Healthier Pregnancies, Better Lives

Qnis

Women, Alcohol, Pregnancy & FASD

What is known and what Scotland can do next

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Executive Summary

This report is one publication of the Healthier Pregnancies, Better Lives programme at the Queen's Nursing Institute Scotland. The main findings and recommendations also appear as a series of blogs on the QNIS/ HPBL website [read blogs here], as well as on Twitter (@HPBL_Scot). It is divided into four sections:

Section One

The review explores available evidence of women's drinking both nationally and internationally. The impact of drinking patterns is discussed and, in relation to pregnancy, the highest risk patterns for the pregnant woman and her unborn child are described. Many women are into week 4, 5 or even later when their pregnancies are confirmed. For this reason, the importance of preconception care is highlighted. Some factors put women at increased risk of drinking in pregnancy including the vulnerability associated with adverse childhood experiences and familial history of drinking. Post-traumatic stress related to domestic abuse and mental health issues will also be described.

Section Two

The types of screening tools most commonly used to collect information on alcohol consumption are described, and the advantages and disadvantages of using them are discussed. Alternatives to using standardised screening tools will be noted, as will some of the legal and ethical concerns around the use of the information collected.

Aspects of what enables the development of a positive relationship between the pregnant woman and the health professionals are described, along with the issues that get in the way of this important step. These enablers and barriers will be explored. The internal view of the health professional includes attitudes, beliefs and values that may help or hinder the process. The internal view of the woman, and how she perceives the health professionals, depends on her past experiences in life. The external aspects - for example, the noise of a busy clinic or the problem of seeing a different health professional at every visit - will be highlighted. Issues that affect both pregnant women and health professionals, such as stigma, will be discussed. The impact of the partner's drinking will be described. Some post-natal aspects, such as the effect of alcohol on breastfeeding, will be noted.

Section Three

Although this neurodevelopmental condition has the word 'Fetal' in the title, this is a lifelong condition. The physical issues that people with Fetal Alcohol Spectrum Disorder (FASD) experience across the life course will be described. Problems encountered by children, young people and adults themselves, as well as their parents, carers and siblings will be addressed. The behavioural aspects of Fetal Alcohol Spectrum Disorder (FASD) will also be described, and the problems experienced at different ages will be highlighted. The implications for a parent, carer or sibling of a person with FASD will be noted too.

Section Four

This fourth section will describe and explore some of the training around prenatal alcohol exposure that evidence has shown to be effective. The need for improved knowledge, understanding and communication between health professionals and prospective parents, before and after conception, will be highlighted. Suggestions on improvements and further development of training to be made available to health professionals will be offered. Finally, recommendations for ways forward in this area are suggested for the Queens Nursing Institute Scotland, for Partners in Scotland's Coalition for Healthier Pregnancies, Better Lives Healthier Pregnancies, Better Lives (qnis.org.uk) and for Scottish society.

Introduction

The Queens Nursing Institute Scotland is an independent charity that still embodies the broad reach idea of the original National Health Service (NHS), from 'cradle to grave'. QNIS (Queen's Nursing Institute Scotland) has been doing so since 1889. In the decades before the NHS was created, Queen's Nurses were trained and deployed across Scotland to care for the 'sick poor' in their homes and communities. (learn more here). They often had the triple duty of being a midwife, district nurse and health visitor.

Although Scotland's Queen's Nurse programme was paused for decades, it was reintroduced in 2017 as an intensive leadership development opportunity for excellent clinicians nominated by their employers. In modern times, QNIS has been supporting and championing Scotland's extensive workforce of community nurses and midwives. (What is Community Nursing?) These community-based practitioners in every rural corner and urban neighbourhood throughout Scotland are still front and centre in the care of babies, children, women of potential childbearing age and the full range of adults.

Any of these patients may be affected by Fetal Alcohol Spectrum Disorder (FASD) in some way: as parents and carers, as family members and, of course, as the person directly affected by prenatal alcohol exposure. The reality is that community nurses and midwives already encounter people with FASD (whether or not this condition is recognised), they also see their parents, carers and siblings.

This report builds on work already being carried out in Scotland's communities. Raising awareness and increasing understanding of FASD will help community nurses and midwives engage more effectively with those affected and the key people in their lives. The continuing professional development proposed in this report will focus on heightening their competence and confidence in this area of practice.

The main topics explored here are alcohol, women, pregnancy and FASD. An important, and potentially very useful, difference between the genders is that women have far more contact points with health professionals than their male counterparts do. From well-woman clinics, through sexual/reproductive health services to antenatal, postnatal and child health clinics; as well as cervical and breast screening, women have relationships with many services run by community nurses or community midwives.

From health screenings and preconception/ interconception counselling to the care of people affected by FASD, Scotland's community nurses and midwives have unique opportunities to get to know women, for example;

- from her childhood (maybe even from her own birth) through baby clinics, health visiting, school checks and other early years encounters
- from cervical smear and breast screening checks
- as the sibling of a baby who is routinely being seen at clinic
- through previous pregnancy
- through caring for her parents as they get older

Unlike hospital-based midwives, whom the pregnant woman often doesn't meet until she attends her first antenatal (booking) session, community-based practitioners may have already formed a trusting relationship with her. This can help avoid discomfort or ambivalence about discussing alcohol. Community nurses may have discussed drinking with her on earlier occasions for other reasons.

Evidence suggests that, in some areas of Canada, many women are not changing their drinking behaviour while trying to conceive (Tough et al., 2006). There have been a number of systematic reviews and commentaries on preconception interventions to reduce the risk of alcohol exposed pregnancies (AEP) (Parkes et al., 2008; Reid et al., 2015 and 2019; Sher, 2022). Reid et al. (2021) concluded '…many interventions were efficacious at reducing AEP risk during the preconception period through preventing unplanned pregnancies' (2021.2414).

Reid et al.'s review explored the idea of not preventing alcohol exposed pregnancy per se, but rather approaching the topic from the

direction of reducing the risk of pregnancy among women who continue to drink. They suggest doing this with informed advice on the use of effective contraceptive methods. The word 'effective' is important, as it has been shown in some studies that contraception was used, but inefficiently and therefore unsuccessfully.

Even so, a World Health Organisation review of European Union (EU) case studies explored the prevention of harm caused by alcohol exposed pregnancies (Schölin, 2016). The study concluded: 'The evidence on pre-conception interventions shows promising results in encouraging changes in risky drinking and greater use of contraception among women . . . This review shows that interventions for pregnant women can be effective, although overall the evidence is not conclusive' (2016.vii).

Reid et al. (2021) also noted that women who are vulnerable for a number of reasons including depression (or other forms of psychological ill health) could be identified through preconception/interconception care and receive timely help.

The importance of preconception interventions in reducing the risk of alcohol exposed pregnancies is shown in the international evidence. Major impacts of alcohol on the foetus occur during the first trimester, when organs, including the brain, are rapidly developing. Even when a pregnancy is planned and prepared for, many women are into their 5th or 6th week of pregnancy before they know they are pregnant, particularly if they have an irregular menstrual cycle. A relaxed chat with a community nurse prior to that time could help prevent the possible harm of early pregnancy alcohol exposure. An example of this is found in the QNIS/HPBL study (2022) in which community nurses noted their continuing contact with families; sometimes enabling them to have general discussion about preparing for a 2nd or 3rd pregnancy.

In terms of approaching reproduction desires, contraception utilisation and preconception care, Michele Stranger Hunter's ground-breaking work with One Key Question (OKQ) - is now used in more than 30 American states and is a very good model.

Asking one question, then carefully listening to the answers, can be highly effective. It creates a safe and open space for conversations and discussion of appropriate next steps. OKQ is now a programme within Power to Decide in the USA. Michele is now a consultant on QNIS' Healthier Pregnancies, Better Lives programme. She is currently helping to co-create a bespoke Scottish version of this successful initiative.

IJBPE-Vol-10-Issue-Ask Women what they want - Stranger Hunter/Hammarberg/Sher

https://powertodecide.org/about-usnewsroom/new-study-reveals-increased-patient-satisfaction-for-power-decides-one-key.

Section One

THE QUEEN'S NURSING INSTITUTE SCOTLAND

Women and Alcohol

When exploring the issue of drinking in pregnancy, it is relevant to briefly explore the more general issues of alcohol consumption among women. For many years, even if large scale epidemiological surveys included women, these data were not analysed separately by gender. This seems surprising now, but the traditionally held picture of 'a drinker' and even more importantly 'a problem drinker' with all the well-recognised attributes, was male. Such a misleading picture led to little attention being paid to the issue of women's drinking and the problems they may develop (Plant, 2008). In many countries alcohol consumption levels have been decreasing for the past two decades.

The major shift to an in-depth examination of women's drinking came with the development of the worldwide, multidisciplinary project – Gender, Alcohol and Culture: An International Study (GENACIS) (Wilsnack, 2012)

The Monitoring and Evaluating Scotland's Alcohol Strategy (MESAS) data set supplies the most robust comparative data on alcohol consumption and related problems in Scotland. In Scotland, as in almost all countries, men's drinking still outpaces women's drinking. In the decade from 2003 to 2013, women's mean weekly consumption dropped from a high of 10.6 units in 2003 to 8.6 units in 2013 and stayed at that level until 2017. The unit system of measuring drinks will be discussed later in this review.

