

18 July 2024



Dear Health and Social Care Secretary,

Prenatal alcohol exposure and resulting lifelong brain damage is a key health and care issue throughout the UK. Championing joined up thinking and small spend-to-save investments can have profound impact. Can you help?

As The National Organisation for FASD we welcome the commitment that the new Government has made to a 'prevention-first NHS' and to improving the wellbeing of children.

Preventing and recognising the impact that FASD (Fetal Alcohol Spectrum Disorder) has on all aspects of our communities including health and social care can aid you in your work, as it is a missing link frustrating progress across the system.

In September 2021 the DHSC¹ identified the challenges that society faced relating to this preventable condition that impacts between 1.8% and 3.6%² of the population in the first FASD Needs Assessment for England. The figures are much higher in children and young people within the care system and are even larger in the adopted population.

More people have FASD than autism, but few are diagnosed and supported. These are the people within health, social care and educational systems for whom traditional responses are not working, at great cost and with tragic impact on those individuals and their families. Joined up policy can change that and have profound impact on the nation's health.

Despite identifying significant needs and social costs in failing to assess people for the condition and supporting those that have FASD, very little was done to address these needs. A much greater emphasis and funding was placed by the former Government on smoking cessation while pregnant. Regrettably, research and nationally statistics show that much fewer women smoke while pregnant compared to those who drink alcohol and the damage that alcohol can cause is much greater and lasts a lifetime.

We ask you to:

- **Meet with those whose lives were changed by prenatal alcohol exposure to hear the concerns and dreams**
- **Ensure diagnosis and support for people with FASD as called for by NICE, SIGN, DHSC**
- **Publicise the CMOs' guidance on avoiding alcohol in pregnancy with at least equal emphasis as national efforts to reduce tobacco use in pregnancy**

¹ <https://www.gov.uk/government/publications/fetal-alcohol-spectrum-disorder-health-needs-assessment>

² <https://onlinelibrary.wiley.com/doi/10.1111/acer.14705> (the National Autistic Society states 1% of the population is autistic).

In 2022 NICE produced Quality Standard 204³ for FASD identifying the first 5 priority areas to improve quality of care in ensuring pregnant women are aware of the risks associated with prenatal alcohol exposure, identifying alcohol-exposed pregnancies, making timely and detail assessments of individuals who might have FASD and supporting those that have it.

We ask for an opportunity to brief your staff on an embargoed copy of our forthcoming report to be released on 9/9 international FASD Awareness Day based on Freedom of Information requests to all Integrated Care Boards, Welsh Health Boards and NHS Trusts which shows that the majority of ICBs and NHS Trusts are not taking action and suggests steps for progress, including:

- A Green Paper based on the DHSC FASD Health Needs Assessment and NICE QS 204, examining how recommendations can be implemented and overseen on a national level
- Establishment of an FASD Prevention and Response Fund equivalent at least to 0.1 – 0.2% of the alcohol duty to put UK spending in this area on par with other countries and on par with the proposals for reducing smoking in pregnancy.
- Support from NHS England for an ongoing audit of progress following NICE Quality Standard 204, including lived experience.
- ICBs should be given clear guidance by NHS England that they are expected to commission services to support FASD.
- Recently introduced SNOMED CT codes for FASD should be promoted by the Chief Medical Officers and others to ensure FASD can be tracked through routine electronic patient records and included in a future national FASD database.
- Similarly, the digital health records for maternity services need to be updated to include mandatory and consistent coding and prompts for discussing and recording dose, pattern and timing of alcohol-exposed pregnancies.
- Any nationally funded programme for those with Autism and Learning Disability should be extended to include FASD and their staff should have mandatory FASD training

Your ability to achieve your goals will be frustrated and ineffective if you do not take on board the need to seriously address the ‘hidden epidemic’ caused by prenatal alcohol exposure. We would welcome discussions with you and your team to explore concrete suggestions for how to address this huge and largely unrecognised hidden disability that impacts so many of our fellow citizens either as people affected for life by alcohol before they were born or as the families that love and care for them.

Sincerely,



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³ <https://www.nice.org.uk/guidance/qs204>