

## Chapter Five

### **Drinking in pregnancy: Shifting towards the ‘precautionary principle’**

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#### **Introduction**

Debate rages both in academic circles and in the media over communicating messages to the public regarding alcohol consumption during pregnancy. Do women need accurate information enabling them to decide about the risks of alcohol consumption or is it better to send simple messages that tell them what they must do? This chapter considers how research-based evidence is translated into risk communications through three key mechanisms: ‘official’ publications and guidance issued by government departments or health authorities; websites run by advocacy groups; and midwives at the front line in delivering advice to women. The focus is on the UK, and, to a lesser extent, other countries (USA, Australia, New Zealand), where the ‘risk narrative’ around drinking in pregnancy and pressures towards adopting the ‘precautionary principle’ have emerged and strengthened over recent decades. Used initially in the context of environmental risk, there is no one definition of the ‘precautionary principle’. It is generally applied in situations where there is uncertainty or lack of clarity regarding the evidence for policy action and is intended to avoid policy stagnation (ILGRA 2002).

The chapter is based on literature sources, on analysis of policy documents in the UK and on an analysis of the website of one major international advocacy group. We recognise the value of adopting a feminist critique to examine issues around drinking in pregnancy; but this is available elsewhere (e.g. Ettore 1992; 1997). Rather we draw on framing theory as our conceptual framework as this allows us to examine how different strands of action and different groups of stakeholders have increasingly come together to create a ‘risk narrative’ around alcohol consumption in pregnancy that sits uneasily with available evidence but, through the adoption of the

‘precautionary principle’, has gained a dominant position in informing policy and practice.

Concern over drinking in pregnancy is not new. In past centuries there was awareness of the possible effects of alcohol consumption on reproduction (Sclare 1980). Alcohol consumption has frequently been seen to threaten women’s traditional gender roles and the social status quo or to result in a declining birth rate, unhealthy children and the ‘degeneracy of the race’ (Warner 2003; Ziegler 2008). By the mid-20<sup>th</sup> century, amid changing social conditions and rapid changes in women’s social roles, increasing drinking problems were seen as ‘the ransom of emancipation’ (Shaw 1980, p.19). At this time, understanding of the possible effects of heavy drinking during pregnancy was still uncertain although improving; but, ‘Such uncertainty has not deterred some individuals with a sense of evangelical purpose from engaging in petulant political campaigns for instantaneous governmental action regarding this hazard’ (Sclare 1980). Moreover, as Jessup and Green (1987) pointed out, the most stigmatised female user was the pregnant woman. So, women were again the focus of activist attention. By the end of the 20<sup>th</sup> century, evidence for the existence of foetal alcohol syndrome (FAS) was generally accepted but by now a debate had emerged around the wider concept of foetal alcohol spectrum disorders (FASD). Crowe’s *Fatal Link* (2008) presented the ‘undeniable connection’ between brain damage from prenatal exposure to alcohol and school shootings while on the opposite side, Emily Oster (*Expecting Better*, 2013), part of an emerging group of (largely middle class) critics, argued that gardening was more dangerous than food or alcohol consumption, due to an increased risk of toxoplasmosis which could be contacted from cat faeces. Thus, examination of FAS and FASD must be seen within the context of wider gender- based discourses on alcohol consumption at any particular historical period and with regard to the different ways in which ‘risk’ is framed and communicated.

### *From FAS to FASD*

Knowledge of FAS is generally traced back to a publication by Jones and Smith (1973), who coined the term, ‘foetal alcohol syndrome’. But there had been prior observation and discussion concerning the possible deleterious effects of maternal

transmission of viruses such as herpes, of syphilis, of the effects of maternal rubella in pregnancy, of the use of drugs such as heroin, and of prescribed medication – fuelled by the thalidomide tragedy in 1961 (Sclare 1980). As Saunders (2009) notes, there was also some work on the transmission of alcohol to the foetus; a study by Lemoine and colleagues in France provided a clinical description of 127 children born to predominantly alcoholic mothers (Lemoine et al. 1968). But it was the work of Jones and Smith that opened a wave of interest and research on the effects of alcohol consumption in pregnancy. Sclare reviewing knowledge on FAS, documented the following essential features: growth deficiency, abnormalities of the head and face, brain deficiency, associated features (a range of physical abnormalities) (Sclare 1980, p.60) and concluded that, ‘A substantial body of evidence from clinical sources and animal experimentation has now accumulated to suggest that a characteristic set of physical and mental defects, known as the foetal alcohol syndrome (FAS), may occur in the infants of alcoholic mothers’ (Sclare 1980, p.64). However, he also pointed out that there were still uncertainties regarding what quantity of alcohol, over what time period and at what point in the pregnancy it might be harmful.

