

Briefing for 'FASD Awareness Day - 9 September'

Motion S6M-13767

- International FASD Awareness Day is 9th September 2024.
- Fetal Alcohol Spectrum Disorder (FASD) – is a largely preventable condition arising from exposure to alcohol in pregnancy – it is one of the most common neurodevelopmental conditions in Scotland with over 275,000 people affected, though currently poorly recognised.
- FASD is preventable. The UK Chief Medical Officers advise that those who are pregnant or planning a pregnancy do not drink any alcohol to reduce the risk to the baby.
- FASD affects people's physical health, brain development and maturation, and capacity to learn, throughout their lives.
- In a recent study, 42% of babies had been exposed to alcohol in pregnancy in Scotland, with the UK experiencing the fourth highest rate of prenatal alcohol exposure in the world.
- 15% of pregnancies exposed to alcohol in Scotland involve high, frequent consumption.
- Action is needed to raise awareness of the risks of alcohol use during pregnancy, the need to stop drinking alcohol if planning a pregnancy, to reduce overall population consumption, and to better identify and support those affected.
- This can be achieved by:
 - mandating labelling of alcohol products and menus, including a pregnancy warning
 - fully implementing the World Health Organization's 'best buys' to reduce population consumption by automatically uprating the minimum price, introducing restrictions on alcohol marketing and controlling availability of alcohol
 - developing and implementing a Preconception Strategy for Scotland
 - adequately resourcing the national neurodevelopmental pathways to allow early identification and appropriate support for those with FASD
 - increasing access to training for healthcare professionals to support early identification of those at risk as well as intervention for women before and during pregnancy
 - identifying those with FASD and supporting them and their families across the lifespan

Prevalence and impact of FASD

Fetal Alcohol Spectrum Disorder (FASD) is a spectrum of conditions arising from **exposure to alcohol at any stage of pregnancy**. FASD affects the individual's physical and neurodevelopmental health. It impacts capacity to learn, and is one of the most common, but unrecognised, neurodevelopmental conditions in Scotland.¹

It has been estimated that **around 3-5% of the population have FASD in Scotland**,¹ significantly more than the estimated 0.8% globally.² This is higher than the prevalence of Autism in Scotland at 1%.³ A study by the University of Glasgow, however, suggests that prevalence could be higher than previously thought with **42% of babies having been exposed to alcohol in pregnancy** and 15% having shown signs of exposure to high, frequent consumption.⁴

The social and economic costs of FASD are also substantial, estimated at £2 billion in the UK annually.¹¹ FASD affects people throughout their lives and can significantly impact on ability to engage in daily life and to develop into independent adults when early supports are not put in place:^{5 6 7}

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| • 90% experience mental health problems | • 43% have their education disrupted |
| • 50% experience drug and alcohol problems | • 60% have trouble with the law |
| • 80% experience difficulties with independent living and gaining and retaining employment | • 35% have been imprisoned as adolescents |
| • 61% have disrupted school experiences | • 23% have needed in-patient psychiatric care |
| | • 42% have co-occurring conditions |

Common challenges for those with pre-natal alcohol exposure include difficulties with executive functioning, understanding social cues, boundaries and how to keep safe, dysmaturity, attention and memory challenges, as well as motor and physical challenges.⁹ FASD causes physical impairments to the body and organs leading to conditions of the eye, ears, heart, skin, kidney and digestive system, as well as asthma and auto-immune

conditions, with individuals often requiring specialist support from health, education and social services over the lifespan.⁸ Children within the care system are disproportionately affected by FASD and pre-natal alcohol exposure, with 1 in 3 care-experienced young people having been exposed.¹⁰

The Scottish FASD Strategy Group asks for strategic action on:

- Prevention
- Identification and access to diagnosis
- Support and intervention

Such avoidable disadvantages are incompatible with the recently enacted UNCRC rights of the child (Articles 24 and 27) and Scotland's "Getting it Right for Every Child" (GIRFEC) approach, which aims to improve outcomes and support the wellbeing of all children. GIRFEC, grounded in the Children and Young People (Scotland) Act 2014, calls for a coherent and integrated approach. In March 2020, members of the Children's Parliament reviewed key issues and calls to action from over 1000 children across Scotland; one of the three key issues identified to raise at the fourth Scottish Cabinet Meeting with Children and Young People was "The Right to Protection: a childhood free from the impact of alcohol". This highlights that children and young people are also eager for change. It is vital that more is done to prevent alcohol-related harm and to support young people with FASD in-line with existing policies to help them thrive.

