

Media Release

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Most local NHS bodies not taking action on alcohol, pregnancy, and FASD

The majority of NHS Trusts and Integrated Care Boards in England are not taking action to improve their services related to alcohol, pregnancy and the resulting neurodevelopmental condition FASD (Fetal Alcohol Spectrum Disorder). In Wales the Health Boards are taking at least partial action. These are the findings of a new report by The National Organisation for FASD, based on Freedom of Information requests that explored local and regional progress on steps called for in Quality Standard 204 produced by the National Institute of Health and Care Excellence. While identifying some pockets of progress, the report outlines what it calls “systemic confusion” across England and Wales and a failure to commission needed services and training as outlined in NICE QS 204. NICE called for improvements to ensure women are being given appropriate advice throughout pregnancy about the risks of alcohol exposure to the fetus and that fetal alcohol exposure is being noted. NICE also reinforced guidance that prenatal alcohol exposure should be ‘actively considered’ as a cause for neurodevelopmental delay, and said services should provide needed assessments and management plans when FASD is suspected and diagnosed.

“NHS policy makers across the country are missing an opportunity to prevent primary and secondary harm from alcohol exposed pregnancies and undiagnosed FASD. This comes at great cost to overstrained services and some of the most vulnerable people in our society,” said Sandra Butcher, Chief Executive of National FASD. “Studies show more people have FASD than autism but most are undiagnosed and not receiving the appropriate support too often with tragic consequences. We can change this and call upon the new Government with its emphasis on prevention to raise the priority of alcohol in pregnancy at least on par with that for smoking in pregnancy, which affects far fewer but receives far more funding.”

Two years after the NICE Quality Standard, and in the wake of a 2020 report from then Public Health England calling this a ‘public health priority’ and a 2021 Department of Health and Social Care FASD Health Needs Assessment calling for action, this new report highlights that the vast majority of English ICBs that replied by the deadline are not commissioning for diagnosis and management of care for children (70%), young people (73%), and adults (87%) and the majority of Welsh Health Boards have not commissioned services for diagnosis and management of children (67%), young people (67%) and adults (83%). There are unclear lines of responsibility between ICBs/ Health Boards and Trusts, as well as within Trusts between different services.

Prof Raja Mukherjee MBE, the country’s leading FASD expert wrote in the report, “Quality Standards should force individual practitioners to look at how they are delivering clinical services. Where there is a failure, it is inherent on the local commissioners and clinical experts to consider how this can be changed. In a resource limited environment, it is possible to still deliver quality services.”

The National Organisation for FASD is calling for a Government Green Paper on FASD, an FASD Prevention and Response Fund equivalent to 0.2% of the alcohol duty which would put spending in

England on par with other countries with similar rates of FASD, and for NHS England to work with them to do a more complete audit of progress following NICE QS 204.

Greater Manchester is one area highlighted for the positive steps it has been taking. According to Roisin Reynolds, Strategic Lead-Population Health for NHS Greater Manchester, “NHS Greater Manchester takes its responsibilities, for the prevention of harm from alcohol-exposed pregnancies and the need for those with FASD to be diagnosed and supported, seriously. Since 2018, we have been a national exemplar in FASD prevention, awareness raising through our award-winning Drymester campaign, diagnosis, treatment and support. We believe that this work matters and are encouraging other areas to take a similar approach. At the heart of our work are the people who have lived experience of this condition, and we are pleased to continue our relationship with National FASD to develop our Greater Manchester FASD Network, bringing people together and providing resources and support across our local communities.”

Ends

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PLEASE NOTE - A media photo event will take place in Salford at 12:00 pm to mark international FASD Day on 9/9 highlighting that more than 660 babies with FASD may be born Greater Manchester in the next year with FASD. For details contact: info@nationalfasd.org.uk

SEE BELOW – A media pack including additional quotes and background information.