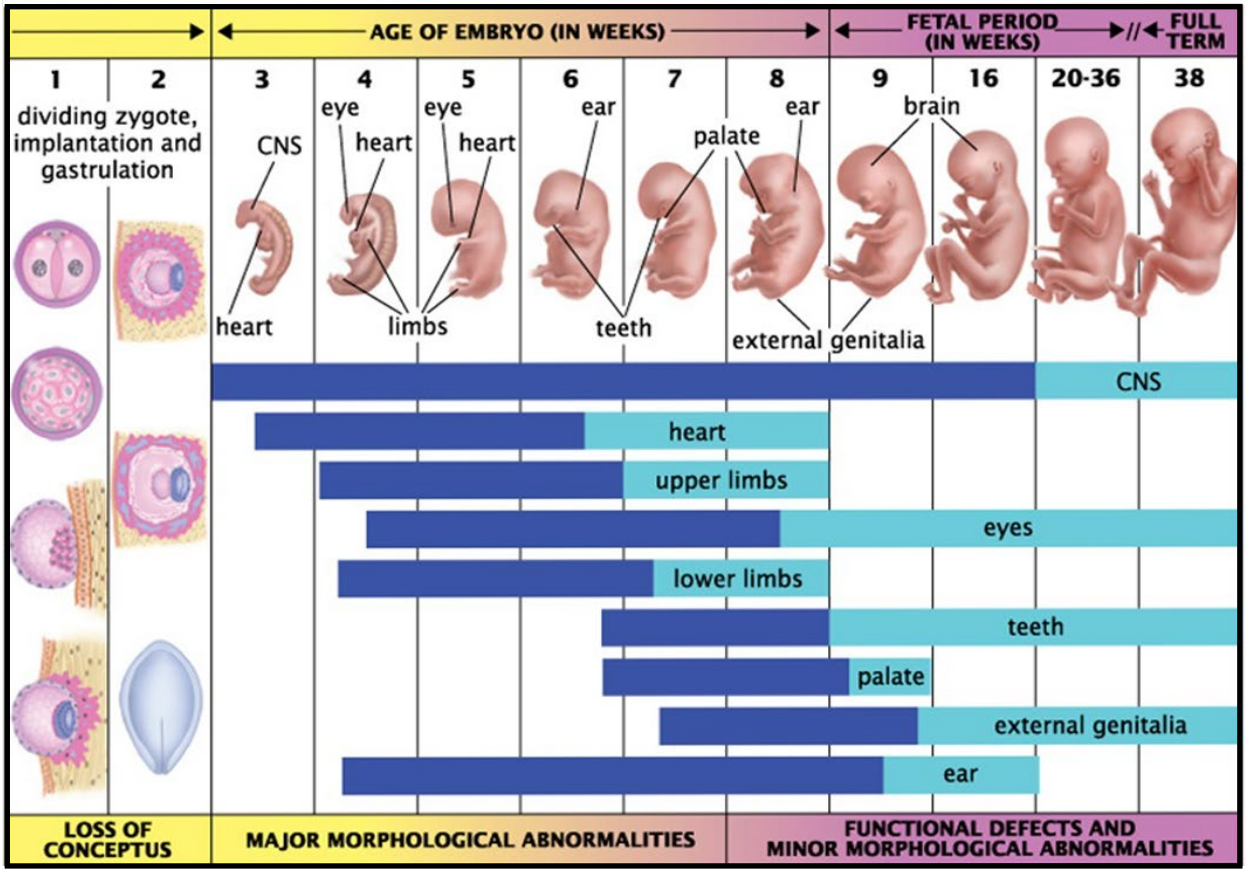
The 2019 MESAS report (the last one prior to the Covid-19 pandemic which changed the picture) reported '…. alcohol-specific death and alcohol-related hospital stays were more than twice as high in men as in women and were highest in the 55-to-64-year age group' (MESAS 2019. 4). Interestingly, although consumption rates went down, mortality from alcohol-specific causes began to rise in 2012 and has risen for both genders. In relation to pregnancy, the age group of 55-64 years may not seem relevant. Even so, it is important to bear in mind that drinking begins much earlier and increases over many years before it reaches the stage of hospitalisation for serious complications. This puts development of heavy drinking well within the reproductive years.

There have been recent reports of teenagers developing alcohol-related liver disease. This is relatively rare, but there is now evidence of alcohol-related effects on the liver in pregnant women (Italian Association for the Study of the Liver (IASF) 2016; Esposito, 2014). The possibility that the toxic effect of acetaldehyde (a breakdown product of alcohol) may adversely affect the foetus has also been reviewed (Hard et al., 2001). Developing liver damage, a well-recognised sign of heavy drinking (Simpson et al., 2019), often goes undiagnosed until 18 months to 2 years prior to a patient's hospitalisation and eventual death. Furthermore, evidence suggests that serious liver damage decreases fertility and increases the risk of spontaneous abortion. (IASF, 2016)

Alcohol-related harm is affected by socioeconomic deprivation. Alcohol-related hospital admissions were 7 times higher, and alcohol-related mortality rates were 8 times higher, in Scotland's areas of high deprivation when compared to the least deprived areas (MESAS, 2019). This is a well-recognised fact and no surprise to community nurses and midwives working in these geographical areas. Although it is clear alcohol-related birth defects are found across the socioeconomic spectrum, the combination of poor nutrition and alcohol intake does have a synergistic negative effect.

As will be noted, the data reported in this Report are mainly taken from studies conducted pre-Covid-19. Undoubtedly Covid-19 has had an impact on alcohol consumption in Scotland. Given that off licences were considered 'essential retailers' when on licenced premises were closed, it is not surprising that off licence sales rose (McLean and Dean, 2020). The longer-term impact of Covid-19 on alcohol consumption and related problems is as yet unknowable.

However, two related articles warn that FASD is likely to be 'collateral damage' from the pandemic, especially if effective contraception is not readily available to people of reproductive age (Sher (a) 2020 & Sher (b) 2020). However, the steep rise in mental health problems already showing in the data may well mean that alcohol consumption and the related problems will also rise within the next year.



Moore K.L. (1988) *"The Developing Human" Clinically Oriented Embryology*

Drinking Patterns

It is not only how much people drink, but the way in which they drink. In other words, the pattern of their drinking. As with any alcohol related issue, the risks to the foetus are typically influenced by three aspects of the pattern of alcohol consumption.

- Quantity of alcohol consumed.
- Frequency (how often) the mother drinks.
- Timing of drinking: in relation to pregnancy, this means the period of gestation

The most damaging pattern of drinking for the foetus is heavy episodic drinking, known in the UK as 'binge drinking'. In fact, this has always been the pattern of drinking in Scotland, as is the case in other Northern European countries. It also has a negative cultural meaning. Clinicians asking someone how much they drink often get the response 'Don't worry, I am not a binge drinker', when, in fact, their pattern of drinking does define them as such.

In relation to patterns of drinking, the Scottish health survey (McLean and Dean, 2020) reported the percentage of women drinking more than five days a week fell from 13% in 2003 to 9% in 2017. However, the majority of this consumption still took place within a three-day period.

There are a number of definitions of a binge. It can be defined by timing - drinking more than a certain amount of alcohol within a specific time or drinking to get drunk - but the most widely used definition is by amount.

WHAT IS A UNIT OF ALCOHOL?

1 unit

Single (pub) measure of spirits; whisky, vodka, gin, rum etc
- 25ml
- 5% ABV

1.4 units

Bottle of Alcopop
- 275ml
- 5% ABV

1.5 units

Champagne or sparkling wine
- 125ml
- 12% ABV

1.7 units

Standard bottle of premium strength lager/beer
- 330ml
- 5% ABV

2 units

Bottle of fruit cider
- 25ml
- 5% ABV

2.3 units

Pint of lager, beer or ale
- 4% ABV

2.4 units

Standard glass of wine
- 175ml
- 13.5% ABV

2.8 units

Pint of lager, beer, ale or cider
- 5% ABV

3.2 units

Large glass of wine
- 250ml
- 13% ABV

10.1 units

Bottle of average strength wine
- 750ml
- 13.5% ABV

28 units

Bottle of spirits; whisky, vodka, gin, rum etc
- 700ml
- 40% ABV

NHS Grampian

The UK guidelines for weekly alcohol consumption are 14 units for people who are not pregnant. A binge is defined as drinking 6 units for women and 8 units for men on a single occasion. Sounds simple – except, what is a unit? Is it a drink, a glass, a bottle or a can? (Kerr and Stockwell, 2012; Mukherjee et al., 2013). In fact, a 'binge' (the riskiest type of drinking for the foetus) amounts to two large glasses of wine. This is not an unusual amount for women of reproductive age to drink during a night out or a dinner at someone's home. It must also be taken into account that alcohol measures poured at home are often two to three times larger than pub measures.

A popular practice before the Covid-19 pandemic was for young women to meet together in someone's house to get ready for a night out. Each woman would bring some alcohol, usually vodka, cider or wine. A large jug or other receptacle would be found, and all the alcohol would be poured into it. Each woman would then take it in turns to drink from the jug though a long straw. Indeed, glass or plastic goldfish bowls are actually advertised and sold for this purpose.

Putting it in context, this means that a single gender group (young women) meet in someone's home (a safe space) and drink a large amount of alcohol in a relatively short space of time. Then, while their blood alcohol levels are still rising and they are feeling powerful and strong, they go into a mixed gender group in a pub or club (a less safe space). This is a higher risk way of drinking and may lead to more high-risk behaviours such as unsafe, unprotected sex.

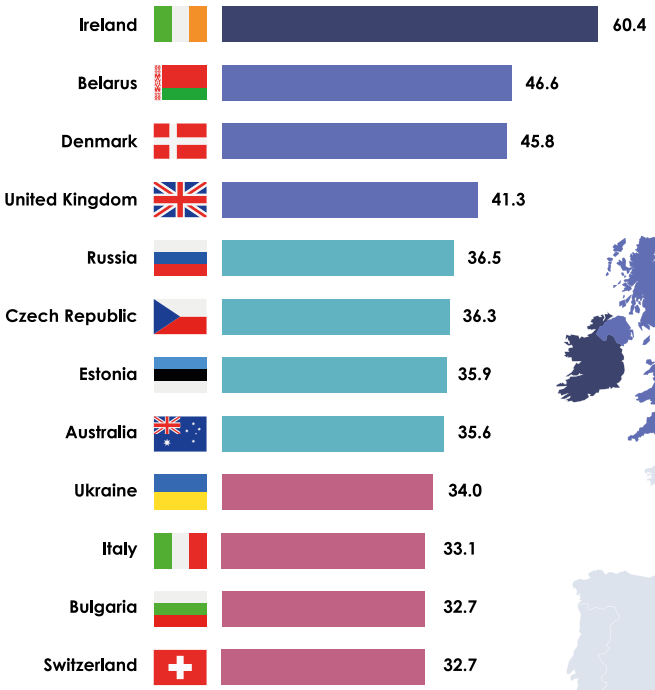
For women who are a little older, but still of reproductive age, one of the issues on social occasions is remembering how much she has drunk, how many glasses of wine, spirits or other alcoholic beverages. The problem arises when someone at the party or dinner keeps 'topping up' her glass. She then has no exact way of knowing how much she has really consumed.