Action to prevent FASD

FASD is preventable. As the UK Chief Medical Officers make clear, alcohol and pregnancy do not mix. They recommend that the safest approach for people who are pregnant or planning a pregnancy, is to not drink alcohol at all, to keep risks to the baby to a minimum. NICE guidelines published in 2022 highlight that while around half of pregnancies are unplanned, FASD is preventable by avoiding alcohol during pregnancy and avoiding pregnancy when consuming alcohol.¹² Alcohol at any stage of pregnancy risks the child developing a neurodevelopmental disorder. However, **over a quarter (28%) of women in the UK are unaware of this advice.**³⁸ Awareness of the weekly drinking guideline to keep risks to their own health low is even poorer, at 23%.¹⁷ Mothers of children with FASD are found to have a higher level of genetic vulnerability to addiction.¹⁵ Individuals with FASD are also more susceptible to alcohol addiction in addition to having a genetic vulnerability to poorer metabolism of alcohol.¹⁶ During FASD Awareness Day we will continue to use the #NoAlcoholNoRisk hashtag to share the key message that alcohol and pregnancy do not mix and encourage others to do so.

A prevented case of FASD means a child is born with the ability to reach their potential and saves an estimated £1.5 million across the lifespan.

The UK Government has recently published a Preconception Strategy which recognises the importance of embedding preconception health in all policies, including those seeking to prevent alcohol-related harm.¹² The development of Scotland's Preconception Strategy has recently restarted,

and it is hoped that this will be an important step forward in taking action to reduce harm. To reduce the prevalence and impact of FASD in Scotland, we must:

- raise awareness of the risks of drinking during pregnancy,
- reduce overall population consumption,
- ensure those affected by FASD are identified and supported appropriately.

We have three specific recommendations:

Raise Awareness: Introduce mandatory alcohol labelling to increase awareness of the risks associated with drinking

It is vital that women are aware of the risks of drinking during pregnancy or if planning a pregnancy, whilst avoiding demonising women or stigmatising FASD. Because of life circumstances some women may feel unable to give up alcohol and they should have easy access to appropriate advice on contraception.

People have a right to know what is in their drinks and the potential impact on their health and that of their baby. Providing **information via labels and on menus** has the potential to facilitate behaviour change, by routinely giving people the information they need when deciding whether to purchase or consume an alcohol product. Alcohol labelling is also supported by the World Health Organization's Global Alcohol Action Plan 2022-30¹⁸ and the European Framework for Action on Alcohol 2022-25.¹⁹

The failure of the **current voluntary approach to alcohol labelling is well-evidenced**. A review of UK alcohol labels in 2022 found that important health information was missing, where 35% failed to display current guidelines and 97% did not warn of the health harms related to drinking.²¹ Only 5% provided nutritional information. The vast majority were only pictorial and of these, 30% were illegibly small.²² Only 15% of alcohol products provided a written explanation of the risks of drinking during pregnancy, all of which were illegibly small.

“Alcohol is just so appealing, and I can see why some people start drinking it. There needs to be more warnings on bottles of the health harms it can cause though.”

Focus Group Participant, Alcohol Focus Scotland (2024)

The public support mandatory labelling. For example, 57% support labels displaying a warning on drinking when pregnant or trying to conceive, 77% support including the number of units, 56% support including nutritional information and 53% support labels displaying a health warning on specific conditions.²³ This is supported by focus group research with young adult drinkers, which also found that the **Scottish public don't trust alcohol manufacturers to include information voluntarily**.²⁴

Research shows that women seek out more health information than men and prefer stronger labels using words, black and red colours, and effective pictograms to emphasise alcohol risks.²⁵ The Scottish Government should **mandate, monitor and enforce alcohol labelling standards (including a pregnancy warning), in line with World Health Organisation recommendations**.