Following the work of Jones and Smith, the concept and diagnosis of FAS underwent rapid refinement and enlargement (Benz et al. 2009). ‘Foetal alcohol effects’ was introduced to describe behavioural and cognitive effects in the absence of full FAS symptoms but its clinical imprecision meant that it was not adopted longer term. By 1996, five separate classes of prenatal alcohol effects had been distinguished by the United States Institute of Medicine; but Benz et al. (2009) comment that the IOM guidelines consisted of vague categories that did not clearly define the diagnostic criteria used and led to an inconsistent approach across clinics. Subsequent amendments to the classification in 1997, 1999, 2004 and 2005 and the development of the Canadian diagnostic criteria in 2005 attempted to improve diagnostic precision (Benz et al. 2009). By 2004, extensive discussion and collaboration resulted in a consensus definition of FASD:

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD encompasses all other diagnostic terms,

such as FAS, and is not intended for use as a clinical diagnosis. (Williams et al. 2015: e1396)

As the quotation highlights, FASD is not a discrete category and is not intended as a clinical diagnosis; it remains, therefore, open to interpretation and debate.

There is little disagreement with the message that ‘heavy’ drinking during pregnancy carries a significant risk of FAS or a degree of harm to the foetus, especially during the first nine weeks of pregnancy (Striessguth and O’Malley 2000; British Medical Association 2007). But, as is seen in the sections below, opinions differ regarding consumption of low to moderate amounts of alcohol during pregnancy and there is no consensus on what constitutes a low risk. In the absence of conclusive evidence on the effects of low to moderate alcohol consumption on the foetus, the ‘precautionary principle’ is adopted by many health and advocacy organisations. Women are advised to abstain from alcohol when pregnant and, in some cases, abstinence is also advised when trying to conceive. In the following sections, we will look at three examples of how the evidence on drinking in pregnancy is interpreted and conveyed to the public – in ‘official’ policy and guidance documents, in advocacy group advice, and by midwives in their day-to-day encounters with pregnant women.

### *Framing ‘risk’: from moral to medical to public health model?*

It is only within recent decades that the rationale for advice on drinking in pregnancy shifted from a predominantly moral or Eugenic model towards an evidence-based, medical model and then a public health model (Lowe and Lee, 2010). This is reflected in recent advice to women on drinking during pregnancy. O’Leary and colleagues (2007), for example, examined policy in seven English speaking countries, including guidelines from relevant medical, nursing, and non-professional sources. They found that policies could be grouped into three categories: those that recommend abstinence alone; those that recommend abstinence as the safest choice but also indicate that small amounts of alcohol are unlikely to cause harm; and those that advise that a low alcohol intake poses a low risk to the foetus. Most of the guidelines stated that they were based on evidence from literature reviews. Despite the variation in advice documented by O’Leary et al., the perception that there is insufficient evidence to

conclude that any level of alcohol consumption during pregnancy is low-risk has led to the wider application of the ‘precautionary principle’ and the message that pregnant women (in some sources including women intending to become pregnant) should abstain from alcohol. As Low and Lee (2010) among others argue, given that the evidence base for the advice to pregnant women is unclear and contested regarding the consumption of low/ moderate levels of alcohol, messages based on the ‘precautionary principle’ reflect a new construction of ‘risk’ since it formalises a connection between uncertainty and danger. Thus alcohol consumption during pregnancy has become framed in terms of risk and danger to the foetus – a frame that is promoted through some channels and contested in others. When we look more closely at these shifts – as we do below – we see that the moral model persists, in some form or other, across frame shifts.

### **Framing the issue: what the scientific research tells us**

The evidence for risk from drinking during pregnancy that is cited as the basis of policy and public health communication derives from research that uses a range of study designs and measures to investigate the possible short-term and longer-term effects of maternal alcohol consumption on the foetus and the development of the child. These studies reflect a particular construction of ‘risk’, which is not necessarily shared even within the research community. Indeed, for many years, feminist researchers have argued that whether or not women are at risk during pregnancy, they are stigmatised and pathologised by the body of literature on the foetal alcohol syndrome (Gomberg 1979; Ettorre 1992). Moreover, how ‘risk’ is constructed and interpreted from research findings may not reflect how it is interpreted and acted upon by pregnant women, by different social groups, by relevant health professionals and by the general public.

There is a large literature on the effects of alcohol on the foetus; but in this chapter we will focus on findings from reviews and longitudinal studies, on the assumption that the latter are the best way to research longer-term effects.

### *Reviews and longitudinal studies*

A main finding from the existing body of work is that there is little evidence of harm from maternal low/ moderate levels of alcohol consumption.

In a review of 24 prospective studies and two quasi-experimental studies, Mamluk et al. (2017) concluded that evidence of harm arising from drinking 32 grams a week or less (up to two UK units of alcohol up to twice a week) compared with no alcohol was sparse. The review found some increased risk of babies being born SGA (small for gestational age) but little direct evidence of any other detrimental effect. The authors also noted the lack of research and evidence regarding possible benefits of light alcohol consumption versus abstinence. Considering the implications of the review findings, the authors suggest that:

The recently proposed change in the guidelines for alcohol use in pregnancy in the UK to complete abstinence would be an application of the precautionary principle. .... For some, the evidence of the potential for harm—mostly coming from animal experiments and human studies of effects due to higher levels of exposure will be sufficient to advocate that guidelines should advise women to avoid all alcohol in pregnancy, while others will wish to retain the existing wording of guidelines (Mamluk et al. 2017, p.11- 12).

An earlier systematic review by Henderson et al. (2007) of research conducted between 1970 and 2005, also found no significant effects of drinking up to 12 grams a day on miscarriage, stillbirth, intrauterine growth restriction, prematurity, birth weight, small for gestational age at birth, or birth defects including FAS.

