



HSE Position on Prevention of Fetal Alcohol Spectrum Disorders (FASD)

September 2022

Summary

- Alcohol use during pregnancy causes Fetal Alcohol Spectrum Disorders (FASD) and is the leading preventable cause of neurodevelopment disorder.
- The prevalence of FASD in Ireland is estimated at 2.8-7.4% of the population.
- FASD is often an invisible disability and is associated with lifelong physical, mental, educational, social, and behavioural difficulties.
- FASD is preventable through avoiding alcohol during pregnancy.
- Effective actions to prevent FASD include public health measures targeting the price, availability and accessibility of alcohol, pregnancy warning labels on alcohol products, communications campaigns, routine screening and brief interventions by healthcare professionals, healthcare supports for pregnant women, training and professional development supports for staff, and research and public health surveillance. Timely diagnosis and treatment for children with FASD is required.
- This position paper outlines 14 actions for the HSE for the prevention of FASD and the response to children and adults with FASD.

Background

The World Health Organization (WHO) has called for action on the prevention of alcohol use in pregnancy and the prevention of Fetal Alcohol Spectrum Disorders (FASD) in its *Global Action Plan on Alcohol*.ⁱ FASD is a group of disorders caused by prenatal alcohol exposure and are associated with a range of lifelong physical, mental, educational, social, and behavioural difficulties. FASD comprise Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome, Alcohol Related Birth Defects, and DSM-5 Neurodevelopmental Disorder - Prenatal alcohol exposure.

Alcohol has an adverse effect on the developing brain, and on body organs. There is no evidence-based, defined, safe amount of alcohol that can be consumed during pregnancy to prevent a child being born with FASD. The greater the amount of alcohol that has been consumed during pregnancy, the greater the risk to the development of the embryo and fetus. International studies confirm that the higher the alcohol consumption in a country, the higher the rates of FASD.ⁱⁱ This association between prenatal alcohol exposure and FASD is strong and consistent from study to study, in all countries, nationalities, ethnic and socio-economic groups.

FASD is often an invisible disability, yet prenatal alcohol exposure is the leading preventable cause of neurodevelopmental disorder.ⁱⁱⁱ The average risk from prenatal alcohol exposure is high, with women who drink during pregnancy having a 1 in 67 risk of giving birth to a child with FAS and a 1 in 13 risk of (non-FAS) FASD.^{iv} A study in Manchester

in three mainstream schools found that 1.8% of the children screened had FASD, twice the prevalence of Autism Spectrum Disorder.^v

The prevalence and epidemiology of FASD in Ireland is not known. As there is no register of persons with neurodevelopmental disorder in Ireland, no up to date data are available on cases of FASD in Ireland. A 2017 systematic review and meta-analysis estimating prevalence of alcohol use during pregnancy showed Ireland had one of the highest prevalence of all countries studied.ⁱⁱ It estimated that between 2.8 - 7.4% of the population of Ireland might have FASD. In Ireland, two in five pregnancies are unplanned, increasing the chance the embryo and fetus will be exposed to alcohol, and many women will not know they are pregnant in the early weeks.

The best available evidence estimates that about 600 Irish babies are born each year with Fetal Alcohol Syndrome, with a further 9-10 times this number of babies born annually in Ireland who have other Fetal Alcohol Spectrum Disorders (FASD). Only a small proportion of children with FASD have visible facial features (facial dysmorphism); the majority of children with FASD have no visible signs of disability at birth and difficulties may not manifest until preschool or school age. There are no standard diagnostic policies or guidelines for diagnosing or treating children with FASD in Ireland.

There is no national strategy in Ireland for the prevention of FASD or for the response to children and adults with FASD. There are, however, a number of policies and strategies that include actions to reduce alcohol use in pregnancy and prevent FASD (see Appendix 1).

Preventing FASD in Ireland

FASD is preventable through avoiding alcohol during pregnancy. A national whole of government strategy is needed to drive evidence based measures that lead to a reduction in FASD in Ireland and to drive appropriate assessment and intervention strategies when the diagnosis is suspected or made.

