

# FASD Challenge 2025



The mission of **FASD Challenge 2025** is *to challenge all forms of systems discrimination and absence of acknowledgement of FASD in advertising, documentation, procedures, services, commissioning, and legislation, to address the decades of silence surrounding FASD.*

Your mission should you choose to accept it, is to make a challenge... whenever FASD is absent...

For example, from an image, or a list of neurodiverse conditions, or when eligibility criteria bars FASD. Or perhaps when someone produces a document, procedure, policy or even legislation or a relevant training session etc and doesn't include FASD.

You would reach out to them, and politely enquire why FASD has not been considered or included and then tell them what you have seen in their service that needs changing or challenging. Please do it courteously and supportively to create positive change and positive relationships.

If each of us, undertook 25 challenges during the year, or at least every time that we noticed something important that needed challenging, then FASD will have moved forward leap years. Keep a log of what you challenged and what changed, or what new relationship you built with someone to create change, and at the end of the year, we will have real examples to celebrate.

The motto of the FASD Challenge 2025, is *one small leap per person, and one giant leap for the FASD Community.*

Let's make 2025 our best FASD year yet. If you are posting on social media, use the hashtags [#FASDChallenge2025](#) [#FASDOneGiantLeap](#)

**Terminology**

In the UK the agreed diagnostic term for the condition has been updated to **Fetal Alcohol Spectrum Disorder** and replaces older terms such as Fetal Alcohol Syndrome, Alcohol Related Neurodevelopmental Disorder and other terms previously used.

**Definition of Fetal Alcohol Spectrum Disorder**

Fetal Alcohol Spectrum Disorder is a term used to describe the permanent impacts on the brain and body of individuals prenatally exposed to alcohol, resulting in a spectrum of physical, neurological, emotional and behavioural characteristics in addition to their strengths and abilities. FASD is regarded as a permanent, lifelong brain based condition that identifies people as having a disability with rights and entitlements protected in law under the Equality Act 2010

**Alcohol Harm**

Alcohol is a teratogen which can harm the baby's developing brain and body. Alcohol passes through the placenta straight to the baby and creates more damage to the developing foetus than other substances, including marijuana, heroin, and cocaine. There are over 400 potential conditions associated with prenatal alcohol exposure. There is no known safe level of alcohol consumption. The UK Chief Medical Officer advises abstaining from alcohol when pregnant or planning to become pregnant.

**Prevalence**

FASD is a leading cause of preventable non-genetic developmental disability in the UK. International research places FASD between 2-5% of the population and a recent UK prevalence study identified it affected 3.6% of the population. The National Autistic Society, suggests autism affects 1-2% of the population, so FASD has a prevalence rate that is potentially double. Additionally, many children with FASD are care experienced, and a UK study identified that approximately 70% of adopted children may be prenatally alcohol exposed. This means that individuals in foster, adoptive, or kinship families and those in residential care are most likely to have experienced prenatal alcohol exposure and need to be screened for FASD.

**Key Challenges**

FASD has been a diagnosable condition since 1973. In the UK, there is no national awareness campaign on TV, no awareness posters at the point of sale of alcohol, and a lack of messaging among communities. In addition, many practitioners across health, education, social care and justice have not heard of this condition. FASD largely sits outside of local services, policies and commissioning. We are seeing progress from a lot of FASD parent advocacy, but it is time to raise the challenge if we are to create effective social change.

**Key Documents**

There are key documents guiding commissioners to address FASD, most notably.

In **2021**, the UK Department of Health and Social Care created a health needs analysis regarding FASD and an outline of what needs to be addressed. <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment/fetal-alcohol-spectrum-disorder-health-needs-assessment>.

In **2022** the NICE quality standards for FASD were released which formally adopted the SIGN 156 NICE standards and identifies key actions for prevention, diagnosis, assessments and support. <https://www.nice.org.uk/guidance/qs204>

In **2024**, a Freedom of Information request to commissioners, identified that the majority of localities across the UK had failed to implement all actions identified in these two documents. <https://nationalfasd.org.uk/not-commissioned-report/>

This is not an exhaustive list, simply a summary of key headlines where gaps are particularly evident. You can add to it over the year as part of your list of challenges, when you see things that need to progress with FASD in the UK.

**General**

We need

- the SIGN quality standards to be enacted fully by commissioners providing funding to develop FASD programmes and pathways and by actively monitoring implementation.
- to challenge all services that exclude and discriminate FASD (by focusing solely on other conditions such as autism and/or learning disabilities) due to eligibility and policy decisions.

**Awareness & Prevention**

We need

- clearer labelling on all alcohol bottles.
- warning messages and posters in pubs, shops, and all points of sale.
- visible awareness campaigns in public places driven by public health teams.
- all family planning clinics, women's services and GP surgeries need to provide clear information about the risks of alcohol in pregnancy.
- health services to ask pregnant women about alcohol consumption and record responses.
- referrals for women who are pregnant to specialist midwives and alcohol recovery teams for non-judgemental support throughout the pregnancy.
- recording of alcohol exposure in children's health records and to be identified in placement and permanency records for children in foster care and those being adopted.

**Health & Diagnosis**

We need

- local access to free and prompt NHS assessment and diagnosis.
- comprehensive multidisciplinary assessments that identify both strengths and challenges.
- well written post diagnostic FASD management plans.
- holistic support for the allied health, disability and mental health conditions that present with FASD.
- training for all allied health professionals so that there is a baseline awareness of FASD.

## **Education**

We need

- SEND categories that accurately identify a correct category for people with FASD within education, health and care plans (EHCPs) and in education settings.
- specialist and alternate provision to be commissioned specifically for students with FASD with complex education needs, much like specialist autism provision that exists.
- training for schools, teaching assistants, and allied professionals to be trained in FASD and understand correct accommodations to enable students to engage and thrive.

## **Social Care**

We need

- local FASD specialist support pathways and FASD peer support.
- equal access to all systems and services that support people with disabilities including access to children with disabilities teams, respite care and direct payments.
- advocacy to navigate services when access to services is declined.
- training for all social care practitioners and mandatory training for those working with care experienced families and safeguarding.

## **Adolescent and Adult Services**

We need

- effective cognitive assessments and mental capacity assessments for positive transitions to adult social care and adult support systems so that adults have support with housing, higher education, independent living, mental health and financial and practical support.
- training for recovery practitioners and access to correct drug, alcohol and gambling support services so that they are tailored to enable supportive recovery programmes.
- training for all police, courts and probation practitioners and adjusted services to ensure that individuals with FASD get fair and correct access to justice and recovery programmes.

## **List your own suggestions here**

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## FASD Challenge 2025 Log Sheet

Challenge Number	What was your concern?	When and where did you notice it?	What did you do?	What changed?
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