The risk of long-term effects appearing as the child grows older has been much debated. But again, the results from prospective studies have not established a clear link between maternal alcohol consumption in pregnancy and problems emerging up until the child is seven years old. For instance, two large, longitudinal follow-up studies, one from the UK and one from Denmark, found no increased risk of socio-emotional difficulties, cognitive deficits or executive functioning in children at seven and five years old.

In the UK study (Kelly et al. 2010; Kelly et al. 2017), women were grouped into five categories: never drinker (teetotallers); not in pregnancy; light, not more than 1-2 units per week or per occasion; moderate, not more than 3-6 units per week or 3-5 units per occasion; heavy/binge, 7 or more units per week or 6 or more units per occasion. At age five years (Kelly et al., 2010), children born to mothers who drank up to 1-2 drinks per week or per occasion during pregnancy, were not at increased risk of clinically relevant behavioural difficulties or cognitive deficits compared with children of mothers grouped as not-in-pregnancy. These results were confirmed at seven years old. Kelly et al. (2017) reported that low levels of alcohol consumption during pregnancy are not linked to behavioural or cognitive problems during early to mid-childhood.

The Danish study (Skogerbø et al. 2012), which also examined a large cohort of women and children, found no significant effects of low to moderate alcohol consumption on executive functioning at five years. The definition of ‘a drink’ followed the definition from the Danish National Board of Health, with one standard drink being equal to 12 grams of pure alcohol. Low drinking was defined as the consumption of between one and four drinks per week, and moderate drinking was defined as the consumption of between five and eight drinks per week. Despite the results of the study, the authors concluded that:

Even though this study observed no consistent effects of low to moderate levels of prenatal alcohol exposure on executive functioning at the age of 5 years, and only unsystematic and insignificant associations were found for binge drinking, alcohol is a known teratogen, and safe levels of alcohol use during pregnancy have not yet been established. Consequently, women should be advised that it is safest to abstain from using alcohol when pregnant (Skogerbø et al. 2012, p.9).

It is, perhaps, not surprising that this public health caveat was proposed in the conclusion of the Danish paper since the research was supported by the USA Centers for Disease Control and Prevention (CDC) and the authors were based in public health institutions. Researchers, especially those in the public health field, tend to adhere to the zero risk frame in their conclusions even though they report mixed attitudes and behaviours among their study respondents and a lack of evidence for

harm from low levels of consumption. It is, however, but one example of how the 'precautionary principle' has succeeded in becoming a dominant influence in conveying academic findings into the public arena. Risk continues to be present even in the absence of evidence. As Brown and Trickey (2018, p.4) note with respect to the UK guidelines, the precautionary principle 'contrasts with the informed choice approach that underpins alcohol advice for the general population', and they conclude that, '... it does appear that the underpinning rationalisation in relation to pregnancy is values-based rather than evidence-led' (Brown and Trickey 2018 p.14). In the next section, we look at how this is manifest in official policy and guidelines.

### **Frames in official guidance and policy**

Two key themes can be identified from an assessment of the official guidance and policy issued by the British Government, medical councils and health authorities between 2000 and 2018: 1) risk and uncertainty, and movement from foetus to baby and 2) employment of the ideology of the 'good' mother.

#### *Risk and uncertainty*

Guidance from all sources begins from the basic principle that there is risk and uncertainty attached to drinking in pregnancy. All sources acknowledge that the impact of low level drinking on the foetus is generally unknown or believed to be limited. Nevertheless, the guidance remains that women should not drink any alcohol while pregnant. For example, the National Institute for Clinical Excellence (NICE) who provide guidance, advice and information services for health, public health and social care professionals produced the following guidance in 2008, which continues to be their advice as of October 2018:

Pregnant women and women planning a pregnancy should be advised to avoid drinking alcohol in the first 3 months of pregnancy if possible because it may be associated with an increased risk of miscarriage.

If women choose to drink alcohol during pregnancy they should be advised to drink no more than 1 to 2 UK units once or twice a week (1 unit equals half a pint of ordinary strength lager or beer, or one shot [25 ml] of spirits. One small



[125 ml] glass of wine is equal to 1.5 UK units). Although there is uncertainty regarding a safe level of alcohol consumption in pregnancy, at this low level there is no evidence of harm to the unborn baby (National Institute for Health and Care Excellence (NICE 2008, p.15).

A similar message is communicated by the British Medical Association (BMA) who have advocated since 2007, when they first published guidance about foetal alcohol spectrum disorder, that ‘Women who are pregnant, or who are considering a pregnancy, should be advised not to consume any alcohol’ (British Medical Association [BMA] 2007, p.12). In their updated guidance the BMA recognised that the evidence for harm from low-to-moderate levels of alcohol consumption is inconclusive. Nevertheless, it is advised that the safest option for women is abstinence from any alcohol (BMA 2016, p.21).

Significantly, within sources of guidance, a shift towards advocating abstinence can be witnessed. At the turn of the millennium the official guidance provided by the Chief Medical Officer (CMO) was that in order

to minimise risk to the developing fetus, women who are trying to become pregnant or are at any stage of pregnancy, should not drink more than 1 or 2 units of alcohol once or twice a week, and should avoid episodes of intoxication (Department of Health [DoH] 1995, p.27).

