also have Attention Deficit Hyperactivity Disorder (ADHD).

##### 3. Memory

The processes used to acquire, store, retain and retrieve information. Includes overall memory, verbal memory, and visual memory.

##### 4. Cognition

The process of knowing, perception, awareness, and judgement. This domain includes IQ, verbal and non-verbal reasoning skills (e.g., critical thinking), the ability to understand concepts or learn new skills and facts, and the intake and output of information.

##### 5. Executive function

A set of higher-level skills involved in organising and controlling one's own thoughts and behaviours. This includes impulse control, inhibition response, hyperactivity, working memory, planning and problem solving, shifting and cognitive flexibility.

##### 6. Language

Includes expressive and receptive language skills. Expressive language skills refer to how a person uses words to express themselves, whereas receptive language is the ability to understand words and language. Higher-level skills include advanced vocabulary, understanding word relationships, and paraphrasing.

### 7. Adaptive behaviour, social skills, or social communication.

The life skills which enable an individual to participate successfully in day-to-day activities. These include daily living skills (e.g., age-appropriate self-care), communication skills and socialisation skills. Some children with FASD may also be diagnosed with Autism Spectrum Disorder (ASD).

### 8. Affect (emotion) regulation

The ability to modulate our emotions, moods, feelings, and expressions to meet the demands of our environment.

### 9. Motor skills

Skills related to balance, movement and coordination of the muscles of the body. These include fine motor skills that require a high degree of control and gross motor skills that control the large muscles of the body.

### 10. Brain structure/neurology

Structural brain abnormalities (include small head and abnormalities seen on scanning), seizure disorder (without a known causes), significant neurological diagnoses otherwise unexplained (e.g., visual impairment, sensorineural hearing loss, cerebral palsy).

More information on these ten neurodevelopmental domains can be found in the *Australian Guide to the Diagnosis of FASD*.

In addition to impairments in these ten domains, children with FASD may also experience sensory processing issues (e.g., being hyper or hyposensitive to certain sensations), problems with sleep, growth problems, and other health issues relating to birth defects. The most common signs of FASD that you will see in the school environment will be expressed as developmental delays, behavioural challenges and learning difficulties. For more information on how these challenges may manifest in school, have a look at our resources that provide information on how FASD presents in a school environment.

However, it's important to remember that FASD is primarily a brain-based disorder. For children with FASD, the focus should be on understanding that their performance is based on **brain injury**, not deliberate misbehaviour - these children **'can't'**, not **'won't'**, learn and behave like others. Understanding FASD as a brain-based disorder encourages empathy, patience, and the use of a range of new teaching and learning skills and techniques.

## Step 2

### School support team and parents/caregiver meeting

Although the exact procedures may vary between schools, regions, states, and territories, the usual first step when school staff identify that a child may need an assessment for a neurodevelopmental disability is to arrange a meeting with the parent or caregiver to discuss concerns and ascertain whether parents or caregivers share these concerns. Discussing the difficulties or challenges a child is experiencing in the school environment, and the possible need for further assessment, can be a difficult and needs to be handled sensitively. However, effective communication between parents and teaching and support staff is essential to ensure a strong collaborative relationship, which in turn, will have a positive effect on a child's success at school. There are several things you can do to ensure the conversation is positive and productive.

**Firstly**, we don't recommend that you use terms like FASD or neurodevelopmental disability when first speaking with parents or caregivers, as these conditions must be formally diagnosed by health professionals through a multidisciplinary assessment process. The purpose of this conversation is to work towards ensuring the child is appropriately supported in the classroom by gaining a thorough understanding of their needs, strengths, and challenges. Focus the meeting on the observations you (or other teachers and support staff) have made about the child's learning and behaviour in the school environment and be prepared to clearly explain why you think these signs require further investigation or assessment.

**Secondly**, it is also very important to ensure that you take a strengths-based approach when discussing a child's needs in the school environment. Speaking about the challenges a child is displaying in the classroom can be difficult or upsetting for their parents or caregivers, so it's important to also focus on a child's strengths to promote an optimistic outlook and reduce stress. Every individual with or without FASD will have different strengths and challenges, and it's important to acknowledge both to get the 'whole picture' of a child with FASD. Commonly reported strengths of children with FASD include:

- Friendly, very engaging in conversation
- Excels at physical activities like sport or dance
- Musical or artistic
- Generous, compassionate, and kind

**Thirdly**, parents and caregivers have also previously reported that being heard or listened to by teachers and support staff is extremely helpful in this context. It's critical to ensure that you are actively listening to parents and caregivers when communicating about their child's needs. Active listening helps to build a relationship with the child's family based on trust, shared interest and mutual respect. Below is an example of an active listening strategy valued by parents:

1. Listen, empathise, and communicate respect (e.g., "I appreciate you coming in to talk with me").
2. Ask questions (e.g., "May I take notes so I can be sure to remember any concerns?").
3. Focus on the issues (e.g., "Let's discuss what staff have observed in the school environment").
4. Find a first step (e.g., "Let's schedule another meeting next week once you've had time to think about this discussion").

