

**Submission to the WHO consultation on a working document
for development of an action plan to strengthen implementation
of the global strategy to reduce the harmful use of alcohol**

**from The National Organisation for FASD (UK)ⁱ
Submitted 13 December 2020**



1. In its consultation, the WHO asks organisations to reply to the following statement: "We have read the working document for development of an action plan to strengthen implementation of the global strategy to reduce the harmful use of alcohol and have the following comments and suggestions for consideration."
2. The National Organisation for FASD's response: The WHO draft action plan on alcohol harm dangerously omits prenatal alcohol harm. Reducing rates of alcohol exposed pregnancies and thus the incidence of Foetal Alcohol Spectrum Disorders (FASD) needs to be interwoven throughout the document and incorporated into the vision, goals and expected outcomes as does increased support for those living with FASD and their families. No so-called "Global Strategy to Reduce the Harmful Use of Alcohol" can be complete or credible without proper attention given to this key public health issue, recognised as one of the "leading causes of developmental disabilities worldwide"ⁱⁱ.
3. Recommendations: The WHO Global Strategy Action Plan should include measurable actions on increasing awareness of the risks of alcohol in pregnancy, decreasing incidence of FASD and increasing support for those with FASD:
 - a. All countries should have guidance about avoiding alcohol in pregnancy.
 - b. All countries should provide for education on the risks of alcohol in pregnancy.
 - c. All countries should have legislation requiring the labelling of alcohol products to reflect the risk of alcohol exposure *in utero*.
 - d. All countries should be encouraged to support legislation mandating signs warning of the dangers of alcohol in pregnancy at the point of sale (similar to Sandy's law in Ontarioⁱⁱⁱ).
 - e. All countries should demonstrate progress to improve diagnosis, assessment and support for those with FASD.
 - f. The WHO should urgently convene a stakeholder meeting with individuals with FASD and their families/support people.
 - g. The WHO should acknowledge the 9th of September as International FASD Awareness Day (the 9th day of the 9th month highlighting the importance of abstaining for the 9 months of pregnancy) and encourage all countries to use this a key day for increasing awareness of the importance of avoiding the harms caused by prenatal alcohol exposure.

4. The World Health Organisation has a leading role in raising awareness and promoting best practice on public health issues. A focus on alcohol harm is welcome.
5. However, the current draft document dangerously omits one of the key alcohol harms – the lifelong effect alcohol has on a developing fetus or embryo through alcohol-exposed pregnancies.
6. The WHO vision is “improved health and social outcomes for individuals, families and communities, with considerably reduced morbidity and mortality due to harmful use of alcohol and their ensuing social consequences.” This is never going to be achieved if the harm caused by prenatal alcohol exposure is ignored. As the WHO states in the consultation document (p. 4), “limited levels of political will and leadership at the highest levels of governments” is holding back progress. This would also be true of the WHO if it fails to revise its current document and include harms caused by prenatal alcohol exposure. There simply is no excuse for this omission four decades after the first FASD diagnoses.
7. A WHO document (2016)^{iv} recognized that “The lifelong disabilities caused by exposure to alcohol in pregnancy (known as fetal alcohol spectrum disorders), together with other negative effects of exposure to alcohol on the pregnancy, are an important public health concern.”
8. The omission of prenatal alcohol harm and FASD in the current document goes counter to the latest scientific advice. For example, a recent editorial in the BMJ (December 2020) stated, “Evidence suggests three periods of dynamic brain changes that may be particularly sensitive to the neurotoxic effects of alcohol: gestation (from conception to birth), later adolescence (15-19 years), and older adulthood (over 65 years). Highly prevalent patterns of alcohol use may cause harm during these sensitive periods, including low level prenatal alcohol exposure, adolescent binge drinking, and low-to-moderate alcohol use in older adulthood. Although these patterns of alcohol exposure may be associated with less harm to individuals than sustained heavy drinking, the overall burden of harm in populations is likely to be large.”^v
9. Leading UK medical professionals and scientists have long promoted greater attention to these issues. As Professor Sir Al Aynsley-Green Kt wrote in the British Medical Association publication on “Alcohol in Pregnancy,” “The effects of alcohol during pregnancy should be everybody’s business.”^{vi}
10. According to the BMA: “The fetus is totally unprotected from alcohol circulating in the blood system.” BMA (2016) What more devastating alcohol harm can there be than lifelong organic brain damage and other harm caused to developing systems before an individual draws their first breath?
11. Professor Sheila the Baroness Hollins wrote, “It is alarming that awareness of the risks of alcohol consumption during pregnancy remains low, and the needs of those affected continue to go unmet. It is therefore vital that we see stronger commitment and leadership from those who can implement change.” BMA (2016) The National Organisation for FASD calls on the WHO to demonstrate that commitment and leadership by addressing these issues its global strategy on alcohol harm.
12. Leadership from the WHO through inclusion of decreasing alcohol-exposed pregnancies and increased diagnosis and support for those with FASD in the global strategy’s goals and objectives could have a profound impact in setting best practice internationally. For