Such guidance was provided with recognition ‘that alcohol consumption (other than at very low levels) is associated with particular risks to fetal and early infant development’ (DoH 1995, p.24). This guidance was overhauled in 2016, with the publication of new guidelines from the CMO. The new guidance acknowledged that the risks were low if only small amounts of alcohol had been consumed before the pregnancy was known; but stated:

If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.

Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk... (DoH 2016a, p.27).

Such 'shifts' in guidance can also be seen in medical bodies (with the exception of the BMA who have always advocated abstinence). For example, the Royal College of Obstetrics and Gynaecology (RCOG) stated in 1999:

There is no conclusive evidence of adverse effects in either growth or IQ at levels of consumption below 120 gms. (15 units) per week. Nonetheless, it is recommended that women should be careful about alcohol consumption in pregnancy and limit this to no more than one standard drink per day (RCOG 1999, p.3).

By 2006, the guidance was modified to advise that, 'The safest approach in pregnancy is to choose not to drink at all', but that 'Small amounts of alcohol during pregnancy (not more than one to two units, not more than once or twice a week) have not been shown to be harmful' (RCOG 2006, p.1).

A similar message was presented in 2015 (RCOG 2015), but this guidance was removed from the public domain following the updated guidance from the CMO and was replaced in 2018 with the following message:

The safest approach is not to drink alcohol at all if you are pregnant, if you think you could become pregnant or if you are breastfeeding.

Although the risk of harm to the baby is low with small amounts of alcohol before becoming aware of the pregnancy, there is no 'safe' level of alcohol to drink when you are pregnant (RCOG 2018, p.1).

The key element across the guidance is that while there is uncertainty about the impact of low-level drinking on pregnancy and the development of the foetus, no risk is acceptable, and thus a woman should not drink any alcohol while pregnant.

#### *From 'foetus' to 'baby' and the 'good' mother*

Language is an important mechanism in how issues are framed and communicated. A notable development in the guidance across time is the movement from talking about the impact of drinking alcohol on the 'foetus' to discussion of impact on the 'baby'.

Such developments can be seen to happen in conjunction with the movement from talking about ‘pregnant women’/ ‘women who are pregnant’ to ‘mothers’. The clearest example of this development can be seen in the Government guidance. The CMO guidance published in 1995 advocated ‘women who are trying to get pregnant or are at any stage of pregnancy’ should drink no more than 1 or 2 units of alcohol once or twice a week ‘to minimise risk to the developing *fetus*’ (emphasis added, CMO 1995, p.27). The guidance published in 2007 was that ‘Pregnant women or women trying to conceive’ should not drink alcohol, but if they do, they should not drink more than 1-2 units once or twice a week ‘to protect the *baby*’ (emphasis added, HMG 2007, p.3). Between these publications there is a change from ‘foetus’ to ‘baby’, but the woman continues to be referred to as a woman who is pregnant. In the latest guidelines published in 2016, the subject that the advice is targeted at (women who may be pregnant) is presented in direct connection to her foetus, who is now referred to as ‘your baby’:

If *you* are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to *your baby* to a minimum (emphasis added, DoH 2016a, p.27).

This subtle shift in language frames a woman who is pregnant as having a direct impact on the foetus, with the suggestion being that she would want to avoid drinking alcohol, as this is the motherly thing to do in order to ensure protection for the child. The guidance is now framed at being talking specifically to her, rather than general guidance for the population.

Such a message became even more prominent in the final version of the guidance approved by the Government:

If *you* are pregnant or think *you* could become pregnant, the safest approach is not to drink alcohol at all, to keep risks to *your baby* to a minimum (emphasis added, DoH 2016b, p.26).

Here, the focus has moved from women planning to become pregnant, to any woman who thinks she could become pregnant. In reality, this is any woman who is of reproductive age, as public health messages, rightly, advise that no contraception is 100% reliable (National Health Service 2017), unless she knows that she is unable to

get pregnant, such as due to undergoing a hysterectomy. The message also has the impact of advocating that women choose between drinking alcohol and having sex – a choice that is not asked of men, despite suggestions that alcohol impacts the quality of sperm and thus potentially the health of the foetus (Ouko et al. 2009). Thus, framing alcohol consumption as a ‘risk’ can be seen as a mechanism for exercising control over women’s autonomy.

More pronounced connection between not drinking and being a ‘good’ mother is evident in presentation of advice on the National Health Service (NHS) website, which provides a ‘comprehensive health information service’ that ‘help[s readers] make the best choices about [their] health and lifestyle’ (NHS 2018). The guidelines are, expectedly, in line with the Government’s publication in 2016, ‘...the safest approach is not to drink alcohol at all to keep risks to your baby to a minimum’ (NHS Choice 2017). However, as the guidance goes on to discuss the impact on the foetus if a woman has drunk alcohol in the early stages of pregnancy before knowing she was pregnant, the framing of the message changes:

Women who find out they're pregnant after already having drunk in early pregnancy should avoid further drinking.

However, they should not worry unnecessarily, as the risks of their baby being affected are likely to be low (NHS Choice 2017).