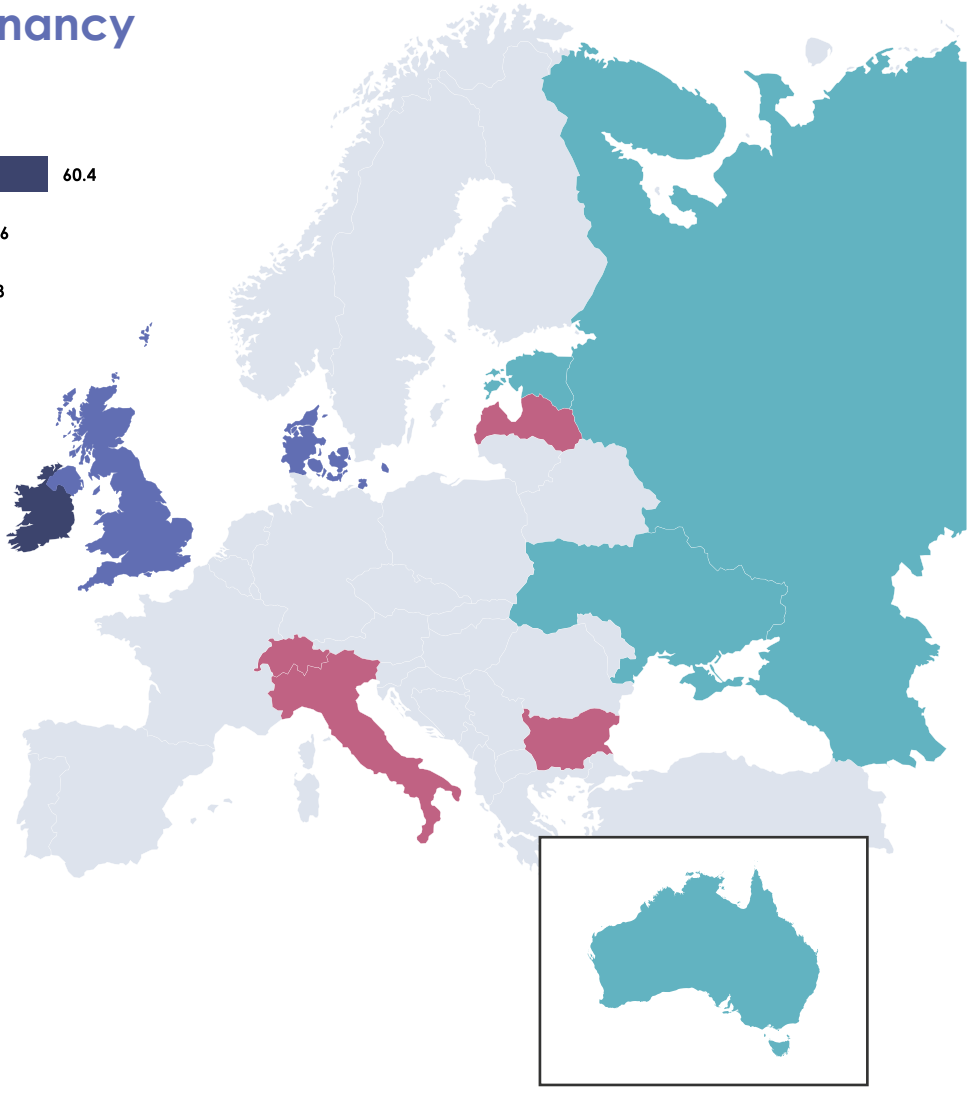
Drinking in Pregnancy

These have been some of the general issues related to women and alcohol in our culture and country. The next issue to consider is alcohol consumption among pregnant women or women who are trying/planning/likely to have/considering having a child. As well as among women who are having unprotected sex or using contraception ineffectively while continuing to drink alcohol.

Some studies have explored the issue of drinking in the general population of pregnant women worldwide (Popova et al., 2017). Popova et al. reported 'Alcohol use during pregnancy is common in many countries and as such, FAS is a relatively prevalent alcohol-related birth defect' (2017. e290). The UK is rated among the top five countries for the number of women who drink during pregnancy. Scotland is not an exception within the UK.

The Worst Countries for Drinking During Pregnancy





Source: The Lancet

Some large-scale studies (Powers et al., 2013 and Petersen et al., 2015) explored a number of potential risk factors during pregnancy, including alcohol. Other studies focussed specifically on pregnant women who were at high risk of unplanned pregnancy through such factors as drinking, having an active sex life and not using contraception (Cannon et al., 2015). A study conducted by Rehm et al. (2011) was primarily focussed on HIV/AIDS transmission but did explore the role alcohol played. They concluded 'Alcohol use is an independent risk factor for intentions to engage in unprotected sex' (Rehm et al., 2011. 51). Obviously, unprotected sex raises the issue of unplanned pregnancy. This issue will be addressed further in this review.

In relation to contraceptive use, a recent report by Guzzo and Hayford (2018) is informative. Using a longitudinal design, this team explored the favoured method of contraception used in adolescence and whether this changed over time. They reported two important findings that may be transferable to other countries. Firstly, 'when teens view using contraception as straightforward and morally acceptable, they use choose more effective contraceptive methods and use them more consistently' (2018. 38). Secondly, and in line with other studies, 'adolescent views and experiences set the stage for long-term patterns' (2018.39). Other studies have reported that contraception was used in some sexual encounters in adolescence, but use was inconsistent (Bruckner et al., 2004). The bottom line is that the contraceptive of choice for adolescents may remain their contraceptive method of choice as adults. This is good news if these adolescents chose effective contraception, but unintended pregnancies in adulthood are much more likely if they choose ineffective contraception or not using the contraceptive methods in the recommended way. However, given the relative inability of an adolescent's pre-frontal cortex to regulate spontaneous sexual impulses, the need to supply compelling information on methods of contraception must be acknowledged. If the original contraceptive choices made in adolescence were for ineffective methods, then there is an opportunity to reassess and make better choices as adults through sexual/reproductive health services and preconception/interconception counselling and care.

Throughout history, it has been observed that drinking during pregnancy can cause harm to the foetus. Frequently historical references were made to woman, alcohol and pregnancy. These were often in religious texts, including the Christian Bible and the Talmud (Horsley and Sturge, 1908; Plant, 1997; Warren and Hewitt, 2009; Warren 2015). Sadly, these references were often dismissed as being too moralistic and judgemental.

In the UK, and Scotland in particular, with its complex history with alcohol, there have been a number of physicians interested in alcohol and children. The general message was that alcohol consumption in pregnancy produces small, sickly children. Many of these messages, alcohol related or not, carried condemnation of the mother with little acknowledgment of, let alone compassion for, the sometimes difficult or stressful realities of her life. A form of judgement that persists.

One good example was an Edinburgh physician (Ireland, 1894) who proposed the idea that women should not think too much while pregnant because it would 'withdraw nourishment needed for the brain of the child she is bearing' (1894.183). More recently, arising from the work by Lemoine et al. (1968) then through Ulleland's thesis (1970) to the now famous Lancet publication (Jones and Smith, 1973), Fetal Alcohol Syndrome (FAS) was first named. Since then, the field of prenatal alcohol exposure has exploded with alcohol being described as the teratogen providing the most commonly known cause of lifelong neurodevelopmental harm. Unfortunately, what has also exploded is the judgemental and moralistic attitude towards pregnant women who drink. This is one of the most criticised behaviours used to judge women.

This theme of 'bad mothers' has haunted the field for centuries and made it much more difficult than necessary to identify and help women who have consumed alcohol during their pregnancies (Jacobs and Jacobs, 2014). The way these judgemental attitudes and stigma effect the attitudes of health professionals and their relationships with pregnant women will be addressed later in this report. Many women continue to drink at pre-pregnancy levels until pregnancy is confirmed. If the pregnancy is unintended or unplanned, then this can mean an even longer delay until pregnancy recognition. One study conducted in Ireland (Mullally et al., 2011) reported the majority of women (between

75% and 81%) drank in the peri-conceptual period. When the period between conception and pregnancy recognition was taken into account, McCormack et al. (2017) reported that the rates of alcohol-exposed pregnancies were even higher than earlier estimates.

The reality is that many women continue to drink into their pregnancy. The reasons for this vary. The most recent evidence from large scale multicounty studies confirms that a high prevalence of women in the UK drink during their pregnancies (O'Keefe et al., 2015; Popova et al., 2017).

Risk Factors for Drinking in Pregnancy

There are many studies exploring which women are more likely to drink when they are pregnant and therefore, those who may be at higher risk of affecting their unborn child (Astley et al., 2000a and 2000b). The list includes:

- Women who drank prior to pregnancy. Few women start drinking in pregnancy if they did not do so before they became pregnant.
- Women who drank in previous pregnancies (Hicks et al., 2014).
- Women who are older (Meschke et al. 2013 Kitsantas et al., 2015) are more likely to continue drinking on pregnancy. However, other studies report younger women more likely to behave in this way (Hicks et al., 2014).
- Women who have smoked or continue to smoke (Hicks et al., 2014).
- Women who report experiences of friends or family members with drinking problems are less likely to stop drinking (Hellmuth et al., 2013; Plant, 2021).
- Women who have experienced Adverse Childhood Experiences (ACE) (Plant, 2021).
- Women who have experienced domestic abuse or interpersonal abuse leading to poorer mental health outcomes (Malta et al., 2012).
- Women who have mental health issues, such as depression, are also more likely to continue drinking in pregnancy - often as a means of self-medication (Holl & Messelt, 2013; Mcdonald et al., 2016).

Women experiencing domestic abuse have been reported to be least likely to stop drinking (Hellmuth et al., 2013; Powers et al., 2013).

The pattern of alcohol consumption is another indicator:

- Women who binge drank pre-pregnancy are more likely to continue drinking during pregnancy (Tan et al., 2015).
- Women who drank in a binge pattern in the year prior to pregnancy (Mcdonald et al., 2014).

It will be remembered that binge drinking is the typical drinking pattern in Scotland. Therefore, the studies describing this pattern of drinking are really just describing the way the majority of Scottish women usually behave. As noted above, women who consumed alcohol in the typical binge drinking pattern prior to becoming pregnant are more likely to continue to drink into their pregnancy, although this is usually at lower levels than pre-pregnancy drinking (Strandberg-Larsen et al., 2008). Studies in other populations have shown drinking may be regular or more occasional throughout pregnancy (Ethen et al., 2009; Skagerström et al., 2011; Mallard et al., 2013). This may be related to the amount the woman was drinking pre-pregnancy. An Australian study (Tran et al., 2015) found that heavy drinkers were more likely to reduce their consumption than lighter drinkers.

One of the confusing issues about the original research on drinking in pregnancy was the way alcohol consumption data were collected and analysed. Information about the amount drunk was collected for 7 days, added together and divided by 7, thus giving a daily intake of 'X'.

This was misleading. When these data were reanalysed, it became clear that most of the drinking took place over two days. This does not change the message that it is wiser not to drink when pregnant and far more robust research has been carried out since then. It does however add room for misunderstanding to the ongoing debate about the risks of prenatal alcohol exposure.

