



## Fetal Alcohol Spectrum Disorder (FASD): Importance of early, accurate, diagnosis and support

### Introduction

Fetal Alcohol Spectrum Disorder (**FASD**), it is one of the **most common** neurodevelopmental disorders, yet it remains **largely undiagnosed** in Scotland. In the absence of a diagnosis each individual's difficulties remain **unrecognised and unassessed**, and sadly often misconstrued as **personality or behavioural issues**. Where some neurodevelopmental conditions may benefit from the adoption of a **needs led approach** within umbrella services, the **lack of recognition** of those with **FASD** results in them being **denied access to the services** themselves. Most individuals with **suspected or diagnosed FASD** are ineligible for intellectual disability or CAMHs services and some of the neurodevelopmental pathways currently being piloted in Scotland. International experience indicates that **integration of FASD** into mainstream services is **key** and follows only from the widespread availability of **training in assessment and diagnosis**.

### Diagnosis and support: key facts

FASD's **'invisibility'** can make obtaining **diagnosis & support** more difficult

The challenges faced by children with FASD can often be attributed to **poor motivation** or **'bad behaviour'**; given that the majority of those with the condition do not have the **physical indicators** of **prenatal alcohol exposure** (PAE). Given this, obtaining a diagnosis can shed light on the aetiology of the child's behaviour; making their difficulties visible, explainable, and targetable with interventions.

Misdiagnosis can **hinder access to correct interventions** and **do harm**

The misdiagnosis of a child's FASD as another **neurodevelopmental condition** (e.g., learning difficulties, autism, and/or attention deficit hyperactivity disorder) can often lead to the child being offered interventions that are **ill-suited to**, or **inappropriate** for, their needs. For example, prescribing stimulant medication for a child whose difficulties are **physiological (FASD)** rather than **chemical (ADHD)** can have unpredictable, and potentially adverse, effects on the child's functioning. Distress can also result from an **inability to recognise themselves** in the misattributed diagnosis and an ability to find like minded peers.

FASD **diagnosis** can be **protective**

A **diagnosis of FASD** can create an **understanding** of what is driving the **behavioural** and **cognitive** difficulties that an individual is experiencing and allows for the targeting of **interventions** and support that has been **tailored** to meet their **needs**.

## Diagnosis and support: key facts

Diagnosis can facilitate a **deeper understanding** of the individual's **needs**

Caregivers of children and young people have reported that receiving a **diagnosis** of **FASD** came with many **benefits**, including providing clarification of the child's **needs**, assisting in **tailoring interventions** for the child, providing **insight** into the child's **behaviours**, and providing **validation** for the child's **strengths** and **challenges**. Individuals with **FASD** have reported that receiving a diagnosis helped them to **understand** and gain insight about themselves and find a peer group with whom they have experiences in common.

Diagnosis can **prevent secondary harms** occurring

Missed, or incorrect, diagnoses **reduce** the opportunity to provide the **necessary care** and **support** that **prevents secondary harms** occurring. In its absence, a high likelihood of **mental health difficulties**, **suicidality**, **addiction**, **offending behaviours** and high use of specialist statutory services are observed.

Diagnosis can **increase** life expectancy

Individuals with **FAS** who are **not diagnosed** in early life are at **high risk** of having a **lower life expectancy** than their peers, estimated at **34 years**. The leading causes of death were external causes and can be considered **secondary harms**, which by definition are avoidable, if **sufficient care** is provided.

## Diagnosis: challenges

### FASD presentation often overlaps with other neurodevelopmental conditions

Individuals with **FASD** often exhibit **strengths and challenges** that are present in other **neurodevelopmental conditions**, including **attention deficit/hyperactivity disorder**, **oppositional defiant disorder**, **autism**, and **conduct disorder**.



### Lack of knowledge/stigma

Healthcare workers have also reported feeling **reluctant** to refer children for **clinical evaluation** given the impact perceived **stigma** and blame for the **diagnosis** may have on the family. However, families report that any risks are outweighed by the positives of a diagnosis and that they are often relieved that **FASD** has been raised.



### Lack of prenatal alcohol exposure evidence

Stigma surrounding **prenatal alcohol use** may **prevent** expectant mothers from disclosing their drinking habits to their healthcare practitioners. This not only **reduces the opportunity** to provide mothers with **support and interventions** to reduce risk, but also results in a **lack of documentation** on **PAE history** that can facilitate later diagnoses.

