FaithAction Roundtable Discussion on Foetal Alcohol Spectrum Disorder

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Present

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Apologies

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Introduction

FaithAction is a network of faith and community organisations involved in social action. We became interested in the issue of Foetal Alcohol Spectrum Disorder (FASD) through one of our member organisations, FASD Network UK. FASD is relevant to faith groups for two reasons: firstly, it is estimated that as many as 70% of children in care have FASD, and there are many carers who are members of faith groups. Secondly, faith and community groups, through their social action work, may be offering support to families experiencing problems with alcohol or affected by FASD.

We recognise that the issue of FASD is a broad one and that there are specialist organisations doing excellent work to support those affected. Our aim in this discussion was simply to bring together interested professionals and faith and community organisations, to gather intelligence on current activity around FASD and to determine whether there are steps that the group or FaithAction could take to improve care for affected families and ultimately to improve public health. This paper is a summary of the discussion.

About FASD

FASD is an umbrella term for a spectrum of behavioural, emotional, physical and neurological issues that affect a developing foetus, caused by the consumption of alcohol during pregnancy. It includes Foetal Alcohol Syndrome (FAS); partial FAS (pFAS); alcohol-related birth defects (ARBD); and alcohol-related neuro-developmental disorder (ARND).

FASD is a series of birth defects whose effects are lifelong. It is a leading cause of non-genetic learning disability in the UK, but one that is completely preventable.[1]

[1] The specialist groups working in this field can provide more detailed information. See for example www.fasdtrust.co.uk/about.php and www.fasdnetwork.org/what-is-fasd.html

Challenges

Lack of public understanding

There is a lack of awareness among the public, not only about FASD, but about the dangers of alcohol in pregnancy. Furthermore, around half of pregnancies in the UK are not planned, so women may be drinking – perhaps heavily – before they even know that they are pregnant.

Inconsistent messages are given to women (see box below). This is combined with the problems of perceptions such as 'my mother drank and it didn't harm me'; the fact that some women drink due to difficult circumstances that they want an 'escape' from (such as domestic violence or HIV diagnosis); and the fact that some women are addicted to alcohol. Some of these women will undoubtedly hide their drinking from health professionals, and even those who seek help to stop drinking may or may not have the support of a specialist midwife, depending on where they live.

Even among those who have heard of FAS, there is a lack of awareness that FASD is a lifelong disability or that it overlaps with other conditions.[2] Awareness of FASD needs to be increased across the population, among women, men and young people: it could be taught in schools as part of sex education.

The need for clear messaging: extract from the NHS Choices website

"The Department of Health recommends that if you're pregnant you should avoid alcohol altogether. And if you do opt to have a drink, it recommends that you stick to one or two units of alcohol (equivalent to one small glass of wine) once or twice a week to minimise the risk to your baby.

The National Institute for Health and Care Excellence (NICE) is the independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. NICE advice on drinking in pregnancy is that women should abstain from alcohol completely during the first three months of pregnancy because of the risks of miscarriage. And for the rest of pregnancy to drink no more than one or two units of alcohol once or twice a week.

The Royal College of Obstetricians & Gynaecologists (RCOG) says the safest option for women is not to drink at all during pregnancy, but adds that small amounts of alcohol in pregnancy (not more than one to two units once or twice a week) have not been shown to be harmful."
www.nhs.uk/conditions/pregnancy-and-baby/pages/alcohol-medicines-drugs-pregnant.aspx
(accessed 24.04.2015)

Lack of professional understanding

Within the medical profession, there is misunderstanding and old knowledge regarding FASD: for example, the belief that because someone does not have the facial features associated with FAS, they are unaffected. Doctors need to be taught how to recognise FASD. Trainee midwives are not necessarily taught about the condition and may be confused about how to advise women, although the Royal College of Midwives has always advised no alcohol in pregnancy because the risks are not clear. Research in the British Journal of Midwifery found that 38% of midwives had seen an infant with FAS but less than 2% felt "very prepared" to deal with the subject.[3]

[2] Mukherjee, R., forthcoming.
[3] Winstone, A. and Verity, C. (2015) Antenatal alcohol exposure: An East Anglian study of midwives' knowledge and practice. *British Journal of Midwifery* 23:3, 180-186.