The greatest predictor of drinking alcohol during pregnancy is people's drinking patterns before pregnancy. The most effective measure to reduce the incidence of FASD is therefore to reduce the population's alcohol per capita (APC) consumption. Over the last 50 years, alcohol use in Ireland has trebled and in 2019, we had have one of the highest rates of per capita alcohol consumption in the world at 10.8 litres per capita.^{vi} A cross-societal approach is needed to prevent FASD. It is not purely a woman's problem; 74% of alcohol is consumed by men.

The commercial interests of industry act against the population's health through aggressive marketing, lobbying against effective public health measures, corporate social responsibility strategies that can deflect attention, and extensive supply chains.^{vii} Some recent research also indicates that alcohol industry-funded bodies may omit and misrepresent the evidence on key risks of alcohol consumption during pregnancy.^{viii}

The WHO's 'best buys' of proven effective and cost effective interventions to reduce harmful alcohol use are to increase the price, ban advertising, and restrict availability of alcohol.^{ix} Two specific measures in Ireland's Public Health (Alcohol) Act (2018) - pregnancy warnings on all alcoholic drinks and minimum unit pricing - can have a significant impact. Minimum unit pricing on alcohol was introduced in January 2022. Research demonstrates product warning labels are effective in increasing people's awareness of the risks associated with alcohol use in pregnancy. This measure in the Public Health (Alcohol) Act

(2018) is yet to be commenced. Warning labels, along with other public health measures, will reduce overall alcohol use in Ireland and alcohol-related harm.

Women may have many caregivers during pregnancy and they should get the same information and advice on alcohol from all of them. Research conducted by the HSE to inform its 'Ask About Alcohol' communications campaign found that women do not always receive clear and consistent information on the importance of avoiding alcohol during pregnancy. Further research is needed to understand health literacy during pregnancy, which is a key determinant of health outcomes. Little is known in Ireland on how women find, understand, appraise and apply health information in the context of alcohol and pregnancy.

With clear information, many pregnant women will abstain from alcohol for the duration or the remainder of pregnancy. The HSE has undertaken a number of communication campaigns to promote the advice that "No amount of alcohol at any stage of pregnancy is safe for your baby". The lessons learned from 20 years of FASD awareness campaigns in Canada are that successful campaigns involve a wide range of partners in campaign planning, are most effective with a large, well-defined group of individuals who are lower risk, and use a positive, supportive approach that avoids use of blame, shame and fear-based strategies.^x With sufficient exposure, effective FASD awareness campaigns resulted in changes in risky behaviour and were shown to influence levels of awareness, knowledge, attitudes, and information-seeking behaviour.

Some women will need additional support to abstain from alcohol during pregnancy. Effective interventions include screening and brief intervention (SBI) for alcohol use by healthcare professionals, through implementation of the HSE's MECC (Making Every Contact Count) and SAOR (Support, Ask and Assess, Offer Assistance, Refer) initiatives. However, there are significant challenges to implementing brief behavioural interventions by healthcare professionals.^{xi} Targeted Parent Child Assistance Programmes^{xii} have also been demonstrated to be effective in preventing FASD, but are not available in Ireland. Some maternity units have Drug and Alcohol Liaison Midwife service for women who need more support, but these services are not available in all maternity units.

Timely diagnosis and treatment for children with FASD is required not only to improve children's outcomes, but also to prevent future cases given that FASD can be intergenerational.^{xiii} A national survey of paediatricians in Ireland regarding FASD, reported in 2017, suggests prenatal alcohol exposure may not be considered in the evaluation of children with developmental delay. The lack of FASD specific training reported by respondents is noted and needs to be addressed. The HSE has recently launched a survey with healthcare, social care and educational professionals to better understand FASD awareness, knowledge, service provision, and training needs. The findings will be used to inform the development of professional development supports regarding alcohol in pregnancy and FASD.