ADDITIONAL QUOTES from National FASD experts, also available for interviews:

“The lives of thousands of families across England and Wales are made much more difficult than they should be without the local FASD training and support. This should have been offered when health bodies started to address the NICE FASD Quality Standard. In most areas it just hasn’t happened. This means that throughout the country families are exhausted struggling alone, without understanding why it is so hard or being advised about what could make it easier and the teams they interact with remain ignorant. Even worse is that their numbers are increasing by more than 60 babies each and every day because the messages about the risks posed by prenatal alcohol exposure aren’t being effectively communicated. In 2024 all public bodies should be committed to making the lives of those with FASD and their loved ones easier not continuing to bury their heads in the sand.” (605,479 live births in England and Wales in 2022 (ONS), = 1659 per day therefore 4% = 66) Brian Roberts, Director of Education and Wellbeing, National FASD

“Fortunately, during my very recent pregnancy, I didn’t drink alcohol; however, I have in the past. My baby has not suffered any risks from prenatal alcohol consumption. However, throughout those 9 months not one medical professional asked me about potential alcohol exposure, or educated me about the risks, some didn’t even know what FASD was. I am angry that my former self and thousands of other women would not have been and will not be as fortunate without a concerted effort to explain the risks. FASD is preventable with the correct advice, information and guidance. We must change as knowledge really is power! It’s the power for woman to make decisions to safeguard their baby for a healthy future.” Alice Sewell, Training Project Officer, National FASD

“Pregnant women rely on their midwives for accurate, up-to-date information about things that could harm their developing baby. Alcohol and pregnancy is not compulsory learning for midwives and many say they feel ill-equipped to talk to women about the risks associated with an alcohol-exposed pregnancy. Two years on from the publication of the quality standard many local areas are not ensuring their midwives have had expert training on alcohol and pregnancy and are not evidencing that all pregnant women are being given written and verbal information about the risk of harm of any alcohol in pregnancy, nor that they are asking about alcohol exposure and recording the information throughout the pregnancy. This is potentially putting pregnancies at risk and local areas have a responsibility to ensure pregnant women have the information they need to have healthier pregnancies. FASD is a common condition, yet it is preventable.” Joanna Buckard, Director of Innovation, National FASD

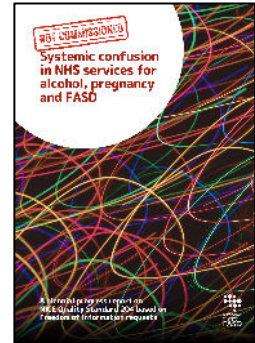
“Midwives are uniquely placed to offer key public health messages to women during their pregnancy but often alcohol use remains unexplored. By providing accurate information about the risks of prenatal alcohol exposure, we can empower women to make informed decisions about the health of their baby. It is vital that midwives and midwifery services take action to reduce the number of babies born being born with FASD.” Katie Liddle, Registered Midwife & Research and Project Officer, National FASD

CASE STUDY (available for comment/interview – there are others mentioned in the report):

Sharon Jackson, mother of 5 with FASD is available to speak about how important it is for training about FASD across services as called for in NICE QS 204, based for example on experiences trying to get help for her daughter from neurological services for unexplained seizures. “As mum to 5 with FASD I know how important it is that people with FASD are diagnosed and get the right support. FASD is complex and it’s important that services across the NHS get the right training as called for by NICE. Too many think alcohol, pregnancy and FASD isn’t something they need to worry about when it is something we all should be addressing. For example, my daughter has seizures and the neurologist have no understanding of the way her brain has been affected by alcohol in utero.”

SUMMARY -EMBARGOED FOR RELEASE UNTIL 9/9/2024 12:01 am

Not Commissioned: Systemic confusion in NHS services for alcohol, pregnancy, & FASD
A biennial progress report on NICE Quality Standard 204 based on Freedom of Information requests <https://nationalfasd.org.uk/not-commissioned-report/>