Reduce Population Consumption: Implement the World Health Organization's 'best buys'

Drinking during pregnancy does not happen in isolation and is one symptom of Scotland's **continued unhealthy relationship with alcohol**. One in five people drink above the low-risk drinking guidelines.²⁶ Alcohol consumption in women is common and over 40% of pregnancies in Scotland are estimated to be unplanned,²⁷ with the proportion of unplanned pregnancies recently increasing during the COVID-19 lockdowns.²⁸ It is therefore **not enough to wait until someone is pregnant or planning to become pregnant** to then warn them about the risks of alcohol consumption during pregnancy. The shift to home drinking during the pandemic has created new drinking patterns that may sustain into the longer-term, leading to increased overall consumption. The impact of these changes may be greater on women, with a 44% rise in the alcohol-specific death rate for women in the UK between 2019-22 compared with 39% for men.²⁹

With the high prevalence of FASD in comparison to Autism, there needs to be more joined up thinking on neurodevelopmental conditions within parliament, ensuring FASD is included within this work. Whilst research in this area is limited, there appear to be various epidemiological and symptomatological overlaps between FASD and Autism with both conditions underdiagnosed - in some cases co-existing - and impacting on functioning.³⁰ Policies that reduce the overall level of alcohol consumption at a population level are essential, as the higher the average consumption in a population, the higher the consumption among women who might become pregnant. The World Health Organisation's three 'best buys',³¹ the most effective and cost-effective measures to reduce alcohol consumption and harm, are to **increase the price, reduce the availability and restrict the marketing of alcohol**.

AFS recommends that the Scottish Parliament and Scottish Government should:

- * **Introduce an automatic uprating mechanism for Minimum Unit Price (MUP), along with a harm prevention levy**

Increasing the price of alcohol is one of the most effective ways to reduce consumption of alcohol and related harms. The Scottish Parliament's bold action to introduce a 50p per unit MUP in 2018 reduced consumption by around 3%, saving an estimated 156 lives per year.³² However, inflation has eroded the potential benefits of MUP, and so the MUP will be increased to 65p per unit in September 2024. We urge the Government to create an automatic uprating mechanism to adjust MUP for affordability in the future. We also call for an alcohol harm prevention levy on retailers' profits from MUP to support local prevention, treatment, and recovery services.

- * **Introduce statutory alcohol marketing restrictions**

Introducing statutory restrictions on how heavily and attractively alcohol is marketed would reduce consumption and lessen the social pressure on women to drink. The display and promotion of alcohol products in shops is often prominent and visible, further increasing accessibility and impulse purchasing. An analysis of consultation responses on marketing by the Scottish Government in 2023 showed that Public Health and Third Sector organisations were consistently in favour of restrictions on alcohol advertising and promotion.³³ The Government are expected to consult on specific proposals during 2024, and we urge all members of the Scottish Parliament to support future efforts to restrict alcohol marketing and realise people's human right to health.

*** Develop a national strategy to control the availability of alcohol.**

The widespread availability of alcohol in Scotland makes it easy to obtain and gives the message that drinking is a normal part of everyday life. Licensing boards approved 85% of new premises applications in Scotland in 2021-22 and a further 23,269 occasional licences were granted.³⁴ Ease of access has also increased as a result of online delivery of alcohol becoming more common, with alcohol often available within the hour leading to greater impulse purchasing. We need to understand what people think about the role of alcohol in their communities. We also need licensed premises to be required to provide alcohol sales data as a condition of their licence. This will inform a national strategy on alcohol availability that is focused on building safer and healthier environments.