By shifting from referring to the pregnant woman in the second person when suggesting abstinence, to referring to her in the third person when advising not drinking alcohol, there is an implicit message that the ‘good’ woman/mother will know she was pregnant or might be pregnant and will not have consumed alcohol. It is only ‘other’ women, and thus ‘bad’ women/ mothers, who would have consumed alcohol and thus put *their baby* at risk.

Increasingly, therefore, official advice has moved towards the ‘precautionary principle’ framing while recognising that the evidence base for the advice is unclear. The question arises – how did this happen and what influenced this shift? Advocacy action is one source of influence on government and in the next section we look at the work of The National Organisation on Foetal Alcohol Syndrome (NOFAS) as an

example of how an advocacy group frames research evidence and conveys it to the public and how this may be one important influence on the government response. There are other advocacy groups and they do not all frame women's alcohol consumption in the same way; for example, National Advocates for Pregnant Women (NAPW) in the USA (Campbell and Ettore 2011; NAPW n.d.) and British Pregnancy Advisory Group in the UK (BPAS n.d.) take a very different approach to that of NOFAS. However, we have chosen NOFAS as it is perhaps the most prominent and internationally influential organisation and it has successfully promoted its particular message on alcohol consumption in pregnancy.

### **The National Organisation on Foetal Alcohol Syndrome (NOFAS): An advocacy frame**

#### *Framing the issue and the solution*

The US based NOFAS, is a not-for-profit organisation which declares its mission:

NOFAS works to prevent prenatal exposure to alcohol, drugs, and other substances known to harm fetal development by raising awareness and supporting women before and during their pregnancy, and supports individuals, families, and communities living with Fetal Alcohol Spectrum Disorders (FASDs) and other preventable intellectual/developmental disabilities (NOFAS 2017).

NOFAS advocates abstinence in the pre-conception period and throughout the pregnancy, with this message encapsulated in the strap lines on their digital and written materials: 'Prenatal Alcohol Exposure. No safe amount. No safe time. No safe alcohol. Period' and 'Play it Safe. Alcohol & Pregnancy Don't Mix' (NOFAS n.d., a). This clear abstinence message is also delivered by the numerous affiliate organisations throughout the world. NOFAS-UK states:

The best thing a woman can do for her unborn baby is to avoid alcohol at all stages of pregnancy and whilst trying to conceive (NOFAS-UK 2018 a).

Thus the message that NOFAS wants organisations to unify around and spread is one of abstinence in the pre-conception period and throughout the pregnancy.

NOFAS also suggests reasons why women continue to drink in pregnancy. In an undated position statement, on the EU FASD Alliance website, entitled ‘Drinking during pregnancy -who is responsible?’ it is claimed that ‘up to 50% or more of women may drink during pregnancy’ (EU FASD Alliance n.d., a). A range of reasons are offered including confusion due to inconsistent and conflicting advice given by health professionals or contained in media articles, unawareness of pregnancy in the early stages particularly if unplanned (‘many’ pregnancies are described as unplanned), ‘addiction’ to alcohol, and alcohol advertising which portrays fun and friendship as intricately linked with drinking alcohol (EU FASD Alliance, n.d., a). The appropriate response is seen as provision of awareness and education and support for those who have consumed alcohol before the pregnancy was known, but also action to counter advertising alcohol as fun and to ensure that messages on the harm associated with alcohol consumption are clearly conveyed. Coalitions and networks are crucial to national and international advocacy organisations in order to disseminate a unified message – in this case that no alcohol should be consumed during pregnancy. A strong advocacy network has evolved around this framing of the issue.

### *The advocacy network*

NOFAS was established in 1990 with the aim of promoting research and awareness of FAS by Patti Munter whose interest was rooted in her work with Native American people living on reservations (NOFAS, 2014, NOFAS, 2017). NOFAS was established during what Armstrong and Abel (2000 p.276) describe as a period in the US when FAS went from being ‘an unrecognised condition to a moral panic’, with the high level of concern not reflecting the evidence on prevalence or impact. They suggest that FAS rapidly became seen as a ‘social problem’ as it resonated with broader social concerns about the harmful impact of alcohol on American society and a perceived increase in child neglect and abuse. The NOFAS Affiliate Network was established in 2002 in order to ‘unite organisations in an international coalition

with the purpose of preventing FASD and meeting the needs of people living with the disorders while each member organization maintains its identity and autonomy' (NOFAS, n.d., b) The stated objectives are '...to open lines of communication among FASD organizations, share resources, unify core values, messages and priorities, and increase advocacy for FASD recognition and investment' (NOFAS, n.d., b).

With three types of membership Affiliates, FAS Resource Organisations and NOFAS Partners, the network reaches across a large number of organisations. Affiliates are autonomous, independent organisations that are described as 'usually the most familiar with FASD resources in their state or location' (NOFAS, n.d., b) they are primarily US based; only three of the 34 Affiliate organisations are not American (Australia, UK and Ukraine). FASD Resource Organisations have an interest in FASD and offer resources such as information but are not active members of NOFAS and currently all are US based. NOFAS Partners are organisations with which NOFAS has 'official and unofficial' partnerships and includes government agencies, practitioners, and societies - for example the Centers for Disease Control and Prevention (CDC), National Institute on Alcohol Abuse and Alcoholism (NIAA) and American College of Obstetricians and Gynaecologists (ACOG) (NOFAS, n.d., b).