example, a 2019 study by National Organisation for FASD, based on Freedom of Information requests to all Clinical Commissioning Groups and NHS Trusts in the UK, found that there is an alarming lack of focus by public health and care service providers on FASD. Not one CCG said they have a policy on commissioning services for Foetal Alcohol Spectrum Disorders. Nearly 80% said they do not provide diagnosis for children with FASD. 92% said they do not provide diagnosis for adults. Only 19% of Trusts and Health Boards said that they provide post-diagnostic services for those with FASD.^{vii}

13. That said, key public health entities in the UK are beginning to recognise FASD in a way they have not done before. A clear statement to this effect was made on 17 January 2019 by then health minister Steve Brine, “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.”^{viii}
14. By ignoring the alcohol harm from alcohol-exposed pregnancies and Fetal Alcohol Spectrum Disorders in this strategy document, the WHO is positioning itself sorely out of synch with leading medical bodies not just in the UK but around the world. It would be ignoring the latest scientific advice and denying the human rights of those with FASD to be seen and heard in key public health messaging.
15. The Scottish Intercollegiate Guidelines Network (SIGN) is part of the Evidence Directorate of Healthcare Improvement Scotland. Its objective is to improve the quality of health care for patients in Scotland by reducing variation in practice and outcome, through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence. In 2019, SIGN published new guideline on “Children and Young People Prenatally Exposed to Alcohol.” SIGN states on its website, “Alcohol consumption in pregnancy has the potential to cause significant fetal damage... It is estimated that approximately 3.2% of babies born in the UK are affected by fetal alcohol spectrum disorder (FASD), which is three to four times the rate of autism.”^{ix} According to SIGN 156: “FASD is characterised by damage to the developing brain, leading to abnormalities in how the brain works.” “Alcohol can destroy brain cells and damage the nervous system and other organs of the baby at any point during the nine months of pregnancy (including before pregnancy is confirmed).” “There is no known safe level of alcohol consumption during pregnancy. Even low to moderate levels...can negatively impact a fetus and these adverse consequences can persist into adulthood.”
16. Over the past year, England’s National Institute for Health and Care Excellence (NICE) has been working on a Quality Standard on FASD^x. NICE provides national guidance and advice to improve health and social care. This NICE Quality Standard on FASD is currently scheduled to be published in July 2021. It will highlight areas where the quality of care needs to be improved. The present draft highlights the need for improving care in five areas: the advice pregnant women receive, the recording of alcohol-exposed pregnancies in both maternal and child notes, referral for assessment, access to a neurodevelopmental assessment, and a care management plan. NICE emphasises the importance of diagnosis by stating: “Diagnosis at the earliest possible stage allows for early intervention and treatment programmes and a better overall outcome for an individual with FASD.”^{xi}
17. When entities like the WHO fail to focus on the harm caused by alcohol in pregnancy a) those with FASD are denied a proper understanding of their brain-based condition and thus the appropriate support that can be life-changing for them and b) women and families are

failed by not being adequately educated and supported to achieve the best possible outcomes for the pregnancies (in addition to FASD, alcohol exposed pregnancies also have increased risks of infertility, miscarriage, stillbirth, premature birth and Sudden Infant Death Syndrome) (BMA, 2016). It is not enough for the WHO to only cover these risks in publications about pregnancy^{xii} - the topic also should be directly addressed in strategies on reducing alcohol harm (and those that focus on developmental disabilities) if there is to be a comprehensive approach to addressing the magnitude of this public health challenge.