Another source of confusion when comparing international studies is the size of a 'drink'. In the UK one drink (defined as one unit) contains 8gms. of alcohol, while an Australian unit contains 10gms. of alcohol as do most European countries. Other countries such as Canada and the US (United States) contain 13.5 -14gms per drink. Comparing international drink sizes is revealing. A 'drink'

in Austria contains 20 grammes of alcohol per drink, which means four Austrian drinks are the equivalent of 10 UK drinks. This is a substantial difference. The final confusion comes from the conflicting definitions of light, moderate and heavy drinking. Almost every study uses a different definition, which means comparing research across countries requires more care, particularly in the interpretation of results.

Mixed messaging only adds to the complexity of trying to understand the relationships between alcohol, women and pregnancy. Over the years, health professionals have given conflicting recommendations. For example, some medical textbooks suggested that IV alcohol be used as a treatment for premature labour. This may seem shocking now but as recently as 2005, the Cochrane Database carried out a review into the use of IV alcohol in preventing threatened preterm labour (Haas et al., 2005). Reassuringly, the authors concluded: 'Ethanol is generally no longer used in current practice due to safety concerns for the mother and her baby. There is no need for new studies to evaluate the use of ethanol for preventing preterm birth in threatened preterm labour. However, it would be useful for long-term follow-up studies on the babies born to mothers from the existing studies in order to assess the risk of long-term neurodevelopmental status'. (2005.1). So far, no such studies have been undertaken.

Section Two

THE QUEEN'S NURSING INSTITUTE SCOTLAND

Taking a Drinking History from Women Before, During or After Pregnancy

When collecting alcohol consumption information all data are, by definition, about past drinking. Studies can be conducted prospectively, when women in early pregnancy are asked about their prior alcohol consumption and are then followed to determine pregnancy outcomes. Others are carried out retrospectively, by identifying babies who have been affected and asking the mothers about their drinking early in the pregnancy.

There are strengths and weaknesses to both. Prospective studies may provide more accurate alcohol consumption information as the questions are about recent behaviour. However, they are expensive as large numbers of respondents are needed to produce enough pregnancy outcomes involving alcohol-affected babies. Retrospective studies are less expensive; however, accuracy may be affected by a longer time period between perinatal drinking behaviour and the questioning.

Another major factor in seeking an alcohol history concerns how the mother is feeling if she has given birth to a baby whose health is in some way impaired. She may respond in either of two extremes. Guilt is a very powerful emotion, and some mothers might exaggerate their alcohol consumption to reinforce feeling responsible for the effect on her baby. Other mothers will significantly underestimate or downplay their alcohol intake due to fear that they will be judged harshly or blamed for any negative outcome.

There are a variety of reasons why a woman may not be able to give an accurate account of her drinking. This does not necessarily mean she is being dishonest or trying to be deceptive. Several issues can get in the way of accuracy (Stahre et al., 2006; Herring et al., 2006; Gmel et al., 2010). Wanting to minimise her alcohol consumption may be one, however there are other, more likely reasons, such as;

1. Her memory of the occasions when she drank being impaired or unreliable
2. Her feelings about what 'counts' as drinking; for instance, the belief that wine with meals is not really 'drinking'
3. The size of the glass out of which she was drinking – a goldfish bowl is not on any chart as a measure!
4. The frequency of her glass being 'topped up' or refilled when she is not noticing

If a woman is not completely forthcoming or accurate in recalling her alcohol consumption, then part of the responsibility rests with the health professional. There is a clear connection between the way they ask these questions, and the quality of the answers. On the positive side, health professionals can be trained to frame these questions in a manner that encourages the woman to provide a more complete and accurate account of her drinking. Conversely, if a woman feels judged and that the professional asking only cares about what she drank, not why, then the information can be skewed. It can feel like a cross-examination, not a compassionate conversation.

Few people report there being nothing positive for them about their drinking (Plant, 2021). People who drink heavily will, if encouraged, usually offer some reasons for drinking, e.g., 'it reduces my anxiety'; 'it helps me deal with an abusive relationship'; or simply 'it makes me feel good'. Even in fairly extreme cases, a person with a drinking problem will say 'it makes me feel good' or 'the only time I feel normal is after I have a drink or two'.

When a health professional only focuses on the negatives of alcohol consumption, it can result in the woman feeling she is not being properly heard or understood. In fact, she may even feel invisible, as in: 'This person doesn't really see me or want to help me'. She may believe 'This person must think I am really stupid because the only aspects of my drinking they want to hear about are the negative ones'. Simply focussing on the negatives may mean she begins to shut down or chooses not to give an accurate description of her drinking. It certainly will not help the developing relationship.

However, for the woman herself, there will always be some good reasons (reasons that make sense to her) for drinking. So, community nurses and midwives need to ask about, acknowledge and try to understand, the positives as well as the negatives. This can be a very helpful way for the health professional to show she really is interested and wants to understand the woman's situation. In counselling, the three reasons given by clients for successful therapy are being heard, accepted and understood (Casement, 2013). For a frightened, pregnant woman who is concerned about her drinking, these three qualities are the starting point for a real conversation about alcohol.

It has long been acknowledged that the most important aspect of healthcare, where alcohol is involved, is keeping the person in touch with services. If a woman believes she will be judged or criticised because she is drinking, she may not attend regular antenatal clinics. However, the evidence is clear that sporadic or delayed attendance for antenatal care increases risks for both mother and baby (May et al., 2020; Popova et al., 2021). For this reason, developing a relationship of mutual trust and respect is a hallmark of good practice.

Alcohol Screening Tools

At the outset, it is worth saying that no-one drinks 'alcohol'. People drink wine or beer, gin and tonic or vodka, or some other alcoholic beverage. So simply asking 'What is your favourite alcoholic drink?' is often a good start.

There are several ways of recording an alcohol history. Some are brief and give snapshots of the important measures of consumption, such as the number of drinking days in the week and largest amount consumed on any one occasion. Some are more detailed. Tried and tested screening tools include TWEAK (Russell, 1984), T-ACE (Sokol et al., 1989) and the Alcohol Use Disorders Identification Test (AUDIT) (Saunders et al., 1993).

The T-ACE screening tool, based on the original CAGE questionnaire, (Ewing, 1984) interestingly replaced the question 'Have you ever felt guilty about your drinking? With 'How many drinks does it take to make you feel high?' This was an important change. Removing the word 'guilt' may make the question more acceptable, particularly to women.

The one measure all these tools have in common is the 'T' which stands for tolerance. Everyone who drinks will develop a tolerance, which means over a period of time they have to drink more to get the same effect. These tools measure the amount each woman has to drink before she feels the effects (or before she feels drunk). The idea is that the more alcohol it takes to reach this point, the greater the number of years the woman has been drinking. In terms of pregnancy, more alcohol may mean a greater chance the baby could be adversely affected.

Numerous studies have compared a variety of tools for sensitivity and specificity (Chang Dawson et al., 2001; Kesmodel et al., 2001; Strandberg-Larsen et al., 2006; Parkes et al., 2008; Burns et al., 2010; Balachova et al., 2018; Bakhireva et al., 2021; Dozet et al., 2021). Some of these screening tools have been updated to improve both sensitivity and specificity, for example, TACER-3 (Chiodo et al. 2014, et al. 2019). Even so, most of these screening tools are now between 30 and 40 years old. They were designed before much of the work on prenatal alcohol exposure was conducted and the possible risks of relatively low levels of alcohol were being explored.

In the UK, the two commonly used screening tools are the AUDIT or one of its shorter versions, i.e., AUDIT-C (with 'C' standing for Consumption), and the Fast Alcohol Screening Tool (FAST). The AUDIT is a 10-item screening tool developed by the World Health Organization from a multi-country collaborative project (Saunders et al., 1993). The purpose was to assess alcohol consumption, drinking behaviours, and alcohol-related problems. It was designed for use in primary health care, medical clinics, and hospital units.

The full AUDIT's10 questions raised concerns about its appropriateness for use in busy clinic settings. The AUDIT-C uses the first 3 questions from the original AUDIT and is now often used in antenatal clinics and other settings with pregnant women. The FAST consists of a subset of questions from the AUDIT. The FAST was initially developed for use in emergency departments but is now used in a variety of health and social care settings. Comparisons between the FAST, the AUDIT-C and the original AUDIT reported FAST performing better than either of the other two screening tools (John et al., 2021)

One Scottish study collected information from AUDIT, AUDIT-C and a past week's drinking history (Symon et al., 2016). An interesting aspect of this study was the length of time between the actual drinking events asked about (preconception and around week 10-12 of pregnancy) and the time the information was collected (at a mid-pregnancy ultrasound session – 19 -21 week's gestation). The authors concluded 'Women reported higher consumption levels when completing the retrospective diary, especially about peri-conceptual 'binge drinking'. Routine clinical practice methods may not capture potentially harmful or irregular drinking patterns.' (2016: 53). Other studies have also reported the advantages of using a week's diary method of collecting alcohol consumption information.

The gold standard for collecting accurate and detailed information remains analysis of the past week's drinking history (Plant, 1984; Heeb and Gmel, 2005). This method of collecting information provides a much more detailed picture of the woman's drinking pattern, the context, and the amount drunk on each occasion. The method involves recording the past week's drinking history in the form of a table. The health professional starts by asking for the information for the day prior to interview, enabling recall confidence, then goes back over the past week enquiring about:

- times the woman drank
- what she was drinking (i.e., type of alcohol)
- the amount of each beverage type
- where she was drinking
- with whom she was drinking

- These specific details enable health professionals to calculate:
- total week's consumption
- total daily consumption
- number of drinking days
- largest amount drunk on heaviest drinking occasion in that week

This method can take a lot longer than the brief screening tools described above suggest. The advantage is the detailed and very recent information collected. Prompts such as: 'It may be helpful to remember who you were drinking with or where you were' encourage the woman to recall the context of her drinking and the amount consumed.

If necessary, and if the woman agrees it is called for, then this history-taking can begin an intervention by enabling her to take stock of:

- which days she was drinking most heavily
- which days she drank the least
- who she was with when drinking most
- who she was with when drinking least
- where she was (geographical location) when she drank the most
- where she was (geographical location) when she drank the least

This method of collecting alcohol consumption information may take a while and therefore is not often used in busy clinics. Nevertheless, it can be a robust way of enabling the woman to step back from her drinking pattern and if/when she wants to, explore ways to reduce her drinking. All this useful information can then become the first step in helping her to reduce or stop drinking during her pregnancy. She can begin to see options such as changing the venue with her heavier drinking friends by suggesting they go for dinner at a restaurant instead of to a pub or meet them later in the evening. She can also become more aware of who her lighter or non-drinking friends are and spend more time with them. Using this method, the woman becomes part of a team, along with the health professional, in reducing or stopping her drinking.

