

Fetal alcohol spectrum disorder: prevention, identification and support need more resources

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Up to 17 per cent of UK children could have symptoms consistent with fetal alcohol spectrum disorder (FASD). Before this study no UK estimates existed.

About the research

Fetal alcohol spectrum disorder (FASD) is a group of lifelong conditions. It is caused by exposure to alcohol in pregnancy that affects learning and behaviour, and can cause physical abnormalities.

FASD is considered a hidden disability because most individuals with it do not show physical features. It is thought to be under-diagnosed; in England there is only one specialist clinic.

The societal and economic costs associated with FASD are considerable, estimated at \$1.8 billion per year in Canada.

The UK has the fourth highest level of prenatal alcohol use in the world, yet rates of FASD are unknown.

Some countries (USA, Canada, Italy) have used in-school screening and concluded that up to 10 per cent of children are affected, with rates as high as 30 per cent among children in care.

Before this study no estimates existed on how many people in the UK may have FASD.

The results from this study are an important starting point in addressing this evidence gap.

Researchers and clinicians studied the development of almost 13,500 children born in the early 1990s to assess symptoms relevant to FASD. Using a wide range of information on the children's development and their mothers' drinking in pregnancy, they then estimated the prevalence.

Although guidance on drinking during pregnancy has changed since the study information on prenatal alcohol exposure was collected (1991-1992), rates of drinking in pregnancy in the UK remain high.

FASD is likely to remain a significant public health concern in the UK.

Policy recommendations

- A current UK prevalence study is urgently needed. In-school screening (active case ascertainment) studies are the preferred approach internationally and should be carried out in the UK.
- Up to date data is needed for government and service commissioners to plan for and provide appropriate levels of service.
- This study reveals a mismatch between likely prevalence and clinical expectation that FASD is a rare condition. Early recognition and management of the disabilities associated with FASD can help reduce the risk of long-term adverse outcomes and the societal costs.
- Diagnostic capacity must be increased, as people with FASD can benefit from existing specialist services (e.g. speech and language therapy, educational psychology, mental health services).
- Improved services for families are required to offer peer support, reduce the risk of future alcohol-exposed pregnancies and help them understand how best to support their child.
- As part of the UK Alcohol Strategy, there needs to be coordinated, UK-wide, comprehensive action and training on FASD prevention, diagnosis and support that extends across the individual's lifespan.
- There is still inconsistency in national guidelines about prenatal alcohol use; NICE should update their antenatal guidance in line with the Chief Medical Officer's recommendations (abstinence during pregnancy).

Key findings

- The research looked at the development of 13,495 children from Bristol's Children of the 90s study, who were born in and around Bristol between 1991 and 1992.
- The results are based on a screening tool, which is not the same as a formal diagnosis.
- A positive FASD screen was defined as problems with at least three different areas of learning or behaviour, with or without growth deficiency and with or without the facial features of fetal alcohol syndrome (which are a smooth philtrum, thin upper lip and small eye openings).
- Based on maternal reporting of drinking in pregnancy, up to 79% of children in the sample were exposed to alcohol in pregnancy.
- Up to 25% of these children were exposed to binge levels of alcohol in pregnancy.
- Up to 17% of the children in the sample screened positive for symptoms of FASD.
- Other recent studies (2015) suggest that three quarters of women drink during pregnancy, with 1 in 3 at binge levels. This suggests that many individuals in the UK population today could also have symptoms of FASD.

Advice updated in January 2016 from the Chief Medical Officer states that if you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep all risks to your baby to a minimum.

It also states that the risk of harm is likely to be low if you have drunk only small amounts of alcohol before you knew you were pregnant or during pregnancy.




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Further information

McQuire, C. et al. (2018). Screening prevalence of fetal alcohol spectrum disorders in a region of the United Kingdom: a population-based birth-cohort study. *Preventative Medicine*. <https://doi.org/10.1016/j.ypmed.2018.10.013>

O'Keeffe LM, Kearney PM, McCarthy FP, et al. Prevalence and predictors of alcohol use during pregnancy: findings from international multicentre cohort studies. *BMJ Open* 2015;5:e006323. <https://doi.org/10.1136/bmjopen-2014-006323>

National clinic for Fetal Alcohol Spectrum disorders (FASD), Surrey and Borders Partnership NHS Foundation Trust <https://www.fasdclinic.com/>

NO FAS-UK (The National Organisation for Foetal* Alcohol Syndrome-UK) <http://www.nofas-uk.org/>

Based at the University of Bristol, Children of the 90s, also known as the Avon Longitudinal Study of Parents and Children (ALSPAC), is a long-term health-research project that enrolled more than 14,000 pregnant women in 1991 and 1992. It has been following the health and development of the parents and their children in detail ever since and is currently recruiting the children and the siblings of the original children into the study. It receives core funding from the Medical Research Council, the Wellcome Trust and the University of Bristol. Find out more at www.childrenofthe90s.ac.uk.

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**Foetal is the British spelling, fetal the international medical spelling*