18. Again, according to SIGN 156: "FASD [is] a lifelong disability that requires accommodations and supports to maximise success." "It is critical that FASD is recognised as a physical, behavioural and neurodevelopmental health condition."
19. Not only are people not diagnosed but many are misdiagnosed. "A significant proportion of children currently diagnosed with ADHD or autism may have undiagnosed FASD as an underlying cause of their learning problem." Mukherjee and Cook (2016)^{xiii}
20. The BMA (2016) emphasises: "Following diagnosis it is vital that appropriate treatment and support systems are implemented at the earliest possible stage to ensure the best outcomes for the child and their family, as well as to prevent the onset of secondary problems."
21. The secondary problems that can arise when FASD is ignored can be devastating, including mental health problems, addictions, homelessness, sexual vulnerability, suicide, problems with the legal and justice system, and more.
22. Ignoring FASD comes at a great cost to society. For example NICE (Briefing Paper, 2020) says, "Based on data from the US, the annual cost of FASD in the UK is estimated to be over £2 billion."
23. Birth mothers of those with FASD advocate for increased attention on these issues as silence has devastating impact. As one birth mother said, "It's the right for both the mother and child to have an FASD diagnosis. Diagnosis of Foetal Alcohol Spectrum Disorders is still too difficult to access, even when birth mothers come forward and express their concerns....90% of birth mothers knew within first year that their child was different, yet for some it took till adulthood to get a diagnosis and the impact of a late diagnosis for many have been addiction, mental health, justice systems and sexual exploitation. FASD is sometimes multi-generational – we can break this cycle." Pip Williams, Founder UK-EU Birth Mothers-FASD Network, Co-Founder, FASD UK Alliance, Meeting with Deputy Chief Medical Officer Prof. Gina Radford, 22 October 2018.^{xiv}
24. The WHO should convene a meeting with adults and young adults with FASD and other stakeholders including birth mothers. It's important to hear the voices of those with FASD when considering the impact of prenatal alcohol harm. They are key stakeholders who have a right to be heard.
25. Consider the following quotes from people with FASD in the UK who have been sharing their truths with UK policy makers.
26. "FASD is a time bomb waiting to explode. There must be so many people out there now with wrong diagnosis and without any understanding of what is wrong with them." Adult with FASD in response to survey by the National FASD Advisory Committee, presented at Meeting with Deputy Chief Medical Officer Prof. Gina Radford, 22 October 2018.^{xv}