Creating a 'team' underscores the importance of building a relationship based on trust through effective and compassionate communication. If successful, the health professional will be perceived by the pregnant women as helping her make a change she wants for herself. The past week's drinking diary is a good example of how this can be successfully carried out in practice.

Drinking a large amount on any occasion is now well recognised as the riskiest drinking pattern for the foetus. However, even the past week's drinking history may miss special occasion drinking, such as weddings and other celebrations (Muggli et al., 2016). For a more complete picture of a woman's drinking history, it is now recommended that special occasion drinking also be considered and recorded (Plant, 2021).

Because this method is more time consuming than using a brief screening tool, it may be particularly useful if the woman is being seen for preconception care. Case notes can then be revisited and assessed with the health professional prior to conception to help her manage her alcohol consumption leading up to, and during, her pregnancy.

The issue of asking 'sensitive' questions in a busy clinic is clear. One way forward is to use the Single Binge Drinking question. Translated from US measures to UK ones, the question would be: 'In the last 3 months, how often have you drunk two large glasses of wine (7 units) or more on a single occasion?' or asked another way: 'How often in the past 3 months have you drunk 4 large glasses of wine (almost 11 units) or more in a week?' If the answer to either confirms relatively large amounts fairly often, then the authors suggest it will 'effectively and quickly identify the majority of women at risk of an alcohol-exposed pregnancy' (Johnson et al., 2010).

The 4Ps questionnaire has also been viewed as useful to assess prenatal alcohol exposure (PAE). The 4Ps stands for Parents Partner Past and Present and includes questions on drinking problems in a family or by a partner, plus two questions assessing use of alcohol, tobacco and other drugs 'in the month before you knew you were pregnant' (Chasnoff et al., 2005; Chasnoff et al., 2007). This question 'before you knew' is problematic. Many women still calculate their pregnancy from when they received a positive pregnancy test. However, if the answer suggests a possible concern, then the health professional could proceed to using the past week's drinking diary.

Several of the more concise alcohol screening

tools have been designed or redesigned for use with pregnant women. The screening tools exist and have been validated. Yet, there is no consistency across the health services. Which tool to use when (or whether using any tool is helpful) remain unresolved in Scotland. This prompts the question: 'What are the key advantages and disadvantages of using an alcohol consumption screening tool?'.

Advantages of using screening tools

One advantage of using a standardised method for collecting the information is that it 'normalises' alcohol-related questions. It simply becomes another part of a routine clinical appointment. For a health professional lacking either experience or confidence, this becomes a 'crib sheet'. If all health professionals are known to ask the same questions of every woman, the issue of stigma is reduced. If a woman asks, 'Why are you asking me that?' the answer is simple 'we ask everyone'.

If a specific tool is adopted for routine use, then the woman can be asked the same questions at every appointment. This provides consistency and also creates an opening for either the woman or the health professional to raise any questions or concerns that may have arisen since the previous visit.

On a broader level, a standardised screening tool can provide a consistent measure of alcohol consumption in every geographical area. In turn, this can help provide a countrywide picture of what is happening with alcohol consumption among pregnant women. This would then enable monitoring of consumption level increases or decreases, which would assist service provision that is tailored to specific geographical areas and their needs over time.

Standardised screening tools also allow identification of possible trends in alcohol consumption among pregnant women and facilitates international comparisons. Identifying countries where alcohol consumption is high can be used by countries where consumption is on the increase to see what services, policies and practices should be considered for adaptation. This can assist in making proactive strategic decisions for funding.

Disadvantages of using screening tools

For many community nurses and midwives, the benefits of standardised screening tools may not be evident. Reluctance or scepticism may or may not be reasonable. It is worthwhile trying to understand, and then weighing, the reasons behind this reluctance against the potential benefits of using standardised screening tools.

Some nurses and midwives believe that suddenly employing a standard screening tool without 'gently introducing' the subject of alcohol consumption, may be perceived as too challenging or too judgemental. Done insensitively, it can trigger an unnecessarily negative reaction. Such a reaction can either adversely affect the developing relationship between the health professional and a pregnant woman or lead to defensive or possibly inaccurate reporting. In these cases, the time 'saved' by using a short, standardised tool may result in time lost. That is because relationship damage cannot be instantly repaired. In addition, extra investments of time may be necessary to correct records or obtain accurate information.

A major disadvantage of using one of the standard screening tools is that many of these were designed to identify heavy/problem drinking. In relation to pregnancy, health guidelines in Scotland, as in many countries, are not directed toward heavy/problem drinking, but rather any level of alcohol consumption. Some of these screening tools can give more nuanced scores. For example, T-ACE which does ask about feeling the effects of alcohol.

Since high doses of alcohol are riskier for the foetus, many screening tools focus on how much the woman drank on a single day, usually a day from the previous week. When a time period is not specified, the usual wording "asks about a typical day". It doesn't make sense to say "when alcohol was consumed. Because our Scottish pattern remains one of drinking little during the week and then concentrating drinking on a Friday and Saturday night, many women will say they don't have a typical day. Health professionals too often stop asking for further information. One way around this unhelpful communication is to be clear the question refers to a typical drinking day. Currently however, none of the recognised screening tools include this language.

Furthermore, screening tools conflate 'use' and 'misuse' of alcohol therefore any amount of alcohol is interpreted as a 'problem'. This raises the important issue of how the information is recorded in the case notes and used later when the woman in question is no longer pregnant. Scores that may trigger referral to alcohol interventions may be achieved by any woman who had 2 or 3 drinks – but a referral may be inappropriate. She may simply need to know it is wiser for her and better for her baby to stop drinking now.

There can be far reaching ethical consequences of conflating 'use' and 'misuse', which must not be ignored (Bell et al., 2016; Lee et al., 2016; Bennet and Bowden, 2022). Good policy and practice must be both ethical and well-grounded in the evidence. It is vital not to medicalise a culturally acceptable social behaviour until there is a definitive proof it is necessary. The woman's perspective and preferences and her rights cannot not be ignored even when, perhaps especially when, she is pregnant.

Standardised questionnaires are not the only way to measure and assess alcohol consumption. More accurate ways of measuring the presence or absence of alcohol can be found by using laboratory screening tests (using blood and urine samples). However, these have not been shown to be useful for understanding anything other than very recent alcohol use. Likewise, breathalyser testing will only reveal alcohol use within the previous few hours.

Testing hair samples to assess the presence of alcohol consumption during pregnancy provides a much longer-term view of whether alcohol or other drugs have been consumed. However, at this point such testing methods are neither cost effective nor practical. (Symon et al., 2016).

At birth, the first faeces of the baby (meconium) can be tested for biomarkers that assess the prevalence of alcohol use during the second and third trimesters of pregnancy. However, it does not record that important first trimester (Abernethy et al., 2017; Howlett, 2019). This may be useful in large scale, anonymous surveys. Yet, as an inherently retrospective measure, it will not help any woman achieve her desired outcome from that specific pregnancy, i.e., a healthy baby unharmed by alcohol exposure. It must also be remembered that laboratory tests, such as this one may have legal implications and increase the risk of involvement of social services. (Motherisk Commissions 2018).

A UK survey (Schölin et al. 2019) explored aspects of communication about alcohol consumption which either helped or hindered the provision of advice to pregnant women that would be accepted and potentially helpful. Although the midwives in this study believed that women should be given clear information about alcohol use during pregnancy, there was debate about how best to impart information and guidance. Up to 70% of midwives believed that open and relatively unstructured discussions (that is, more 'natural' ones) were more likely to elicit the most accurate and honest reporting of alcohol consumption than any of the standardised screening tools.

A survey on the knowledge and experience of health care professional conducted in the North of England (Howlett et al., 2019) found that only a small number reported using the screening tools described above. The majority preferred 'simply detailed questioning with no specific tool' (Howlett et al., 2019: 3). This was viewed as particularly important when the relationship between woman and health professional was first developing.

The recent survey carried out among community nurses and midwives in Scotland reported the vast majority of respondents (88%) preferred general discussion to specific screening tools (QNIS/HPBL, 2022). While there are advantages in consistently using recognised screening tools, a sensitive discussion was perceived as being more desirable and effective. Developing a trusting, respectful relationship was seen as a better way to understand a woman's alcohol history. Then, based upon that understanding, provide helpful assistance to women who want to change their drinking habits.

The confusion some women feel in relation to governmental and public health messages about drinking during pregnancy is often mirrored by health professionals themselves. A study of midwives in England and Sweden, Schölin et al. (2019) found that Swedish midwives had little difficulty in giving clear messages about not drinking throughout pregnancy, but the English midwives were far less sure about giving such a message. Schölin concluded the general public health message in Sweden was unequivocal; that is, 'No drinking in pregnancy!'. By contrast,

messages in the UK were not as clear or consistent. This situation of mixed messages still exists in the UK today and leads to confusion and uncertainty for many health professionals, as well as for the women they want to assist.

Mukherjee et al. (2015) in a study of general public knowledge concluded the main issues were 'a lack of knowledge; need for the information to be personally relevant; the need for wider public education; and a lack of clarity in the current guidance' (2014.469). It is worth remembering that community nurses, midwives and other health professionals are also members of the general public and influenced by the same mixed, ambivalent and inconsistent messaging.

The topic of alcohol use during pregnancy and the risk of Fetal Alcohol Spectrum Disorders have rarely been a significant element within the UK's initial education or continuing professional development of health professionals. FASD has largely remained 'under the radar' for practitioners and policymakers, as well as for the public. Nevertheless, most of the relevant research agrees that clear and consistent messages about women, alcohol and pregnancy provide the best means of achieving healthy babies unharmed by alcohol exposure in utero (Eleck et al., 2013).

In relation to bringing about behavioural change through health education campaigns, the evidence for successful alcohol education continues to be bleak. Time and time again, the most visual public health campaigns on alcohol issues have consistently been shown to result in little positive behaviour change. They can change knowledge and attitudes, but they do not change behaviour (Young et al., 2018).

Using regular pregnancy screening and antenatal appointments as a platform for giving and reinforcing advice on alcohol and pregnancy is also limited. Schölin et al. (2019) found that 97% of midwives reported advising against drinking at the initial antenatal appointment but that far fewer did so at subsequent appointments. A one-time message is unlikely to have an enduring or cumulative impact.

Alternatives to Screening Tools

Many midwives and other health professionals believe that open, person-centred, non-judgemental conversations are the best way to introduce the subject of alcohol consumption before and during pregnancy. The goal is a two-way relationship of trust and respect, not simply asking standard questions or delivering robotic messages.