Ensure those affected by FASD are identified and supported appropriately

*** Prevention is key.**

We need to give appropriate focus and attention to the scale of the issue affecting a quarter of a million Scots. There is no end to the benefits of supporting babies to grow in pregnancy without exposure to alcohol. A prevented case means a child is born with the ability to reach their potential and saves an estimated £1.5 million (calculated in 2007) across the lifespan.³⁵ Universal approaches and education from multiple sectors on the importance of supporting alcohol-free pregnancies is essential. In addition, it is also essential that those of childbearing age receive the message that, if they are drinking alcohol, contraception should be explored to avoid an alcohol-exposed pregnancy. **Awareness of the dangers of alcohol should be promoted *prior to pregnancy*** to allow individuals to make informed decisions for their health. While there have been recommendations to invest more money into smoking cessation for pregnant women, more needs to be done in relation to alcohol in pregnancy due to significantly more women drinking (79%)³⁹ rather than smoking (11.5%).⁴⁰

*** Ensure timely identification, diagnosis and support.**

It is estimated that 99% of individuals with FASD are undiagnosed.³⁶ We need to ensure adequate resources are available to enable access to a national neurodevelopmental pathway which offers **timely identification, diagnosis and support** from practitioners who have training, knowledge and competency in FASD alongside the other conditions which pre-natal alcohol exposure is a known risk factor e.g., ADHD and Intellectual Disability. Diagnosis requires a comprehensive multi-disciplinary assessment alongside in-depth interviews with family members and relevant informants, to determine both a pre-natal and neurodevelopmental history. It is vital that practitioners are enabled to access training and that **FASD is included within all neurodevelopmental pathways to allow for a consistent and reliable approach** across health boards in Scotland. Obtaining a diagnosis can be a vital step in making the difficulties that individuals face visible, explainable and targetable with interventions.³⁷

*** A commitment to long-term, consistent support and intervention is essential across the lifespan.**

This is essential to maximise the potential of children and young people with a history of pre-natal alcohol exposure, and it is vital that organisations such as FASD Hub Scotland are available. Families highlight many challenges including a lack of understanding and awareness from healthcare and education professionals, lengthy waiting lists and barriers to assessment, a lack of support as young people transition to adult services and little understanding of FASD within the criminal justice system. The identification of neurodevelopmental disorders, particularly FASD, in these groups would allow the **adaptation of interventions and implementation of supportive structures** that would significantly increase their engagement with services and ability to derive benefit from those offered. Ensuring that the voice of lived experience is heard and listened to within decision-making processes is essential.