The European (EU) FASD Alliance, which is a non-profit international member organization registered in Sweden, was founded in February 2011 'to meet the growing need for European professionals and NGOs concerned with FASD to share ideas and work together' (EU FASD Alliance, n.d., b). The impetus to establish the EU FASD Alliance came from the First European Conference on FASD held in the Netherlands in 2010 and organised by the FAS Foundation of Netherlands (EU FASD Alliance, 2012). There were 160 delegates from 23 countries; since then conferences have been held every two years, with 275 people attending the 2016 conference in London (EU FASD Alliance, 2018). The Alliance's stated aims are to: support its member associations to improve the quality of life for all people with FASD and their families/carers; to increase awareness of the risks of drinking alcoholic beverages during pregnancy; to act as a 'liaison centre' through the dissemination of information, encouragement of knowledge exchange and transfer between national

associations; the development of new national FASD Associations; and by fostering international collaboration on research studies (EU FASD Alliance, n.d. b). The EU FASD Alliance is governed by a Board comprising members from across Europe, supported by a Scientific Advisory Council (experts from across Europe) and a Council of Lifelong Experts (adults with FASD). Membership has grown from nine members to at least 25 members (latest available report is the 2015-2016 Annual Report, EU FASD Alliance, 2016).

These networks operate, therefore, at all spatial levels -local, regional, national and international - and key players within the FASD advocacy networks include a wide range of stakeholders - parents (adoptive, birth and foster) of children with FASD, professionals working with individuals with FASD in particular psychologists, child and adolescent psychiatrists, intellectual disability psychiatrists, special needs educationalists, and practice and policy relevant organisations. The activity of NOFAS-UK is illustrative of how a consistent framing of the issue and its solution is disseminated and used to gain policy attention both through working with relevant stakeholder groups such as professionals and parents and by direct action aimed at policy makers.

#### *NOFAS-UK: conveying the message and stimulating action*

NOFAS-UK is a registered charity, founded in 2003 by Susan Fleischer, an American living in the UK and the adoptive mother of a child with FAS. (NOFAS-UK, 2018b). Susan Fleischer was Chief Executive Officer (CEO) of NOFAS-UK until 2016 and her successor Sandra Butler, is a foster carer of a child with FAS. NOFAS-UK are a founding member of the FASD UK Alliance which is a coalition of support groups for those affected by FASD (birth and adoptive parents, carers, individuals living with FASD, families) and of interested individuals. FASD UK Alliance and NOFAS-UK co-administer a closed Facebook group (FASD UK Facebook Support) and also one for professionals.

NOFAS-UK undertakes three distinct strands of activity, which are illustrative of the overall approach of the network.



Firstly, they provide training and educational materials for professionals (e.g. health, social care, teachers), the general public (in particular pregnant women) and for carers of individuals with FASD (e.g. foster, birth and adoptive parents). Awareness and training are delivered to different target groups in a number of ways. These include:

- films and leaflets targeting specific audiences (e.g. midwives, GPs, pregnant women) – highlighting that the information leaflets for midwives and GPs have been ‘reviewed’ by the Royal College of Midwives, thereby ‘legitimising’ the outputs
- Continual Professional Development (CPD) courses and conferences, including an online FASD course, adapted from the American ‘FASD - The Course’ using a grant from the then Alcohol Research Council (AERC, UK)
- a UK wide programme of study days for midwives which was funded by Diageo (alcohol producer) in 2011 for five years and caused considerable controversy (Mooney, 2011; IAS, 2011). All the materials and training state that there is no ‘safe’ level of alcohol consumption and that women should not drink alcohol when trying to conceive and throughout pregnancy. Mooney (2011) noted that the advice that midwives were being trained to give to women differed from the Department of Health’s advice at the time <sup>i</sup>(no more than 1 or 2 units of alcohol once or twice a week and should not get drunk)
- use of the media and social media. For instance, NOFAS, NOFAS-UK and the EU FASD Alliance are all members of the ‘International Campaign to Raise Awareness of the Risks of Drinking in Pregnancy’. The campaign – ‘Too Young to Drink’ (TYTD) – was first launched on 9<sup>th</sup> September 2014. The 9<sup>th</sup> September has been declared International FAS Day and September FASD Awareness Month. A key aim is to harness social media (Facebook, Twitter and Instagram) and the internet to ‘spread coherent and univocal health messages via all media involved’ (TYTD, n.d.). The campaign which is launched each year on the 9<sup>th</sup> September, uses strong imagery, with all campaigns featuring various images of fetuses either in alcohol bottles (wine, champagne, beer, spirits) or alcoholic drinks (with ice, bubbles, lime slice) to promote a message of ‘zero alcohol in pregnancy’. The network extends across the globe and the materials are produced in seven languages.

Secondly, NOFAS-UK offers support to those affected by FASD (families, parents/carers, individuals) through the operation of a national helpline and a network of support groups for families and carers of individuals with FASD.

The third strand of activity seeks to engage and influence policy makers more directly, in particular the British government.