- The majority of NHS Integrated Care Boards and NHS Trusts are missing a golden opportunity to protect baby's brains and futures with their slow, non-strategic and uncoordinated responses to the 2022 NICE Quality Standard 204 on Fetal Alcohol Spectrum Disorder (FASD). NICE QS 204 is in effect in England and Wales and calls for improvements in care regarding discussions about risks of alcohol in pregnancy during antenatal visits and recognition, diagnosis and support of those with FASD.
- While there are pockets of hope and encouraging progress, more broadly there is systemic confusion and a lack of coordination and commissioning across the NHS.
- Nearly 53% of Integrated Care Boards (ICBs) and 56% of NHS Trusts (not including the 11 specialist ambulance trusts) that replied by the statutory deadline to National FASD's Freedom of Information requests are not taking action to meet the needs of this vulnerable population with FASD and to prevent alcohol-exposed pregnancies. In Wales all the health boards that responded are taking at least partial action.
- There are unclear lines of responsibility between ICBs/ Health Boards and Trusts, as well as within Trusts between different services.
- The vast majority of English ICBs that replied by the statutory deadline are not commissioning for diagnosis and management of care for children (70%), young people (73%), and adults (87%) and the majority of Welsh Health Boards have not commissioned services for diagnosis and management of people for children (67%), young people (67%) and adults (83%). Responses indicate the rest of the NICE QS 204 suggestions for commissioners are not being followed.
- There is a nearly universal failure to track improvements in services over time using NICE indicators.
- Training across the workforce as called for by NICE is not happening in many areas.
- Local pathways are unclear and under resourced. Many responses indicate that local diagnosis is not available.
- Appendices include the questions asked and the responses received and link to the full responses to help spur creative thinking from leaders in different areas.

National FASD calls for strong leadership from Parliament, Government and national health bodies to operationalise the NICE Quality Standard, including:

- Meetings between policy makers and people with FASD and their families.
- English and Welsh Green Papers looking into FASD Prevention and Response.
- 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.
- Support from NHS England for an ongoing audit of progress following NICE Quality Standard 204,
- NHS England and NHS Wales should give clear guidance about the need to commission services outlined in NICE QS 204.
- Each ICB and Health Board should appoint an FASD lead and have in place an area-wide ability to check what the Trusts are doing to track over time improvements in quality of care..
- Recently introduced SNOMED CT codes for FASD should be promoted by the Chief Medical Officers.
- Digital health records for maternity services need to be updated to include mandatory, consistent coding and prompts for discussing and recording dose, pattern and timing of alcohol-exposed pregnancies.
- The risks of alcohol in pregnancy should be promoted at least on scale with smoking in pregnancy.
- Steps need to be taken to increase local and regional diagnostic capacity on a Hub and Spoke model.
- Each area needs to have a plan in place for post-diagnostic support, and preferably an FASD pathway.
- Every management plan should have a named lead on the plan. The FASD UK Alliance draft model management plan could be used.
- Any NHS programme for people Autism and Learning Disabilities or for those with neurodevelopmental conditions must take into account SIGN 156, the DHSC FASD Health Needs Assessment and NICE QS 204.
- There is a need for national level guidance, oversight and funding for FASD training across health and social care sectors.



Additional background information

What is FASD?

"FASD results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum. Each person with FASD is affected differently. While more than [400 conditions can co-occur](#), FASD is at its core a lifelong neurodevelopmental condition. All people with FASD have many strengths. Early diagnosis and appropriate support are essential, especially for executive functioning." (Source: [FASD: Preferred UK Language Guide](#), Seashell Trust/National FASD, 2020)

How many people have FASD?

A recent [gold-standard study](#) by the University of Salford showed that 2-4% have FASD. That's a higher rate than autism. Most people with FASD are unrecognised, undiagnosed or misdiagnosed.

How is FASD diagnosed?

The [SIGN 156](#) guideline is the guidance now across Scotland, England and Wales. It says that to have a diagnosis you need to have "Pervasive and long-standing brain dysfunction, which is defined by severe impairment...in three or more of the following neurodevelopmental areas of assessment": motor skills; cognition; memory; neuroanatomy/ neurophysiology; academic achievement; language; attention; executive function, including impulse control and hyperactivity; affect regulation; or adaptive behaviour, social skills or social communication.

Alcohol in pregnancy in the UK

Over [40% of women](#) in the UK use alcohol during pregnancy, making the UK the [4th highest rate](#) of alcohol exposed pregnancies in the world.

What is the NICE Quality Standard?

[NICE Quality Standard 204](#) (2022) identifies areas for improving quality of care regarding: advice on avoiding alcohol in pregnancy; prenatal alcohol exposure; referral for assessment; neurodevelopmental assessment; and management plan. Unlike guidance, local areas in England and Wales have to 'have regard' for Quality Standards and report on progress in improving care.