It is important that timely assessment and service provision be accessible and allocated on a needs basis with standard needs assessment and recording using a validated tool such as the International Classification of Function. If an existing diagnosis changes to a diagnosis of FASD, service provision in accordance with need should continue. Service improvements being implemented for other neurodevelopmental disorders such as Autism Spectrum Disorder need to be extended to FASD.

Research and public health surveillance is required to inform the prevention of, and response to, FASD. Public health surveillance is, according to the WHO, "the continuous, systematic collection, analysis and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practice." Active case ascertainment and surveillance of FASD is needed. In addition, the continued surveillance

of alcohol knowledge, attitudes and behaviour of the Irish population is required via the national Healthy Ireland survey and other research. A national needs assessment of pregnant women with problem drinking could also inform appropriate service development.

Action Plan

The HSE recommends that the following actions are implemented to prevent FASD. Many of these actions are currently being progressed, and some new actions are proposed that will require resourcing, such as the development of a national strategy on FASD prevention and response in Ireland.

Timeframes identified for achieving the actions are short-term (<18 months), medium-term (< 3 years), and long-term (<5 years).

Development process

The development of this document was led by the Clinical Lead for FASD Prevention at the HSE Alcohol Programme with input, advice and review by the FASD Prevention Expert Advisory Group. The affiliation of the members of this group is listed in Appendix 2.

HSE Actions

No.	Action	Lead(s)	Timeframe	Outcome
1	Advocate for development of a whole of government national strategy on FASD.	HSE Health & Wellbeing	Medium	Enhanced leadership and governance to drive implementation of effective measures for FASD prevention and response
2	Support implementation of the Public Health (Alcohol) Act 2018 in full (provisions on the Content of Advertising, broadcast watershed, and the provision of health warnings on all alcohol product labels are yet to be enacted).	HSE Environmental Health; HSE Health & Wellbeing	Long	Reduced alcohol consumption and alcohol-related harm and delayed initiation of alcohol by children and young people
3	Advise Government on further development of legislation and regulations in order to reduce the accessibility, availability and affordability of alcohol in line with the WHO SAFER initiative ^{xiv} and the WHO Global Action Plan on Alcohol ⁱ	HSE Health & Wellbeing	Long	Reduced alcohol-related harm
4	Strengthen the HSE's alcohol and pregnancy communications campaign with the public and healthcare professionals so that there is sufficient exposure to consistent and	HSE Health & Wellbeing; HSE Communications; National Women and	Short	Improved understanding of the risk of prenatal alcohol exposure

	clear messaging that no amount of alcohol at any stage of pregnancy is safe.	Infants Health Programme; ICGP		
5	Implement training in alcohol screening and brief intervention (SBI) nationally to health and social care professionals via the MECC (Making Every Contact Count) and SAOR (Support, Ask and Assess, Offer Assistance, Refer) initiatives.	HSE Health & Wellbeing; HSE Social Inclusion	Medium	Enhanced skills of professionals to support cessation and reduction of alcohol use during pregnancy
6	Ensure all maternity services adopt and implement the HSE Making Every Contact Count (MECC) maternity module	HSE Health & Wellbeing; National Women and Infants Health Programme; ICGP	Short	Alcohol screening and brief interventions are embedded as routine practice within maternity services
7	Develop and roll out an alcohol digital intervention akin to the www.quit.ie intervention for tobacco	HSE Health & Wellbeing; HSE Communications	Medium	Reduction in hazardous and harmful alcohol use across the population and during pregnancy
8	Develop the role of Drug and Alcohol Liaison Midwives to enhance the provision of evidence-informed alcohol interventions with pregnant women and their families.	HSE Acute Hospitals; National Women and Infants Health Programme; HSE Social Inclusion; HSE Mental Health	Medium	Increased supports for pregnant women to prevent alcohol use during pregnancy
9	Expand the availability of Drug and Alcohol Liaison Midwifery Services, with access to the full range of services for patient support (e.g. detoxification) in pregnancy, as recommended by the national Maternity Strategy and Drug and Alcohol Strategy.	HSE Acute Hospitals; National Women and Infants Health Programme; HSE Social Inclusion; HSE Mental Health	Medium	Access to Drug and Alcohol Liaison midwifery services in place across all maternity units
10	Expand alcohol services for pregnant and post-natal women and develop pathways of care; in line with the strategic priorities for implementation of the National Drug and Alcohol Strategy	Department of Health; HSE Social Inclusion; HSE Health & Wellbeing; HSE Mental Health	Long	Improved accessibility and availability of alcohol services for pregnant and post-natal women
11	Undertake a training needs analysis to ascertain training needs specific to alcohol and FASD prevention for all staff, and use the findings to develop and implement an FASD awareness-raising campaign and professional development plan for healthcare staff	HSE Health & Wellbeing; National Women and Infants Health Programme; ONMSD	Short	Improved staff knowledge and skills in FASD prevention
12	Increase provision of effective universal and targeted parenting supports during pregnancy and the early years, in line with 'Supporting Parents: A National Model of Parenting Support Services'	HSE Primary Care; HSE National Healthy Childhood Programme	Long	Enhanced health literacy in the context of alcohol and pregnancy. and improved health and wellbeing of