This being the preferred method of communication underscores the importance of a skill any health professional must learn: how to listen. This sounds so simple, but careful, active, empathic listening does not always come naturally. Even people who listen well have difficulties when they are nervous, distracted or feel under pressure. Such deep listening is a skill. To properly listen to another person, giving your full, undivided attention, not while also reading the case notes, not when interrupting the woman to save time – is usually an acquired talent, not a given skill among professionals. Discussion at this level requires you to be fully present with that person, no matter what else is going on around you both.

As noted earlier, the introduction of the topic is important. For example, 'Where does drinking fit into your life?' or 'When you are on a night out, how much do you drink?' is more likely to result in a useful response that gets around a tentative 'Do you drink alcohol?' The next question can be 'What is your favourite drink?' As noted earlier, no-one drinks 'alcohol' They drink wine or beer or gin and tonic. One of the benefits of the past week's drinking diary is that it encourages expansion of, and follow-ups to, these questions. Asking someone where they were or who they were with when they drink can help their recall. It can also show the woman that the health professional is genuinely listening to her and interested in her answers. This helps begin the development of their relationship, which is a vital part of how to work together to make this pregnancy the safest, happiest one possible.

If the woman is not drinking, then it gives the health professional the chance to give her positive feedback. In many cultures, to praise or indeed to accept praise is almost an alien concept. Many of us do not realise how powerful one sentence such as 'Sounds like you're doing really well in this area' from a community nurse or midwife can be for an anxious woman. It can help her relax and feel the community nurse or midwife is on her side; perhaps even someone she can ask about something causing her to feel anxiety or upset.

Conversely, if the health professional is concerned about the woman's alcohol consumption, expressing that concern is more natural and likely to succeed in the context of a positive relationship between them. A good relationship can become a great opportunity to support the mother and help the baby at a time of vital importance. It is much easier to walk through an open door with encouraging non-judgemental health professionals than for women to have to knock on a closed one. Think how difficult it would be for a woman who is concerned about her drinking and wants to talk about it, if they are met with a dismissive or judgemental health professional. In that situation, what good can come from the professional asking 'You don't drink, do you?'

NICE National Institute for Health and Care Excellence

NICE QUALITY STANDARD ON FASD (2022) A game changer

All CCGs and NHS Trusts will have to 'have regard' for this Quality Standard. It identifies areas for improving quality of care regarding FASD, including:

1. Advice to pregnant women
2. Discussing alcohol use throughout the pregnancy and recording
3. Referral for assessment
4. Neurodevelopmental assessment
5. Care management plan

Source: NICE Quality Standard on FASD

NICE Guidelines

Some of these issues are addressed in the newly updated NICE 2022 guidelines. The link to this site can be found in 'Useful Websites' at the end of this report. These updated guidelines provide five 'Quality Statements' to provide measures for ensuring quality care and, where necessary, service provision:

Quality Statement One

Pregnant women are given advice throughout pregnancy not to drink alcohol. This section states 'Midwives and other healthcare professionals have training in FASD awareness and alcohol brief interventions. (2022.7)

Quality Statement Two

Pregnant women are asked about their alcohol use throughout pregnancy, and this is recorded' (2022.8)

Quality Statement Three

'Children and young people with probable alcohol exposure and significant physical or behavioural difficulties are referred for assessment' (2022.11)

Quality Statement Four

'Children and young people with confirmed prenatal alcohol exposure or all 3 facial features associated with prenatal alcohol exposure have a neurodevelopmental assessment, if there are clinical concerns' (2022.16)

Quality Statement Five

'Children and young people with a diagnosis of Fetal Alcohol Spectrum Disorder (FASD) have a management plan to address their needs' (2022.20)

As with any government document, there are strengths and weaknesses. At this point a weakness may be that maternal alcohol consumption will still not be recorded in the baby's case notes. This debate has been ongoing for several years, with some of the comments matching those of midwives who feel the baby 'deserves a new start, free of the mother's alcohol history'.

As noted earlier, whatever the final decision, ethical and legal implications must be recognised. Yet if maternal history is not recorded in the baby's case notes, then a firm diagnosis of FASD 'with maternal alcohol history' cannot be made conclusively. This could easily result in no service provision or other support for the child. More broadly, it means there will no robust, reliable way of recording FASD in routine data collection. As the saying goes 'if it's not counted, then it doesn't count'. If the number of babies, children and young people affected remain unknown, money will not be made available for service provision or other assistance; let alone for an adult affected by undiagnosed FASD).

This is an important point particularly for looked after or care experienced children, as well as for young adults classified as care leavers. Also worth highlighting is the section in the NICE Guidelines on 'advice for avoiding alcohol in pregnancy'. Under every heading, it states: 'No routinely collected national data for this measure has been identified' (2022.6). Hopefully, this stark statement of the current situation will encourage some form of routine data collection to finally overcome this longstanding, ongoing issue.

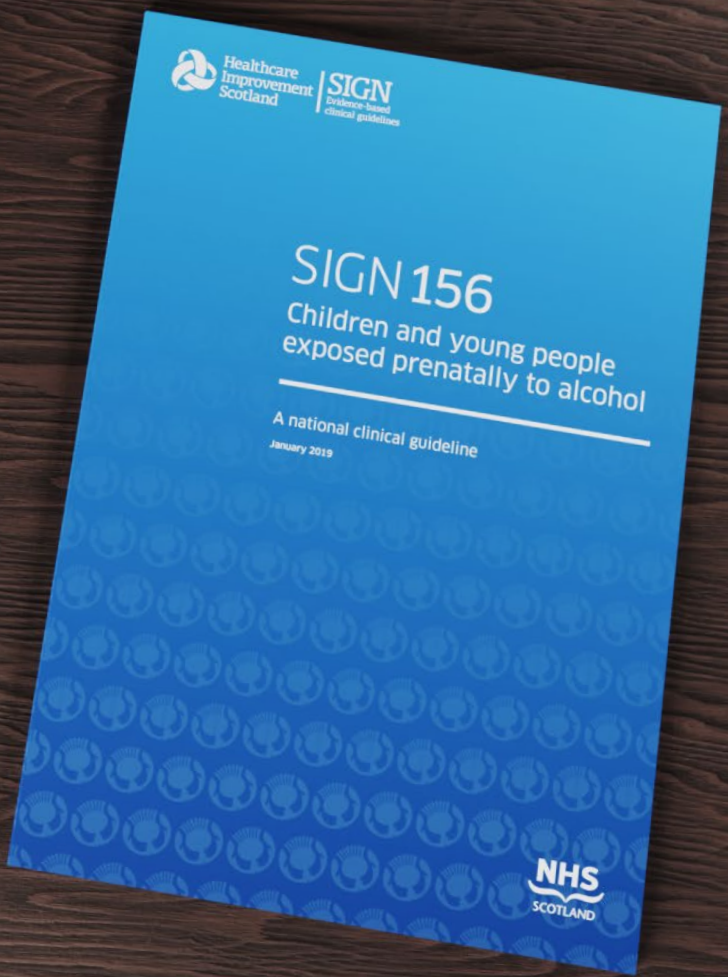
The bottom line is money. To carry out all NICE's laudable aims, there is an inherent, significant financial cost. NICE Guidelines are enforceable in England through the Care Quality Commission, which is a real advantage. Even so, as has been noted: (Lowson et al., 2015) 'Most organisations have robust processes in place to deal with implementing guidance. However, resource limitations and the scope of guidance received by organisations create barriers relating to organisational processes, clinician engagement and financing of new procedures.' (2015 1).

The SIGN (Scottish Intercollegiate Guidelines Network) 156 guidelines in Scotland (2019) were the first in the UK and remain the most focused and pragmatic. This set of guidelines concentrates on the following objectives:

Identification of children at risk of FASD

- Criteria for diagnosis of FASD
- Medical assessment
- Physical examination
- Sentinel features
- Neurodevelopmental assessment
- Multidisciplinary assessment team
- Special consideration in the neurodevelopmental assessment
- Management, treatment and follow up of children and young people affected by prenatal alcohol exposure (PAE)

Links to these are found in the Useful Web Links. At the time of writing, it is unknown if and how the Scottish Government responds to the updated guidance from NICE. The SIGN 156 Guidelines are to be considered for review in October 2022.



Legal and Ethical Concerns

At the extreme end of the legal and ethical debate is whether prenatal alcohol exposure should be viewed and treated as a criminal offence. This debate has been ongoing for many years in countries such as Norway (Söderströmm et al., 2012). In some states in the U.S (United States), women have been imprisoned for drinking alcohol during their pregnancy (Drabble et al., 2011; Roberts et al., 2017). These sentences were carried out under the legal umbrella of child abuse and endangerment.

In the light of this, it may be surprising to hear that even at the most extreme end of alcohol consumption in pregnancy (heavy/problem drinking) some professional bodies in the US are quite explicit about their member's obligations not to be complicit in criminalising or punishing their women patients. For instance, the American College of Obstetrics and Gynaecology (ACOG) state in their Committee Opinions that 'Obstetrician–gynecologists have an ethical responsibility to their pregnant and parenting patients with substance use disorder to discourage the separation of parents from their children solely based on substance use disorder, either suspected or confirmed (2015.131).

To help health professionals with these contentious issues, Hall et al. (2017) and Ewusos et al. (2021) suggest five areas that can usefully focus discussion. These are 'communication related, confidentiality related, professional-duty related, value-differences related and treatment plan-related' (Hall et al., 2017. 80)

Engaging with Women: Enablers and Barriers

Numerous studies have classified into two categories the factors that help or hinder health professionals in their care of pregnant women. Enablers help, while barriers get in the way. (Mengel et al., 2006; Phillips et al., 2007; Stade et al., 2009; France et al., 2010; Kesmodel and Kesmodel, 2011; Beenstock et al., 2012; Seib et al., 201; Doi et al., 2014; Payne et al., 2014; Crawford-Williams et al., 2015; Stone, 2015; Sterne et al., 2015; Schölin, 2018; Schölin et al., 2019; Howlett et al., 2019; Morrison et al., 2020; QNIS, 2022). Most of the participants in these studies are midwives.

The source of these enablers and barriers can be grouped into three distinct areas:

ENABLERS

- Internal to health professionals – ideas and opinions based on the existing values and beliefs of the health professional
- Internal to pregnant women – factors which develop based on how the pregnant woman views herself and how she perceives each health professional
- External to both parties – factors such as the physical setting in which conversations take place

BARRIERS

- Internal to health professionals, within their own knowledge, beliefs and values
- Internal to pregnant women, i.e., within how she sees herself, her life and how she perceives each health professional.
- External to both participants, e.g., within the physical or institutional setting in which conversations and care are taking place.