**Fourthly**, be prepared that a parent or caregiver may find the conversation difficult or distressing. Below are some tips on how to handle this:

1. If parents or caregivers are reluctant to hear or accept observations about their child, it can be important to remind them that you can only report what you have observed in the school environment. Try asking the parents or caregivers how their child operates in the home environment. There may be some shared perceptions about support needs that gives a positive way into discussing the need for further investigations.
2. If a parent or caregiver becomes distressed, it can be useful to re-state the purpose of the meeting - that you are sharing information to ensure their child has access to the appropriate assessments to ensure that supports for successful ongoing learning are put in place.
3. Arrange to meet again if the parent or caregiver would prefer to think about your concerns before continuing the discussion.

**Finally**, when communicating with parents or caregivers, it is important to remember that caring for a child with a disability has a multidimensional impact on caregiver and family functioning. Daily activities can take increased time and effort, and caregivers often experience high levels of stress and worry. In some cases, families may be experiencing trauma in an ongoing or intergenerational manner. It is important to keep this in mind when communicating with parents or caregivers.

For more information on engaging with parents or caregivers, have a look at our family engagement resources.

## Step 3

### Screening and referral to a medical professional

After parents or caregivers give consent, arrangement can be made for screening for neurodevelopmental disorders. This may be done by a general practitioner (GP), a school psychologist, a school health nurse, or possibly another medical professional. There are no standardised screening tools for FASD, partially due to the wide spectrum of possible neurodevelopmental impairments. Allied health professionals may carry out a variety of standardised, validated tests to identify suspected impairments. These are known as direct assessments, as they directly measure brain structure or neurodevelopmental skills (e.g., verbal reasoning). It is very important to note that a teacher cannot conduct screening. However, they do play an important role in recognising when a student requires screening and assessment for neurodevelopmental concerns and can provide valuable information to health professionals during the process.

Teachers or other school staff may be asked to complete rating scales or report observations to assess the functional manifestations of neurodevelopmental impairments (e.g., observations of social communication at school, teacher rating scales to measure attention). These are known as indirect assessments.

In Australia, children require a referral from a General Practitioner (GP) or other medical professional for a FASD assessment. If the screening process identifies the need for a FASD assessment, a child might be referred to a paediatrician, a specialist FASD clinic, a child development clinic, or another health service. Referral for a FASD diagnostic assessment typically occurs when one of the following are identified:

- Confirmed or suspected prenatal alcohol exposure
- Suspected neurodevelopmental impairment
- Distinctive facial features which include a short horizontal length of the eye opening, diminished or absent ridges between the upper lip and nose, and a thin upper lip with small volume.
- The parent or caregiver is concerned there was prenatal alcohol exposure and that their child may have FASD.

## Step 4

### Further referral to a multidisciplinary FASD assessment team

Due to the complex variety of presentation symptoms, FASD can only be diagnosed by a multidisciplinary team. Often, this team will include a paediatrician, psychologist, speech therapist, occupational therapist, social worker, or other allied health professionals. A multidisciplinary assessment is required for an accurate diagnosis due to the complexity and range of issues related to prenatal alcohol exposure. The assessment process will typically include (but is not limited to) the following:

- Completion of standardised rating scales and assessment tools to identify impairments. Examples of standardised tests include the Wechsler Intelligence Scales for Children, or the Developmental Neuropsychological Assessment (NEPSY-II).
- Clinical history taking, including interviewing parents or caregivers to examine developmental, family, psychosocial and medical history.
- Review of records such as maternal, birth, medical, child protection, or academic records.
- Physical health checks such as height, weight, facial features, and head circumference.

## Step 5

### Formal FASD Diagnosis

FASD can sometimes be difficult to differentiate from other neurodevelopmental disorders, as the symptoms of FASD overlap with the symptoms of other disorders such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). It's also important to be aware that FASD commonly co-occurs with other conditions. For example, research has revealed that over 50% of individuals with FASD will also have ADHD. However, even if an individual with FASD has multiple diagnoses, it's important that there is a correct diagnosis of FASD as the therapy and management for each disorder is different.

In the past, some have questioned the need for a FASD diagnosis when there is a potential for stigma for the child and their family. However, parents and caregivers of children with FASD report that the assessment provided them with validation of their concerns, and a better understanding of their child's abilities and needs. Some parents and caregivers report finding the process empowering and reassuring, as it can build knowledge and understanding for all about how to best meet the needs of their child to enable them to live their best life.

Stigma towards parents and caregivers of children with FASD and the children themselves can act as a barrier to early intervention and supports. The language used when talking about FASD is one way to avoid stigmatisation as language has a powerful impact on the way individuals with FASD (and their families) are perceived and treated. The Manitoba FASD Coalition developed a guide to language, which was later adapted for the Australian context by FASD Hub Australia, that can be used to enhance respectful engagement and reduce the negativity and stigma often associated with FASD.