What is FASD awareness month?

The 9th day of the 9th month is International FASD Day. This is to draw attention to the importance of going alcohol-free for the 9 months of pregnancy. In the UK we celebrate September FASD Awareness Month. This year for awareness month, National FASD is releasing a new report "Not Commissioned: Systemic Confusion in the NHS about alcohol, pregnancy and FASD." That report can be found here (it will be live on 9/9).

<https://nationalfasd.org.uk/not-commissioned-report/>

What is the FASD UK Alliance and #FASDStrongerTogether?

The [FASD UK Alliance](#) is a coalition of groups and individuals from across the UK who are united together for positive social change for those with Fetal Alcohol Spectrum Disorder (FASD). Affiliates include small local, regional and virtual groups as well as some of the country's longest standing national organisations devoted to FASD, with links to international networks. The independent groups that comprise the FASD UK Alliance are all asking people throughout the month to pledge to do more to help raise awareness of FASD. All sister organisations in the Alliance will use hashtag: #FASDStrongerTogether

What is the National Organisation for FASD?

The National Organisation for FASD, founded in 2003, is dedicated to supporting people with Fetal Alcohol Spectrum Disorder (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy. www.nationalfasd.org.uk • www.fasd.me • www.alcoholandpregnancy.info • <http://alcoholandpregnancy.info>

Key official quotes

“There is no known safe level of alcohol consumption during pregnancy. NICE, [Fetal Alcohol Spectrum Disorder Quality Standard 204](#) (2022).

“Drinking any alcohol can cause difficulties in pregnancy and can result in Fetal Alcohol Spectrum Disorder (FASD), causing lifelong disabilities for children. There is no safe time or safe amount of alcohol to drink during pregnancy.” Public Health England, [“Maternity high impact area: Reducing the incidence of harms caused by alcohol in pregnancy”](#) (2020)

“There is no known safe level of alcohol consumption in pregnancy. Even low to moderate levels of PAE [prenatal alcohol exposure] can negatively impact a fetus and these adverse consequences can persist into adulthood.” SIGN 156, [“Children and Young People Prenatally Exposed to Alcohol”](#) (2019)

“The government recognises the importance of FASD.” Department of Health and Social Care, [“FASD Health Needs Assessment for England”](#) (2021)

“There is no ‘mild’ FASD.” [“FASD Health Needs Assessment for England”](#) (2021)

“Prenatal alcohol exposure should be actively considered as a possible underlying cause for neurodevelopmental delay.” SIGN 156, [“Children and Young People Prenatally Exposed to Alcohol”](#) (2019)

“The needs identified for this population group focus on: a lack of robust prevalence estimates in England; the importance of multi-sector working to support individuals through the life course; better training and awareness for health professionals; better organisation of services to improve accessibility; a need to develop innovative approaches to support those living with the condition.” [“FASD Health Needs Assessment for England”](#) (2021)

“[W. Sussex] appears to be gatekeeping access to its services ... The council has a duty to ensure there is sufficient educational provision available in its area to meet demand. The lack of suitable placements for the boy in the council’s SEN schools suggests it is not meeting this duty.” [Local Government and Social Care Ombudsman ruling](#) (2021) that a local area couldn’t exclude someone with FASD from services for those with ‘autism and learning disability.’

“No specific public health messaging on fetal alcohol spectrum disorder (FASD) has been undertaken in the last five years.” Maggie Throup, Parliamentary Under-Secretary for Health and Social Care, [Hansard, 21 Sept 2021](#) (Note this coincides with the 2016 release of the CMOs’ guidance)

“If you are pregnant or think you could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.” [Chief Medical Officers guidance](#) (2016)

“The Government take alcohol concerns, across the board, very seriously and even more so when they relate to pregnancy. We are making progress—I hope—to prevent future FASD cases, and trying to change the landscape on prevention and treatment for those affected. But there is not an ounce of complacency in us—there certainly is not in me. We will continue to work towards improvements in the area.” Steve Brine, then Health Minister, [Hansard, 17 Jan 2019](#)