Recommendations

The health system should decide on and publicise a single, clear message of no alcohol in pregnancy. This message should be promoted to the public and to health professionals such as midwives.

Professionals should learn from the Making Every Contact Count campaign,[4] which encourages health professionals to talk to people about healthier lifestyle choices, offering advice and ways to change behaviour.

Challenges of diagnosis

Diagnosis of FASD, especially in the absence of the typical facial features associated with FAS, is difficult and requires long training on the part of doctors – but it is not impossible. While there are informal NHS diagnostic teams in various locations, there is only one FASD-specific diagnostic clinic to serve the UK, and it is expensive for an individual to gain a diagnosis through this. There is therefore currently a chicken-and-egg situation whereby a lack of diagnosis means that treatment is not sought. These issues are connected with the issue of funding (see below).

While diagnosis is vital, so is post-diagnosis support. The same symptoms may need to be managed differently if the underlying cause is FASD rather than another condition, such as attention deficit hyperactivity disorder (ADHD). Attachment disorders are also sometimes blamed for the symptoms: since most children with FASD come through the care system, they may or may not suffer from disordered attachment, and the factors can be confused. However, ascribing the behaviour of a child with FASD to attachment disorder can prevent a family from getting the correct support.

Recommendation

The health system should ensure that information about prenatal exposure to alcohol is sought from mothers, as it already is in some areas, and recorded in the child's Red Book.

Challenges for parenting

Children with FASD can be difficult to parent, especially as many common parenting strategies do not work for them. It is therefore not necessarily a case of parents needed to 'parent better', but to 'parent differently'. Unfortunately, parents are sometimes blamed for the child's behaviour, and sent on parenting courses where they are taught strategies that are destined not to work. In addition, stigma can prevent parents who suspect their drinking might be the cause of their child's difficulties from seeking help. On the other hand, foster carers and adoptive parents have no way of knowing whether or not a child's birth mother drank during pregnancy, which again can make it difficult for them to obtain effective support.

Schools may also face difficulties in catering for the needs of children affected by FASD. Children may be misunderstood by school staff, especially since many of those affected meet expected developmental milestones and can be sociable and articulate. However, their poor short-term memories can mean that they struggle to learn – and this can be misinterpreted by schools as laziness. They might exhibit difficult behaviour, but lack the ability to learn from their mistakes even when they are repeatedly punished or excluded from school. The children often want to be part of society, and are aware that they are failing to fit in, which can lead to mental health problems, or difficult behaviours in order to get out of the situation in which they find themselves. As a result, many affected children are home-schooled, meaning more pressure for their parents as they add the role of teacher to those of carer and advocate.

[4] www.makingeverycontactcount.co.uk

Public policy

Labelling alcohol is a way of educating people, and around 80% of alcohol in the UK is now labelled with a symbol designed to discourage drinking in pregnancy – although such labels are, of course, easy to ignore. Universal approaches such as this could be expanded: in parts of Canada there is billboard advertising about FASD, for example. However, they need also to be combined with targeted approaches, such as those directed at women when they become pregnant and are more likely to listen to relevant messages. The UK lags behind other countries when it comes to activity around and investment in FASD services. Western parts of Canada are thought to have good public education on the issue, and Australia is earmarking funding for FASD.

In Canada, attempts have been made to quantify the costs of FASD to the national economy, with one study finding that the total adjusted annual costs associated with the condition at the individual level were $21,642, while the annual cost of those affected, from day of birth to 53 years old, was $5.3 billion.[5] In the UK, the FASD Trust believes that preventing just three cases would pay for the services needed to support families since, for example, many adults with FASD become involved in the criminal justice system.