				parents and their children
13	Develop a model of care for child neurodevelopmental disorders to include FASD. As part of the model of care, adopt the International Classification of Function ^{xv} , a validated tool for standard needs assessment, and provide interventions and supports to children and adults with FASD	HSE Primary Care; HSE Disabilities; HSE Mental Health; Children's Health Ireland	Long	Standardised approach to FASD identification, assessment of need, interventions and supports in place
14	Explore potential for screening and appropriate surveillance of cases of FASD cases	HSE Public Health; National Women and Infants Health Programme; HSE National Screening Service	Medium	Improved identification of FASD and better use of data to inform service response

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Appendix 1

The actions proposed in this HSE Position Paper are supported by the following national strategies:

1. Reducing Harm Supporting Recovery Mid Term Review Strategic Priorities (strategic priority 2) <https://www.gov.ie/en/publication/e2ac4-mid-term-review-of-the-national-drug-strategy-reducing-harm-supporting-recovery/>
2. National Maternity Strategy 2016-2026 (actions 16 and 17) <https://assets.gov.ie/18835/ac61fd2b66164349a1547110d4b0003f.pdf>
3. National Strategy for Women and Girls 2017-2020: creating a better society for all (Actions 2.16 and 2.24) https://www.justice.ie/en/jelr/national_strategy_for_women_and_girls_2017_-_2020.pdf/files/national_strategy_for_women_and_girls_2017_-_2020.pdf
4. Healthy Ireland Strategic Action Plan 2021-2025 (Strategic action 4.1) <https://www.gov.ie/en/publication/441c8-healthy-ireland-strategic-action-plan-2021-2025/>
5. Sláintecare Implementation Strategy and Action Plan 2021-2023 (Actions (3) relating to Healthy Ireland Alcohol Policy to reduce harm and support recovery; commitment to introduce minimum unit pricing) <https://www.gov.ie/en/publication/6996b-slaintecare-implementation-strategy-and-action-plan-2021-2023/>
6. 2012 Steering Group Report on a National Substance Misuse Strategy (Prevention Pillar actions 3 and 6: Treatment and Rehabilitation Pillar actions 2, 3, 4, 8, 9, 12, and 19) <https://www.lenus.ie/handle/10147/214613>

Appendix 2

FASD Prevention Expert Advisory Group Membership

- HSE Strategy and Research, Health and Wellbeing
- HSE Community Operations, Social Inclusion
- HSE Community Operations, Public Health
- HSE Community Operations, Health and Wellbeing
- HSE Community Operations, Primary Care
- Faculty of Paediatrics, RCPI
- Institute of Obstetricians & Gynaecologists, RCPI
- Faculty of Public Health Medicine, RCPI
- Child and Adolescent Mental Health Services (CAMHS)
- ICGP
- HSE, Office of the Nursing and Midwifery Services Director (ONMSD)
- HSE National Women and Infants Health Programme
- Drug and Alcohol Liaison Midwife
- Service user representative
- Tusla
- Psychology researcher/academic
- Public health researcher/academic