ENABLERS

Enablers internal to health professionals

This begins with how health professionals perceive their role. If talking with, and listening to, women about their drinking and lifestyle are understood as part of their role, then they may feel relaxed and confident about how and why they ask relevant questions. They may see asking such questions as their right and responsibility. Conversely, if they are uncertain about whether taking an alcohol history or having knowledge of FASD is part of their role, they may have little confidence or even willingness to raise these issues.

Wearing a uniform can be an enabler when it offers a sense of privacy and protection for the professional and the woman. Similarly, if the health professional believes they are providing each woman with all the information she needs to make an informed choice, then this can be seen in a positive light by the woman.

Midwives involved in these studies were generally keen to learn more about alcohol, pregnancy and FASD. Some health professionals thought having alcohol usage on a checklist of routine questions would be useful. A recent Scottish survey of community nurses and midwives confirmed that this is broadly absent from current practice with 1 in 5 respondents revealing that they did not routinely raise alcohol related issues. (QNIS/HPBL Survey, 2022)

Some saw information leaflets being sent prior to the first antenatal visit as potentially helpful in 'opening the door' for them to discuss alcohol consumption. It prevented alcohol-related questions from coming as a surprise during the initial appointment. A Swedish study (Bortes et al., 2015) reported 'It was 2.6 times more likely that those who received the brochure had abstained completely since pregnancy recognition at their first prenatal visit' (2015.289).

However, the results of this campaign were mixed. Some studies showed this had a marked impact on women's drinking, while others reported that the subject of alcohol was not followed up during that first antenatal visit, despite being referenced in the literature. A missed opportunity. (Schölin et al. 2019). It should be noted that in this study midwives who reported being most willing to engage in conversations about alcohol were those who had been trained in Alcohol Brief Intervention (ABI).

In the Scottish survey (QNIS/HPBL, 2022), 70% of respondents reported feeling comfortable or very comfortable having these conversations. The main reasons given were that it was a routine part of their practice and/or they had been trained in Alcohol Brief Interventions or Motivational Interviewing.

Enablers internal to pregnant women

There is a complex psychological and emotional dynamic at work here. An individual's perception of a situation is governed, to a greater or lesser extent, by past experiences of similar situations. Previous positive interactions with healthcare professionals can go a long way toward the woman feeling a sense of trust and therefore, being open to answering any questions. A good previous experience encourages her belief that the current and future experiences will remain good. This underscores the value, and advantage, of a community nurse or midwife who already has a positive history and knowledge of the individual and/or her family.

Enablers external to both parties

These factors depend on the physical context of the appointment. If conversations take place in a local practice where the woman knows, and is comfortable with, the layout she is more likely to be at ease. A welcoming, familiar environment often invokes a feeling of privacy, which is helpful when sensitive questions are being asked, or when women want to disclose concerns or seek advice. If bringing existing children to the appointment, then the patient will feel more relaxed if the children will be watched by known and trusted people.

Continuity of care is another enabler considered external to both parties. Sometimes, women have no choice over which professional they see at each preconception or antenatal visit. Repeated appointments with a known and respected professional enhances the experience for both parties. Continuity of care provides additional time and space to develop relationships and this in turn supports positive ongoing interactions.

To ensure consistency, the ideal would be for every woman to be asked, about her alcohol consumption compassionately and without judgement, at each preconception or antenatal appointment. Even if the woman is seeing different community nurses or midwives (or in a hospital antenatal setting) there can be a degree of continuity created in her notes if they include her alcohol history and previously expressed concerns. It provides an opportunity to bring up the subject and offer the chance to report any new issues or changes. This also enables the health professional to compare past and present answers and information from previous visits. (Strandberg-Larsen et al., 2006)

BARRIERS

Barriers internal to health professionals

Some health professionals do not feel comfortable asking questions about alcohol. That discomfort presents a significant barrier to securing an accurate alcohol history and preventing FASD. Indeed, in the recent Scottish survey (QNIS/HPBL, 2022) 1 in 3 respondents reported not feeling comfortable discussing alcohol with women of childbearing age and as noted earlier, 1 in 5 do not routinely include this in their practice.

Other studies noted respondents not feeling comfortable giving the message of 'no drinking during pregnancy' or other FASD prevention messages. Linked with this some professionals reported getting no satisfaction from giving advice on abstinence. Some respondents believe the first clinic appointment is too early to bring this up, because a relationship of trust hasn't developed yet. There was concern that information collected at this early stage may not be accurate.

Other issues reported in studies included matters of competence, as well as confidence. Being unfamiliar with current guidelines from government and health bodies or being familiar but thinking they are not consistent is not unusual. This left some uncertain about what information and advice to give women of childbearing age.

Another internal barrier can be when health professionals believe it is not worth giving advice on alcohol and pregnancy because of their conviction that women won't change their behaviour. Feelings of being under pressure because there is already too much to ask about and give advice on in a busy clinic was a common theme. Time constraints and work pressures are not limited to alcohol advice, they commonly influence many decisions made by health professionals.

Other internal barriers to engaging with women about alcohol and FASD also exist. One is the assumption that most women do not drink when they are pregnant, or that women already know not to drink when pregnant. Another is the belief it is not a good idea to ask about the woman's drinking behaviour, as doing so might make her feel guilty or anxious and might make the professional appear judgemental. Such assumptions suggest an underestimation of the prevalence of FASD in the local community. However, a small study of birth mothers (Zabotka et al., 2017) reported that, if the health professional didn't ask about their drinking, the women believed this was unspoken permission to continue to drink.

Many practitioners in the studies reported not having the skills or knowledge to effectively address the situation if the woman says she is drinking or drinking heavily. Some also cited a lack of adequate information around the support available preventing them from signposting the woman in need. A more negative and difficult barrier can be found among clinicians who believe women will deny any drinking or will resist answering questions honestly about their drinking. For the health professional, hearing or seeing hesitation (even losing eye contact) can raise suspicions of secrecy or an unwillingness to speak candidly. That may not be an accurate reading of what women are thinking.

Some midwives had a more holistic view. If women reveal heavy or problem drinking, these midwives say they regard it as indicative of underlying problems. Therefore, they choose to explore the root causes, rather than focusing on taking an alcohol history.

Some midwives didn't want to record information about mother's drinking in the baby's case notes for two reasons; it could lead to the baby being taken into the care system; or they wanted the babies to have a fresh start and not to be labelled by the mother's behaviour. In some respects, this may be seen as compassion. Community

nurses and midwives often see complexity and implications more clearly than other professional groups because they spend more time with their patients and hear more about their life situations.

Years of the Covid-19 pandemic has added stresses and heavier workloads. There is a degree of 'compassion fatigue' in all health professionals. Midwives and community nurses are not exempt. Even prior to the pandemic, the need to support their health and wellbeing was recognised but still not managed well (Gountas and Gountas, 2015). QNIS and COPE Scotland are amongst the leaders in promoting wellbeing among community nurses and midwives. (https://www.qnis.org.uk/wellbeing-practices). When the people responsible for helping others are struggling themselves, another internal barrier among health professionals is reinforced.

Barriers internal to women

Past experiences impact on how pregnant women perceive their current situation. Anxiety about the pregnancy may mean they are not even hearing some of the questions asked (Arch, 2013). This can become even more complex if the past incudes a history of trauma (Hillis et al., 2004; Poole and Greaves, 2012).

Working with a pregnant woman means working with a dyad – both mother and child. Depending on the mother's history, it may even mean working with a triad – the baby, the pregnant woman and any trauma experienced by the woman in childhood or prior to pregnancy. A sensitive, non-judgemental, caring person by her side may make all the difference. For example, this matters during a vaginal examination being carried out by a male health professional. This may throw her right back into a childhood trauma and retraumatise her. Yet, any problems or distress shown by the woman at vaginal exams, risks her being labelled 'a difficult patient' when all she is trying to do is survive flashbacks from her own history (LoGiudice, 2012).

In cases of past (particularly sexual) trauma history, it should never be assumed that the woman will feel safer with a female health professional than their male counterpart. The male may have been the active abuser. Yet, the females in her family may not have protected her. Indeed, they may have ignored the abuse or accused her of lying.

The issue of Trauma Informed Care is important and its relationship to women, substance use, and mental health has to be addressed for healthcare to be helpful and effective. (Wilton and Williams, 2019). The goal is to ensure women are seen holistically, including the complexities of their lives prior to their current situation. This is far preferable to seeing and treating women in 'silos' where care is divided into discrete services. For example, pregnancy, alcohol or drug use, experience of domestic abuse and family history of alcoholism can all be interconnected but are often treated individually. The recent Scottish government/NHS education toolkit is a good resource, offering several useful tools to promote holistic care. (Homes and Grandison, 2021).

If the woman's previous experience of health professionals has been negative, then, before she even steps into the clinic she will be interpreting everything through this lens. It is not difficult to see how this may affect her response to questions (Plant, 2021). Many pregnant women who have had previous negative contact with health services may fear having their children taken into care if they disclose any drinking. This could have a powerful impact on their relationship with health professionals during their pregnancy. Sadly, it is often the case that women who drink heavily and had children taken into care, will become pregnant again very quickly. If their problem drinking has not been addressed, there is a higher risk that the outcome of the next pregnancy will be a baby with lifelong, life-compromising Fetal Alcohol Spectrum Disorders.

Many women who have a drinking problem, believe they can deal with it themselves and do not need help. Sometimes that includes pregnant women. Unfortunately, the time pressure of pregnancy means that allowing women to acknowledge, and seek treatment for, alcohol issues in their own time can jeopardise the health of the foetus. Perhaps more worrying than pregnant women hiding a drinking problem are those who try to avoid the issue altogether by not attending antenatal appointments. With any alcohol treatment – before, during or after pregnancy - the priority is keeping the person in contact with appropriate, person-centred services.

Barriers external to both parties

The barriers to engaging with women about drinking and pregnancy are inherent to being part of a society that either condones or condemns alcohol-related behaviour. Nurses, midwives and other professionals are also members of their community, and they too are influenced by the same beliefs and values. Scotland is often acknowledged as having an 'unhealthy relationship with alcohol' a less than ideal context for honest engagement about drinking.

The setting for such conversations also plays a role. Even when there is a quiet space where women can talk, the fear of being overheard by others can create a barrier of anxiety and distrust. For women experiencing domestic abuse (where confidence and feeling of safety are compromised), voicing fears and getting help in a busy, noisy clinic can be almost impossible. Just because health professionals feel comfortable in health and care environments does not mean their patients do.