Lack of clear evidence to inform decision-making

A major issue is that there is currently a lack of clear evidence about the prevalence of FASD in the UK, which in turn makes it difficult to argue that services for affected families are needed. At the same time, it has so far proved impossible to find funding for a study to show prevalence. In the North East of England, hospitals and universities have agreed to take part in a study to investigate prevalence in the sense of alcohol exposure (by testing meconium and blood in newborns), but the £90,000 needed to fund the study is yet to be found. It is still hoped to launch the study regionally, beginning with Northumberland.

There is, however, evidence to indicate what the level of the problem of alcohol in pregnancy in the UK might be. Figures provided by hospitals show that around 0.5% of women admit to drinking heavily in pregnancy[6] – likely to be an underestimate of the actual rate. On this estimate, around 3,500 children per year are likely to be affected by FASD. In a recent study in Leeds, 28% of women reported that they continued to drink alcohol throughout pregnancy,[7] meaning that potentially many more children are affected.

The World Health Organization (WHO) recognises that there are no reliable global prevalence figures for FASD, but quotes a 2005 study in the USA, which estimated a global incidence of 0.97 per 1000 live births.[8] Other studies from Italy and the USA suggest that prevalence is between 2 and 7%.[9] An epidemiological study in the UK could determine the rate more precisely, and mean that a strategy for tackling the problem could be decided upon.

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[5] Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C., Tran, S., and Koren, G. (2009) The burden of prenatal exposure to alcohol: revised measurement of cost. *Canadian Journal of Clinical Pharmacology* 16(1): e91-102

[6] news.sky.com/story/1299601/mums-to-be-admit-drinking-too-much-booze

[7] Nykjaer, C., Alwan, N., Greenwood, D., Simpson, N., Hay, A., White, K. and Cade, J. (2014) Maternal alcohol intake prior to and during pregnancy and risk of adverse birth outcomes: evidence from a British cohort. *Journal of Epidemiology and Community Health*, Online First: March 10, 2014 as 10.1136/jech-2013-202934

[8] World Health Organisation website. 'Fetal alcohol syndrome: dashed hopes, damaged lives.' www.who.int/bulletin/volumes/89/6/11-020611/en

[9] May, P., Gossage, J., Kalberg, W., Robinson, L., Buckley, D., Manning, M. and Hoyme, H. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews*, 15, 176-192.

Lack of funding for services

'Hub and spoke' models are used widely for services in medicine, whereby 'centres of excellence' filter out to regional centres, which in turn filter to local centres. This model has been proposed for FASD to NHS England, with the idea that that in every city families could access someone with expertise in FASD, but the proposal has so far been rejected on grounds of funding. Developmental specialist teams, where they exist, would be a way of addressing FASD, but the teams would need upskilling.

Historically, Child and Adolescent Mental Health Services (CAMHS) is the route by which families have sought support for FASD. CAMHS are also the only source of current prevalence statistics, which are necessary in order to prove the local need that must be shown before services can be commissioned. However, waiting lists for CAMHS are long and the services provided can be patchy. Meanwhile family relationships are under stress and fostering and adoption placements can break down, as affected children can be so difficult to live with.

In March 2015, the Department of Health Prescribed Specialised Services Advisory Group decided that FASD services would remain the responsibility of local Clinical Commissioning Groups, and that highly specialist FASD services for all ages would not be appropriate for national commissioning by NHS England. It concluded that there is "a lack of incidence and prevalence data, leading to uncertainty around the potential number of referrals per year … it would be very difficult to identify the sub-set of patients who would benefit from referral to a specialist centre."[10] This means that FASD services will be commissioned through 'spot purchasing' and will largely be dependent on the extent to which FASD is understood in local areas.