References

1. Education Scotland (2024). Fetal Alcohol Spectrum Disorder (FASD). Retrieved from: <https://education.gov.scot/resources/fasd/>
2. McCarthy, R., Mukherjee, R. A. S., Fleming, K. M., Green, J., Clayton-Smith, J., Price, A. D., et al. (2021). Prevalence of fetal alcohol spectrum disorder in Greater Manchester, UK: An active case ascertainment study. *Alcoholism: Clinical and Experimental Research*, 45(11), 2271-81. <https://doi.org/10.1111/acer.14705>
3. MacKay, T., Knapp, M. (2018). The Microsegmentation of the Autism Spectrum: Economic and research implications for Scotland. Retrieved from: <https://www.gov.scot/binaries/content/documents/govscot/publications/research-and-analysis/2018/03/microsegmentation-autism-spectrum/documents/00533382-pdf/00533382-pdf/govscot%3Adocument/00533382.pdf>
4. Abernethy, C., McCall, K. E., Cooper, G., Favretto, D., Vaiano, F., Bertol, E., et al. (2018). Determining the pattern and prevalence of alcohol consumption in pregnancy by measuring biomarkers in meconium. *Archives of Disease in Childhood - Fetal and Neonatal Edition*, 103(3). 216-220.
5. Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., Kogan Young, J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioural Pediatrics*, 25(4), 228-38. <https://doi.org/10.1097/00004703-200408000-00002>
6. Streissguth, A. P., Barr, H. M., Kogan, J., Bookstein, F. L. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Retrieved from: <http://accessiblelaw.org/Documents/CDC%201996%20Study.pdf>
7. Popova, S., Temple, V., Dozet, D., O'Hanlon, G., Toews, C., Rehm, J. (2021). Health, social and legal outcomes of individuals with diagnosed or at risk for fetal alcohol spectrum disorder: Canadian example. *Drug Alcohol Dependency*, 219. <https://doi.org/10.1016/j.drugalcdep.2020.108487>
8. Himmelreich, M., Lutke, C. J., Hargrove, E. T. (2020). The lay of the land : Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis. *The Routledge Handbook of Social Work and Addictive Behaviors*. Published online April 7, 2020:191-215. doi:10.4324/978042920312-1-14
9. Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A. S., et al. (2016). Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *The Lancet*, 387(10022), 978-87. [https://doi.org/10.1016/S0140-6736\(15\)01345-8](https://doi.org/10.1016/S0140-6736(15)01345-8)
10. Gregory, G., Reddy, V., Young, C. (2015). Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis. *Adopting & Fostering*, 39(3). <https://doi.org/10.1177/0308575915594985>
11. Moore, E. M., Riley, E. P. (2015). What happens when children with fetal alcohol spectrum disorders become adults? *Current Developmental Disorders Reports*, 2(3), 219-27.
12. Children's Alliance (2023). A preconception care strategy. Retrieved from: <https://childrensalliance.org.uk/wp-content/uploads/2023/05/2-Preconception-care-strategy-report-University-of-Southampton.pdf>
13. Sher, J. (2022). Preconception health, education and care: making and celebrating progress. *International Journal of Birth and Parent Education*, 9(2), 5-9.
14. Alcohol Health Alliance UK (2020). *Drinking in the dark. How alcohol labelling fails consumers*. London: AHA.
15. Edenberg, H. J., & McClintick, J. N. (2018). Alcohol Dehydrogenases, Aldehyde Dehydrogenases, and Alcohol Use Disorders: A critical review. *Alcoholism, Clinical and Experimental Research*, 42(12), 2281–2297. <https://doi.org/10.1111/acer.13904>
16. Warren, K. R., & Li, T. K. (2005). Genetic polymorphisms: impact on the risk of fetal alcohol spectrum disorders. *Birth Defects Research. Part A, Clinical and Molecular Teratology*, 73(4), 195–203. <https://doi.org/10.1002/bdra.20125>
17. Online survey of 1,019 people aged 18+ in Scotland, conducted 12-15 November 2018 by YouGov for AFS. The figures are representative of all adults in Scotland (aged 18+).
18. World Health Organisation. (2024). Global alcohol action plan 2022-2030. Retrieved from: <https://www.who.int/publications/i/item/9789240090101>
19. WHO Regional Office for Europe. (2022). European framework for action on alcohol, 2022–2025: Information sheet. Retrieved from: <https://www.who.int/andorra/publications/m/item/european-framework-for-action--on-alcohol--2022-2025>
20. Noncommunicable Diseases Alliance (2022). NCD Briefing: 8 Public Health calls. Retrieved from: <https://www.bhf.org.uk/-/media/files/what-we-do/in-your-area-scotland-pages/ncd/ncd-briefings-2022.pdf?rev=170c318f49fa4b39ba7c599ae28890fe&hash=1E4D82583304A48981A36CDE39D5AECA>
21. Alcohol Health Alliance UK. (2022). Contents unknown: How alcohol labelling still fails consumers. Retrieved from: https://www.ahauk.org/wp-content/uploads/2022/06/Labeling_Report_2022_.pdf
22. Alcohol Health Alliance UK. (2020). *Drinking in the dark. How alcohol labelling fails consumers*. Retrieved from: <https://ahauk.org/wp-content/uploads/2020/08/DRINKING-IN-THE-DARK.pdf>