One example of this is a report of a roundtable discussion, 'Our Forgotten Children: The Urgency of Aligning Policy with Guidance on the Effects of Antenatal Exposure to Alcohol' (NOFAS-UK, 2018). The discussion was held with FASD stakeholders, including FASD UK Alliance, in the Houses of Parliament in May 2018. It was Co-chaired by Professor Sheila the Baroness Hollins (Emeritus Professor of the Psychiatry of Disability, St George's University, London) and Bill Esterson (Member of Parliament, Chair, All Party-Parliamentary Group on FASD, set up in June 2015) and included representatives of national, regional and local support organisations, clinical and educational experts. The report makes a series of recommendations including an urgent review of Government policy on FASD and increased training of frontline practitioners on FASD (NOFAS-UK, 2018c).

While scientific evidence is often cited as the basis for policy action, the use of experiential evidence is equally valued and well used in framing how the issue is presented and in arguing for policy attention. On behalf of the FASD UK Alliance, NOFAS-UK produced a briefing paper for policy makers based on the experiences of FASD stakeholders. In contrast to other publications from advocacy groups *Hear Our Voices* (FASD Alliance & NOFAS-UK, 2018) does not draw on scientific evidence, indeed it categorically states: 'It is not scientific, it is anecdotal precisely because stakeholders are rarely brought into discussions that impact their lives and futures' (FASD Alliance & NOFAS-UK, 2018, p.2). *Hear Our Voices* petitions the UK Parliament to ensure that the 2016 CMO guidance on alcohol and pregnancy (no alcohol) is consistently delivered across the health service and also embedded into the Personal, Social, Health and Economic (PHSE) and sex education curricula in schools (FASD Alliance & NOFAS-UK, 2018, p.2).

Advocacy approaches are therefore consistent and widespread, framing the issue and the solution in much the same way as public health policy and guidance. As Entman suggests, the advocacy frame is employed intentionally as a tool to promote a particular definition and interpretation of reality (Entman 1993). This is in contrast to frames that emerge and change as a result of interactions and conflicts between social actors and that are dependent on a range of different factors and contexts. We see examples of a more dynamic and shifting framing process in the findings of qualitative studies investigating how midwives and pregnant women perceive the issue of alcohol consumption in pregnancy.

### **Delivering the message – caught between professional ‘dictates’ and real life**

There are a number of small qualitative research studies looking at the attitudes, beliefs and reported behaviour of midwives and other stakeholders towards alcohol consumption in pregnancy. This section considers how midwives, key figures in pregnancy care, respond to the expectation that they will deliver messages according to national guidelines on alcohol consumption during pregnancy.

Midwives tend to support the contention that women are ‘confused’ by messages from different sources providing variable advice and that a clear, unambiguous message is the preferred option. However, very often midwives are reluctant to advise total abstinence as they are aware of the lack of good evidence for that message or feel that small amounts do no harm (Van der Wulp, 2013; Schölin et al. 2018; Crawford Williams et al., 2015).

‘I really think that *a* drink won’t hurt. . . These days everything is very extreme, they say no coffee, no alcohol etc. with limited evidence’ (midwife #3, in Crawford-Williams et al., 2015: 332).

‘.....When you drink two glasses of wine at Christmas or on New Year’s Eve, well, that really will not do any harm’ (Midwife 7, in van der Wulp 2013: e94).

Although trained and expected to convey official messages, not all midwives report doing so, particularly after the first consultation (Crawford- Williams et al 2015; Jones et al. 2011; van der Wulp et al. 2013). As individuals, they are also subject to personal frames of reference and lay understanding of appropriate behaviour when pregnant. In one study, some midwives held a different personal opinion compared to the professional advice they dispensed:

‘In the back of your mind you go “one’s not gonna kill ya” but I prefer to say “no, no drinking”’ (English midwife 5, quoted in Schölin et al. 2018, p.4).

The dilemmas faced in conveying official advice in the real world of everyday practice are also highlighted in discussions on how to respond when women say they have been drinking before they knew they were pregnant (van der Wulp, 2013). The message that drinking anything at all is a potential risk to the foetus is recognised as worrying for some women and linked to fear of being seen as a ‘bad’ mother (Meurk et al., 2014). Anxiety about how others will judge them is not unfounded when we consider the views of midwives regarding women who drink when pregnant. In a study comparing English and Swedish midwives, it was generally felt that, ‘...we should all be singing from the same hymn sheet’ regarding delivering an abstinence message (Schölin et al. 2018, p.5), and that any drinking during pregnancy could indicate an underlying alcohol problem. Comparing the risk discourses of the nine Swedish and seven English midwives interviewed, Schölin et al. (2018) reported that English midwives’ views were quite nuanced and the uncertainty around the risk of drinking small amounts was mentioned. By contrast, Swedish midwives’ risk discourse was binary: either women stop drinking or they continue because they have an underlying drinking problem. Similar attitudes emerged from an Australian study where some practitioners, including midwives, were of the opinion that drinking during pregnancy indicated possible mental health issues, drug use, and other co-morbidities that had to be addressed (Crawford-Williams et al., 2015).

