

## House of Commons, Health Committee Alcohol Inquiry

Submission by Children in Scotland, March 2009

**The Committee is encouraged to give priority attention to the prevention, identification and treatment of Foetal Alcohol Syndrome (and Foetal Alcohol Spectrum Disorder).**

Children in Scotland is the intermediate agency for the children's sector, with over 450 members – from large children's charities to community groups, professional associations and local authorities. Learn more at [www.childreninscotland.org.uk](http://www.childreninscotland.org.uk)

### Context

1. A significant percentage of children throughout the United Kingdom are harmed in various ways and to varying degrees by alcohol. Sometimes the negative effects are caused by alcohol consumption among children and young people themselves. In addition, there is abuse and/or neglect of children resulting from the drinking problems of parents or the other adults in their lives.
2. Scotland has become keenly aware of the alcohol-fueled problems facing children and young people. The report *Hidden Harm* analysed the situation and made recommendations worthy of consideration by the Westminster Health Committee. At the moment, the Scottish Government is in the midst of a major policy initiative around how best to address alcohol-related problems. The efforts made thus far offer useful information and ideas for the House of Commons Health Committee's own alcohol inquiry.

3. In comparison with the attention accorded to parental dependence upon alcohol -- and the misuse of alcohol by children and young people -- relatively little attention (and even less action) has been focused on the extent to which children's lives and life chances have been compromised by exposure to alcohol while still *in utero*. This blindspot is counterproductive. Ignoring the problem of Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Spectrum Disorder (FASD) has not reduced the life-long harm with which many children must live because of foetal alcohol exposure.

### The Basics

4. Foetal Alcohol Syndrome (FAS) is the term used to describe the visible birth defects and the invisible organ/brain/nervous system damage that can result from exposure to alcohol during pregnancy. It is used to describe the most severe form of a wide range of permanent physical, mental and behavioural problems that begin before birth. From malformed faces and limbs to heart problems and diminished intellectual capacity, FAS can and does adversely affect children's lives across the United Kingdom.

5. It is not the case that a child either has full-blown FAS or has *no* damage from foetal alcohol exposure. When the impacts of alcohol on the development of a baby are real, but less immediately obvious, this medical condition is referred to as Foetal Alcohol Spectrum Disorder (FASD). It is akin to a child who is born with a degree of visual impairment rather than complete blindness. The extent of the impairment only becomes evident as the child grows older. Damage can range from minimal to severe.

6. In the case of FASD, it is common for the brain's 'executive functions' -- e.g., a person's ability to plan, learn from experience and control impulses -- to be significantly diminished by foetal alcohol exposure. This happens because alcohol is a *teratogenic agent* (meaning a chemical that interferes with the normal development of a foetus). Some of this teratogenic harm can occur during the first weeks following conception -- i.e., even before the pregnancy has been realised and confirmed by the mother.

## 7. The seven key messages about foetal alcohol exposure are:

- *It is potentially 100% preventable.* The one indisputable medical fact is that no mother who abstained from drinking alcohol throughout pregnancy ever has given birth to a baby with FAS/FASD.
- *It is incurable.* Although regarded as a problem affecting babies and children, the simple fact is that no one outgrows or 'gets over' the harm caused by foetal alcohol exposure. While treatment/support can improve the well-being of a child with FAS/FASD, the developmental damage is irreversible.
- *It is unpredictable.* There is no guarantee that a woman who drinks heavily during pregnancy *will* have a baby with FAS – or that one who drinks moderately *will not* have a baby harmed by alcohol. There are no tests that can determine in advance which pregnancies will result in these alcohol-fueled problems. Little is known about exactly when or how much of what type of alcohol will harm a particular foetus. Thus, there is no guaranteed 'safe' level of alcohol during pregnancy.
- *It can be difficult to diagnose.* Just as there is no test to predict which pregnancy will result in FAS/FASD, so too there is no simple test that proves its presence or absence (except in the small percentage of cases where notable facial/physical anomalies or organ damage are evident). This is true, in part, because this diagnosis is dependant upon accurate recall and reporting of alcohol consumption by the mother.
- *It is under-diagnosed (or misdiagnosed) and under-reported.* For example, based upon international data, a conservative estimate is that there are 900 children in Scotland (0-18) who have FAS -- and *many times more* (i.e., thousands) of children and young people who were damaged in more subtle, but still serious, ways by foetal alcohol exposure. Given its far larger population, the numbers will be far higher in England.

- *It has wide-ranging, serious consequences for individuals, communities and society.* Because FAS/FASD is not a problem that fades over time, many problems of young people and adults have their roots in exposure to alcohol as a foetus. At the deep end (e.g., when manifested by heart or other organ damage), there are major, on-going medical and therapy expenses. All along the foetal alcohol spectrum, however, the diminished 'executive functions' of the brain can lead to numerous problems. These include: learning difficulties and disorders (and failure in school); difficult or anti-social behaviours; inability to secure/maintain employment; and, substance misuse/addiction. Such problems translate into high costs in human and economic terms, as well as extra demands upon public expenditures and services in the health, justice, social work, education and benefits systems.
  
- *Its ill effects can be lessened by proper diagnosis and proper treatment/support.* There are promising therapies and methods of support being developed and refined internationally. Misdiagnosis – that is, mistaking FAS or FASD for other medical/developmental problems – can lead to interventions that waste time, effort and money (and may worsen the situation for the individual affected).

## Recommendations

8. *The identification of children, young people and adults harmed by Foetal Alcohol Syndrome and FASD should be given a much higher priority throughout the United Kingdom than is the case today.* This process must begin with an accurate assessment of the incidence and prevalence of these medical conditions – a task that can be accomplished only once there is a critical mass of health practitioners around the UK able to correctly make this diagnosis. This, in turn, depends upon health professionals reaching a level of agreement and consistency that does not now exist.

9. *Identification of FAS/FASD should be accompanied by the availability of appropriate treatment and effective support for the people harmed by foetal alcohol exposure.* Planning for such provision must be in synch with the identification process, as there currently is neither widespread agreement on the range of assistance needed, nor an adequate workforce in place that is prepared to offer the help that is needed.

10. *However, **top priority** should be accorded to the **prevention** of FAS and FASD across the four nations.* Given the difficulties of diagnosis and the reality that there is no 'cure', the importance of prevention' is greatly magnified. Established public health principles and practices leads to the conclusion that **abstinence** from alcohol is the best advice to give to women who are: a) trying to conceive; b) at high risk of an unplanned pregnancy; or, c) already pregnant. The abstinence message needs to become far more consistent and prominent across the United Kingdom. Mixed messages don't help.

11. *Prevention of FAS/FASD should become a priority not only within, but also well beyond, the health professions.* Because harm from foetal alcohol can occur before a pregnancy is even known, prevention efforts must be strong at the pre-conception level. Accordingly, it is as much a job for educators, youth workers, sexual health counsellors and family planning specialists, as it is for midwives or physicians.

*Children in Scotland encourages the House of Commons Health Committee to accord FAS/ FASD priority in its recommendations for action by the UK Government. Although there are areas of action here that properly are regarded and treated as devolved matters for each of the four nations, FAS/FASD is a public health issue that would benefit from UK-wide cooperation and information sharing.*

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