27. “FASD is complicated and no two people are the alike. Prenatal alcohol exposure can cause damage to any system of the body. In recent medical literature there were found to be over 400 different diagnoses and problems with FASD. Most of the time FASD is invisible. People with FASD can look normal, but struggle with normal day to day tasks. It most common for people with FASD not to have facial features. Most people with FASD will have a normal intelligence. Some will have high intellect and still struggle. The majority will need a circle of external support for their lifetimes. You cannot outgrow FASD. It is permanent and a life-long condition. There is no cure. It is a struggle to find diagnosis, support and help as there is no disability category where they fit into. People with FASD just want to be understood, cared for and most of all loved like everyone else.” Andy Jackson, presentation at meeting with Deputy Chief Medical Officer Prof. Gina Radford, 22 October 2018^{xvi}.
28. “My first Primary School teacher described me as being lazy, defiant, obstructive and evil when I was in Year 1. My GP knew nothing about FASD, even though it was suggested at my adoption medical... I saw CAMHS [Child and Adolescent Mental Health Services] last week and they really told me that it’s not really their job to support people with my conditions. They couldn’t tell me whose job it was....I want people who understand the effects of FASD on minds and mental health...Mental health services who recognise and have services for those affected...Not to be blamed for my conditions, especially when people have been told how these conditions affect me.” Georgia Roberts, teen with FASD, Presentation to the All-Party Parliamentary Group on FASD Roundtable Discussion, 13 December 2018^{xvii}.
29. "It's not right...I would like to be diagnosed. I have every right to be diagnosed." Nyrene Cox, adult with suspected FASD who has been trying for 5 years to get a diagnosis, speaking before the All-Party Parliamentary Group on FASD, 9 May 2019.^{xviii}
30. People with FASD want their strengths to be acknowledged as well. They can be part of the solution to some of these challenges. According to Rossi, another of our advisors said, “Life with FASD has its ups and downs, negatives include being globally delayed in comparison to my peers, causing them to see me as childish. A major positive is the fact that I can see what others can’t and think outside the box creatively.”
31. The National Organisation for FASD has developed a new website funded by the Department of Health and Social Care, as part of a partnership project with Seashell. This website – www.fasd.me – is designed to empower young people with FASD to become better self-advocates and to better understand their condition. As part of this, more than 70 young people with FASD contributed to lyrics for a new song. Please [watch the video and listen to the song](#) before you decide to not include FASD in your global strategy on reducing alcohol harm. We asked young people what they want the world to know about living with FASD. Here is an excerpt:

I see the world with different colours

And I play a different way to the others

The alcohol got in my brain

But I still laugh and smile the same

Because of my pain it’s like Groundhog Day, Groundhog day, Groundhog Day.

Every life is precious, that’s easy to see

I want to show you all my skills, to show the world me

I can feel safe and free

I know that I'll get there

Walk along with me^{xix}

32. The National Organisation for FASD (UK) calls upon the WHO to walk along with those with FASD and their families. Silence is not acceptable on such a major, overlooked and preventable condition.
33. The National Organisation for FASD stands ready to assist in further development of the WHO global strategy to reduce the harmful use of alcohol, including helping to organise a stakeholder meeting.

Sources:

- ⁱ The National Organisation for FASD (formerly NOFAS-UK) is dedicated to supporting people affected by Fetal Alcohol Spectrum Disorders (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy. National FASD, founded in 2003, is a source for information on FASD to the general public, press and to medical and educational professionals. UK registered charity number 1101935. (For more information see our three websites: www.nationalfasd.org.uk; www.preventfasd.info; www.fasd.me)
- ⁱⁱ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5839298/>
- ⁱⁱⁱ <https://www.ontario.ca/laws/statute/S04012>
- ^{iv} https://www.euro.who.int/_data/assets/pdf_file/0005/318074/Prevention-harm-caused-alcohol-exposure-pregnancy.pdf?ua=1
- ^v BMJ (2020): <https://www.bma.org.uk/what-we-do/population-health/drivers-of-ill-health/alcohol-and-pregnancy-preventing-and-managing-fetal-alcohol-spectrum-disorders>
- ^{vi} BMA (2016): <https://www.bma.org.uk/what-we-do/population-health/drivers-of-ill-health/alcohol-and-pregnancy-preventing-and-managing-fetal-alcohol-spectrum-disorders>
- ^{vii} <https://nationalfasd.org.uk/learn-more/policy/ccgs-and-nhs-trusts/>
- ^{viii} <https://hansard.parliament.uk/commons/2019-01-17/debates/19011751000002/FoetalAlcoholSpectrumDisorder>
- ^{ix} <https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol>
- ^x <https://www.nice.org.uk/guidance/indevelopment/gid-gs10139/documents>
- ^{xi} NICE briefing paper, <https://www.nice.org.uk/guidance/indevelopment/gid-gs10139/documents>
- ^{xii} See for example, <https://www.who.int/publications/i/item/9789241549912> and <https://www.who.int/publications/i/item/9789241548731>
- ^{xiii} <https://theconversation.com/how-foetal-alcohol-spectrum-disorders-could-be-a-hidden-epidemic-52835>
- ^{xiv} https://nationalfasd.org.uk/documents/20181022_Roundtable%20DeputyCMO_FIN.pdf
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