Attitudes also differ towards different segments of the target group. Pregnant teenage women were marked out in one instance as ‘high risk’ because they were seen as more likely to binge drink (Jones et al 2011). In particular, midwives have been found to believe that the provision of simple messages is especially important for women

with lower educational attainment, and with mental health or substance use problems. This view is shared by at least some of the public. In one study, safeguarding 'vulnerable' groups featured in discussions among new parents - who did not include themselves as 'vulnerable' and were protective of their own autonomy (Brown and Trickey, 2018). A class-based interpretation of risk behaviours is not new. In the USA for example, it is reported that even many feminists supported early 20<sup>th</sup> century eugenic compulsory sterilization laws for 'defectives' as part of a programme of class based social control (Ziegler, 2008). Furthermore, current perceptions of risk from alcohol consumption are part of a much wider shift towards 'safeguarding' the foetus from a range of possible harms while in the womb, especially among some social groups. Lowe et al. (2015) have shown how UK policies have focused increasingly on concerns over pregnancy and the 'developing brain' and have identified 'disadvantaged women' as most at risk of suffering from stress and depression, thereby causing neurological damage to the foetus resulting in antisocial behaviour as adults. Interestingly, the UK longitudinal studies (Kelly et al., 2010; 2017) suggest that women in less advantaged socioeconomic situations are more likely to abstain when pregnant. They found that mothers in the 'not in pregnancy' group were more advantaged than the 'never-drinker' group but less advantaged than the 'light' drinking group. Schölin et al. (2018) also reports midwives mentioning that women of higher socioeconomic status disputed the abstinence advice.

These studies help to illuminate how individuals draw on evidence from different sources, apply value judgements and use cost-benefit assessments in framing the risk incurred from alcohol consumption in pregnancy and how they balance that risk against other perceived priorities. The complexity and nuances of the issues emerge well from the research and illustrate the existence of conflicting and flexible frames around both the behaviour (drinking alcohol when pregnant) and the pregnant woman.

## **Conclusion**

This chapter has focused on how the evidence on alcohol consumption during pregnancy, in particular regarding low to moderate levels of consumption, has been interpreted and conveyed to women through three major sources of information – government policy and guidelines, online advice from advocacy sources and advice

from midwives. We have shown how a strong ‘risk narrative’ has been created, how the framing of risk has shifted through successive versions of official communication in Britain, and how advocacy and public health communication based on the ‘precautionary principle’ has become increasingly consistent and dominant in the messages given to women.

This frame shift did not take place in a vacuum; it was closely linked to other political and social trends coming, initially, from the US. Armstrong and Abel (2000, p 277) locate the origins of FAS within a ‘new temperance zeitgeist’ and ‘concern about the victimisation of children’ prevailing in America in the 1970s. They argue that preventing FAS became ‘an American crusade’ resulting in ‘moral panic’ and ‘biomedical entrepreneurship’ that included the expansion of the diagnosis to FASD, and the rise of new groups of experts. Among them were doctors and researchers with new opportunities for research funding and ‘a pragmatic interest in framing the issue in terms of low thresholds’ (Armstrong and Abel, 2000, p.279). In the UK, the rise of policy and public concern over alcohol consumption in pregnancy came later. Early studies on drinking in pregnancy among ‘normal’ women were led by Moira Plant (1985, p.102) who concluded that ‘alcohol in moderate doses (*one or two units once or twice a week*) does not appear to cause harm’ (brackets added) and advised against alarmist messages. Ten years later, the conclusion was much the same (Plant 1997, p. 173). But the political climate in the UK was changing. The Blair - Brown’s New Labour government (1997-2010) had brought in a ‘puritanical, almost Cromwellian streak’ (MacGregor, 1998, p.251) which signalled the return of religion to public life, intertwined, in particular, with social welfare policy, and the moral values that activated welfare state developments (Jawad, 2012). In the alcohol field, the rise of a strong public health perspective was accompanied by increased research on public health aspects of alcohol use, the emergence and growth of advocacy activity (Thom et al. 2016), and a growth in researchers sympathetic to the public health framing of alcohol issues and public health aims regarding the necessary policy responses. Against this background, the precautionary principle fitted well within prevailing perspectives on alcohol use and alcohol-related harms (ILGRA 2002).

The increasing normalisation of the precautionary principle regarding drinking in pregnancy reinforced perceptions of a link between alcohol consumption, other

problem behaviours and health issues, and women who drink anything at all during pregnancy risk being seen as deviant and in need of care and control. Along with the ‘official’ drive to provide consistent messages advocating abstinence, informal forms of control and sanctions – such as enlisting partners and the general public to reinforce abstinence messages – are frequently part of research studies’ recommendations for policy and practice (Crawford-Williams et al., 2015a; van der Wulp et al., 2013). As in the past, risk messages have become closely aligned with moral judgements on motherhood and the image of the ‘good’ mother, while the language changes noted above in policy documents – towards personalised, emotive messages – reflect the ethos of wider social policy towards individualised interventions and individual assumption of responsibility. At the same time, as Lee (2017) has argued, interpretation of evidence on alcohol consumption in pregnancy has spawned the belief that simple messages are needed and are in women’s ‘best interests’. In other words, women are required to follow the rules and their rights to choice and autonomy are denied while the responsibility for possible harm to their children rests on their shoulders alone.

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## **NOTE**

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<sup>i</sup> The advice was changed in January 2016 to advise women if they were pregnant or planning a pregnancy they should not drink alcohol at all following a review of alcohol guidelines by the UK Chief Medical Officers' (DoH, 2015).