23. Online survey of 1,126 adults aged 18+ in Scotland conducted 29 February to 18 March 2024 by YouGov on behalf of Action on Smoking and Health. The figures have been weighted and are representative of all adults in Scotland (aged 18+).
 24. Jones, D., Moodie, C., Purves, R. I., Fitzgerald, N., Crockett, R. (2021). Health information, messaging and warnings on alcohol packaging: A focus group study with young adult drinkers in Scotland. *Addiction Research & Theory*, 29(6), 469-78. DOI: 10.1080/16066359.2021.1884229
 25. Correia, D., Kokole, D., Rehm, J., Tran, A., Ferreira-Borges, C., Galea, G., et al. (2024). Effect of alcohol health warning labels on knowledge related to the ill effects of alcohol on cancer risk and their public perceptions in 14 European countries: An online survey experiment. *Lancet Public Health*, 9(7), 470-80. doi: 10.1016/S2468-2667(24)00102-6
 26. Scottish Government (2023). The Scottish Health Survey 2022 – Volume 1: main report. Retrieved from: <https://www.gov.scot/publications/scottish-health-survey-2022-volume-1-main-report/pages/10/>
 27. Online survey of 550 people in Scotland conducted 26 June-1 July 2020 by Opinium for AFS and Alcohol Change.
 28. University College London. (2021). Unplanned pregnancies nearly doubled during lockdown. Retrieved from: <https://www.ucl.ac.uk/news/2021/oct/unplanned-pregnancies-nearly-doubled-during-lockdown>
 29. Office for National Statistics (2022). Alcohol-specific deaths in the UK: Registered in 2021. Retrieved from: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/alcohol-specificdeathsintheuk/2021registrations>
 30. Carpita, B., Migli, L., Chiarantini, I., Battaglini, S., Montalbano, C., Carmassi, C., et al. (2022). Autism Spectrum Disorder and Fetal Alcohol Spectrum Disorder: A literature review. *Brain Sciences*, 12(6), 792. <https://doi.org/10.3390/brainsci12060792>
 31. World Health Organization (2010). *Global strategy to reduce the harmful use of alcohol*. Geneva: World Health Organization
 32. Alcohol Focus Scotland. (2024). Minimum Unit Pricing: Continuing and optimising a life-saving policy infographic. Retrieved from: <https://www.alcohol-focus-scotland.org.uk/resources/mup-infographic-post-vote.pdf>
 33. Scottish Government. (2023). Consultation on restricting alcohol advertising and promotion: Analysis of responses. Retrieved from: <https://www.gov.scot/publications/consultation-restricting-alcohol-advertising-promotion-analysis-responses/pages/1/>
 34. Scottish Government. (2022). Scottish Liquor Licensing Statistics 2021-22. Retrieved from: <https://www.gov.scot/publications/scottish-liquor-licensing-statistics/>
 35. Fetal Alcohol Assessment and Support Team (2018). Evaluation of the Fetal Alcohol Assessment & Support Team: Summary report. Retrieved from: <https://www.faast.ed.ac.uk/fasd-clinical-service-evaluation/>
 36. Fetal Alcohol Spectrum Disorders Awareness Day Parliamentary Debate. Published 2021. Retrieved from: <https://www.parliament.scot/chamber-and-committees/official-report/search-what-was-said-in-parliament/chamber-and-committees/official-report/what-was-said-in-parliament/meeting-of-parliament-23-09-2021?meeting=13316&iob=120817>
 37. Chasnoff, I. J., Wells, A. M., King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2). doi:10.1542/peds.2014-2171
 38. Alcohol Health Alliance (2018) *How we think, what we drink*. https://12coez15v41j2cf7acjzaodh-wpengine.netdna-ssl.com/wp-content/uploads/2018/11/AHA_How-we-drink-what-we-think_2018_FINAL.pdf
 39. Institute of Alcohol Studies. (2020). Women and alcohol: Alcohol knowledge centre briefing. Retrieved from: <https://www.ias.org.uk/wp-content/uploads/2020/12/Women-and-alcohol.pdf>
 40. Office for National Statistics. (2021). Adult smoking habits in the UK: 2021. Retrieved from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/bulletins/adultsmokinghabitsingreatbritain/2021>
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