## Step 6

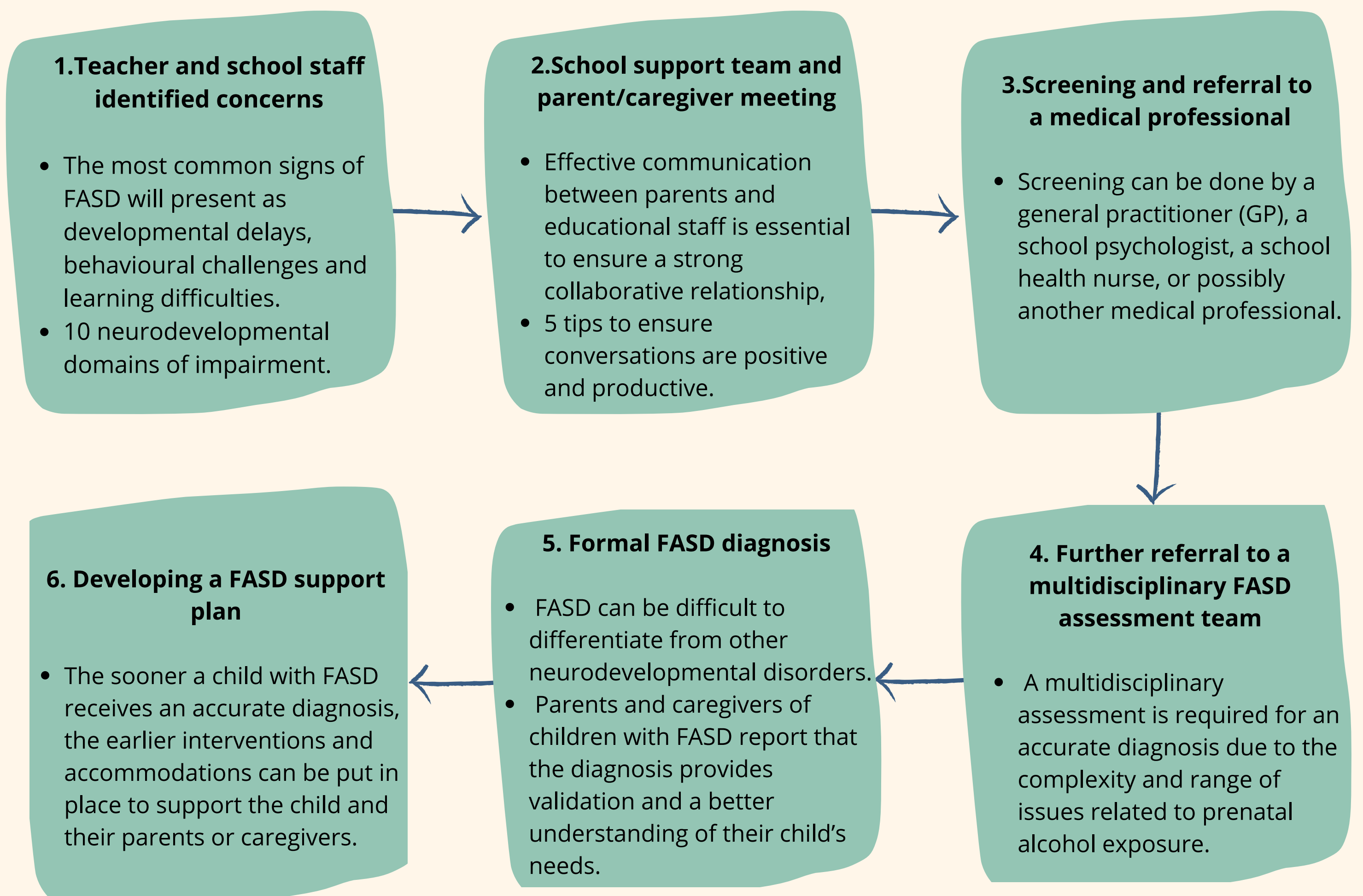
### Developing a FASD Support Plan

Early diagnosis of FASD is crucial to ensure children are appropriately supported to achieve success at school and reach their potential in life. Research has shown that the longer the delay in receiving a diagnosis, the greater the risk of negative long-term outcomes such as a disrupted school experience, mental health problems, incarceration, and substance misuse. The sooner a child with FASD receives an accurate diagnosis, the earlier interventions and accommodations can be put in place to support the child and their parents or caregivers. Early diagnosis can:

- Explain to the child how and why they are different from many of their peers. This can help with building confidence around strengths rather than focusing on perceived failings.
- Increase accessibility to counselling or therapy services aimed at managing the challenges of living with FASD.
- Allow for the development of personalised learning and support strategies for the school environment.
- Reduce the risk of secondary issues (e.g., disrupted school experience) and contribute to positive long-term outcomes.

It is also important to note that receiving a FASD diagnosis can take time. If you notice a child is experiencing difficulties in the school environment, implementing evidence-based strategies to support their ongoing learning can improve a child's experiences at school even if they do not have a specific FASD diagnosis. See our factsheets on classroom strategies and classroom adjustments that can be implemented to ensure a child with FASD is supported in their ongoing learning.

### Summary



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