Dr Raja Mukherjee's clinic has approached NICE to see if it could conduct a broad review of FASD, but the response was that there was no capacity to do this until 2017 at the earliest.

Strategies

Current action and existing support

Sources of support include the FASD Trust,[11] FASD Network UK,[12] NOFAS-UK[13], FASawareUK[14] and European Birth Mum Support Network.[15] Local support groups also exist: for example, FASD Network UK supports families through a virtual community and local groups. There are also useful publications, such as *Foetal Alcohol Spectrum Disorders: Parenting a child with an invisible disability*,[16] the first British parenting book on the subject; *FASD: Strategies not Solutions*[17], an older publication from Canada; and a series of briefings for schools from the Specialist Schools and Academies Trust, including a two-page handout for teachers.[18]

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[10] Department of Health (March 2015). *Prescribed Specialised Services Advisory Group: Recommendations to Ministers*.
www.gov.uk/government/uploads/system/uploads/attachment_data/file/409396/PSSAG_report_acc.pdf

[11] www.fasdtrust.co.uk

[12] www.fasdnetwork.org

[13] www.nofas-uk.org

[14] fasaware.co.uk

[15] www.eurobmsn.org

[16] Brown, J. and Mather, M. (2014). *Foetal Alcohol Spectrum Disorders: Parenting a child with an invisible disability*. See www.fasdtrust.co.uk/news_item.php?wnID=8545

[17] Edmonton and Area Fetal Alcohol Network, Child and Youth Working Group (2007). Online: fasd.alberta.ca/documents/Strategies_Not_Solutions_Handbook.pdf See the Canadian website www.fasdconnections.ca for more materials and information

[18] See complexld.ssatrust.org.uk/uploads/1a%20fasd-class.pdf; complexld.ssatrust.org.uk/uploads/1b%20fasd-briefing.pdf; and complexld.ssatrust.org.uk/uploads/1c%20fasd-info.pdf

In the face of confusing guidance for expectant mothers, health teams in some regions have taken their own decisions to recommend no alcohol at all in pregnancy and for women trying to conceive. In the North East, all 12 Directors of Public Health across the region have agreed to this, and other areas are undertaking similar initiatives.

In the Teesside area of the North East, faith-based regeneration work is going on through an alliance of faith-based and voluntary sector groups. FASD Network UK has been raising awareness of how faith-based organisations are working with some of the most vulnerable and disadvantaged people in communities, and of how FASD is relevant to them.

The role of faith

Many people of faith are involved in the issue of FASD, and faith could be an important driving force for people to work in this area. It can also offer a source of support and connection when times are difficult. The following were the suggestions made by the group as to how faith groups in general and FaithAction in particular can support work around FASD.

Suggestions for Action

Faith groups can help to raise the profile of FASD with the public and the faith sector, as well as with funders and policymakers where possible. They can support initiatives such as National FASD Awareness Day on 9 September, and the Pregnant Pause.[19]

Christian groups can work with Home for Good (run by Care for the Family and the Evangelical Alliance), which encourages more Christians to foster and adopt children.[20]

FaithAction will…

- Meet with Public Health England with a view to encouraging campaigning activity and research on prevalence.
- Explore the possibility of developing a health message toolkit, for faith groups to publicise and share. This could build on FaithAction's existing Community Information Toolkit.
- Approach groups such as the UK Health Forum and Women's Health Equality Consortium to see how together we might campaign for guidance around alcohol in pregnancy to be made clearer.
- Facilitate further contact between those present with a view to future work.

FaithAction's work on FASD is funded by the Health and Social Care Voluntary Sector Strategic Partner Programme run by the Department of Health, NHS England and Public Health England, with particular support from Public Health England.

[19] The Pregnant Pause has used flashmobs that happen at 9:09 on 9 September to raise awareness of pausing from drinking for the nine months of pregnancy. www.nofas-uk.org/pregnant_pause_youtube.php

[20] www.homeforgood.org.uk