One of the studies by Howlett et al. (2019) included community-based health professionals such as health visitors and general practitioners, as well as hospital-based midwives, obstetricians and paediatricians. Many of the responding professionals reported feeling confident in identifying clinical features of FASD, though confidence varied among these professional groups. Identified areas of educational need included asking about maternal alcohol use, screening for FASD and onward referral pathways.

Howlett et al. reported '---health visitors, paediatricians and GPs demonstrated relatively high levels of confidence in discussing FASD with patients. However, Howlett went on to note, 'This is an interesting finding for a group of professionals who otherwise report a lack of training in FASD and a limited knowledge base' (2019:7). This is an important point that reflects the need for surveys to explore respondents' actual knowledge, rather than simply asking whether they believe they know about alcohol and pregnancy. As Howlett noted, the findings may reflect general confidence in their professional communication skills; not a more than superficial understanding of FASD. For professionals, knowing too little about alcohol-affected pregnancies is a barrier to meaningful engagement – but so is being overconfident instead of well-informed

Language and cultural insensitivity are another barrier to taking alcohol histories and conducting helpful discussions about alcohol and pregnancy. Some women are part of ethnic groups, where language and culture combine to impede easy and accurate dialogue with health professionals. This can require negotiation. For instance, in some African societies' feelings are somatised, so that someone with anxiety may describe themselves as having stomach problems or tightness in the chest.

In many cultures, the intimate examination of women by a male doctor is a real issue. If there are language barriers, then sometimes women bring an older child to translate. This may make it difficult to ask intimate questions, which may then go unasked. Think, for instance, of women whose culture or religion forbids alcohol, but who may be using alcohol for self-medication. How will they answer the question 'What, and how much, alcohol do you drink?' Both question and answer must be translated by a child or other family member. The answer will almost inevitably be inaccurate. This could leave women feeling even more lonely, isolated, misunderstood and unaided.

Stigma

Stigma takes many forms, all of them unhelpful in improving knowledge and behaviour related to alcohol, pregnancy and FASD. Stigma – that is, a negative judgement or discriminatory attitudes and treatment – can apply to a person, condition, gender, age, religion, ethnicity, race or socioeconomic status, etc. Stigma often has roots in myths and/or ignorance. In the context of this report, examples of stigma include the belief that women who drink heavily are 'bad'; have low moral standards and are likely to be poor or working class. This extends to the belief that only a 'certain kinds' of women are likely to give birth to a child affected by FASD.

Internationally, especially in North America, Australia and New Zealand, FASD was long recognised as a problem, but one almost entirely affecting indigenous populations. In Scotland, when FASD was not invisible, it was almost always seen as affecting only people living in poverty. Happily, this has changed for the better in recent years and is far less often seen as a problem only affecting a single class or socioeconomic group.

Stigma has an impact on how health professionals see and treat women. Take, for example, the negative and inaccurate stereotype that women who drink during pregnancy have low moral standards and should therefore be considered bad people. In communities where this stereotype prevails, it may affect the way health professionals respond to women in their care. Further, women who are aware that this stigma exists may anticipate unfavourable judgement. Where this stigma becomes internalised, it may even impact on how a woman sees herself, compounding negative associations and leading to negative self-treatment.

In this scenario, there are two common consequences. The first, that women who drink during pregnancy will avoid regular antenatal appointments for fear of discomfort or harsh judgement. The second, that health professionals will avoid discussing alcohol consumption with women unless they already have negative preconceptions about them.

Take for example, middle-class or wealthy women who 'only' drink wine with meals. Despite drinking during pregnancy, these women often avoid stigmatisation from health professionals entirely. They are also more likely to receive benign, understanding treatment. This is because, in a social context, their drinking is not perceived as problematic. The truth, however, is that any woman who drinks during pregnancy is at risk of having a child with FASD. Nothing about the social acceptability of the setting reduces this risk. After all, 'only drinks wine with meals' indicates the context of a woman's drinking but reveals nothing about the amount of alcohol consumed on each occasion. (Morrison et al., 2020)

Ironically, 'nicer', non-stigmatising attitudes and treatment may backfire. Simply assuming all will be well does not make it so. It may just mean cases of FASD that could have been prevented continued without proper warnings or early assistance.

Evidence is clear that the more stigmatised women feel because of their drinking (or drug use)

the less they trust health services. This creates the risk of delay in attending antenatal services or, at worst, nonattendance. (Roberts and Nuru-Jeter, 2010; Roberts and Pies, 2010).

Interestingly, many of the health professional respondents in the Howlett et al. studies (2017, 2019) reported being worried about the eventual stigma for children that so often accompanies an FASD diagnosis. A few even said they considered, or been convinced of, an FASD diagnosis yet made no referral to specialist services because of this stigma.

After talking to numerous midwives in Scotland over many years, one recurring theme is a disinclination to add anything about the mother's reported drinking in pregnancy to the baby's case notes. As noted earlier, phrases such as 'not wanting the baby to be labelled because of their mother's drinking' and 'giving the baby a fresh start' were common reasons cited. Interestingly, many midwives in the Schölin et al. study (2019) reported feeling that standardised screening questions could remove stigma for children.

The ripples on the pool of stigmatising (or hesitating to fully report pertinent information in case notes) are causes for concern. An Australian study of paediatricians (Elliot et al., 2006) reported 12% of respondents would not give a diagnosis of FASD, as they believed it could create stigma. A study in Ireland (Gill and Sharif, 2017) provided similar results. Conversations with clinicians have shown they will sometimes give a diagnosis of Attention Deficit Disorder (ADD) or another similar neurodevelopmental condition because they know there are services in their area for these diagnoses, but not for FASD. Although the motivation may be compassionate or even pragmatic, the question remains 'is withholding such information misguided?

Does it serve their patients well? Certainly, it precludes an accurate assessment/diagnosis, which, in an ideal world, would result in a referral to appropriate services. Misinforming parents or leaving them in the dark also reduces the chances of preventing subsequent alcohol-affected pregnancies.

It is a vicious circle. If children, young people and adults are not properly diagnosed, then the number of cases and the prevalence of FASD remain unknown and inevitably underestimated. In policy and resource allocation terms, what has been counted is what counts. Money, staffing and other resources for much-needed FASD-related services (not to mention FASD prevention) will not be provided.

Unfortunately, Scotland is a prime example of this reality. Although the Scottish Government estimated that 172,000 people currently have FASD (SIGN 156), fewer than 1% have ever been officially diagnosed or appropriately assisted and supported. Accordingly, while the Australian Government has allocated tens of millions to prevent and respond to FASD, the Scottish Government has allocated only 1% of that amount for FASD.

Guilt and shame are both exacerbated by stigma. As noted by Zabotka et al. (2017), guilt persisted 'no matter what the age of the child or the length of time since diagnosis' (2017.262). What has been shown time and time again is no matter how severely health professionals, teachers and others judge the birth mother of an FASD-affected baby, they will never judge her as harshly as she judges herself.

Most of us try to make sense of our actions. Birth mothers of children affected by prenatal alcohol exposure are no different (McBryde et al., 2021). Some adopt the disease model of alcoholism, whereby drinking is an addiction beyond their control. Others rely on advice from family and friends who reassure them drinking will not affect their child. For some, the mistaken belief that alcohol does not pass through the placental barrier reassures them and allows their drinking to continue without fear of negative consequences. Factors such as denial of the extent of drinking (and even denial of pregnancy) have also been reported (Friedman et al. 2007). Denial is a powerful defence mechanism, which we all use, particularly when we are frightened. These psychological and emotional barriers require understanding from health professionals - not stigmatising judgement.

The Effect of Partners' Drinking

It takes two people to make one person pregnant. The importance of partners' involvement in drinking during pregnancy cannot be overestimated. Whether the influence is positive, negative or mixed, partners matter.

For some health professionals, preconception health and pregnancy are still seen as relevant only to women (Coons et al., 2017). Recent evidence has concluded otherwise. For instance, alcohol affects sperm quality in long term drinkers. Changes in hormone levels occur, with decreased testosterone levels, as well as decreased sperm count and motility (Conderelli et al., 2015). Ricci et al. (2017) reported little effect in occasional drinkers, but heavy drinking showed a negative effect on sperm volume. The developing position is that exploring issues of alcohol affecting fertility in male partners may be an important part of preconception care (McPherson and Grieger, 2022; Verbiest and McClain, 2022).

A number of studies report partners who do not see their drinking as having any impact. Those who do not believe their behaviour has any effect on the pregnant woman may continue to drink. In subtle ways, they may even encourage their pregnant partners to continue to drink (May et al., 2005; Bottorff et al., 2014; Elek et al., 2013; Walker et al., 2011).

It is generally reported that the father's drinking is unchanged by pregnancy (Bailey et al., 2008; Borschmann et al., 2019). Even so, pregnancy can be seen as an opportunity to assess male drinking, not only to support their pregnant partners, but also to improve their own health, too (Leggat et al. 2021). The time has come to include men/partners from the time of preconception counselling onwards. Perhaps this can become an opportunity to encourage an alcohol-free pregnancy for both or even an opportunity to discuss effective contraception use if they want to avoid or delay pregnancy.

Age is also a factor. The evidence suggests older parents are usually more able to adjust their alcohol consumption than their younger counterparts (Liu and Mumford, 2017; Patrick et al., 2020). Important points noted by Patrick et al. include: 'Younger parents (e.g., ages 18–24) may require more support to reduce their drinking, possibly to address factors relating to things such as unplanned parenthood, difficulties with financial or other resources, and greater social pressure to drink heavily as is normative among their peers' (2020.1).

Not surprisingly, and now well recognised, are the effects of fathers who engage in heavy/problem drinking on their offspring, for example, stubborn and intransigent behaviour by 12 months of age (Edwards et al., 2001), problems at school (Adkinson et al., 2013), and anger issues in older children (Keller et al., 2022).

This may have as much to do with environment as other reasons, i.e., nurture not nature. It is easy to say, 'well you find that in any family'. However, bear in mind this is a family with a 'secret' a father/partner who is drinking in a problematic way and a mother who is trying to cope with it and to keep herself and her children safe. Secrets like this are far harder to hide when health professionals, such as community nurses and midwives, know the family. They are far more able to identify problems of this nature than health professionals who only see the family members in more anonymous, hospital settings.

Postnatal aspects of alcohol consumption

Breastfeeding

In relation to alcohol, the obvious immediate postnatal issue is breastfeeding.

Interestingly, paternal alcohol consumption is discussed in Horsley and Sturges' classic book 'Alcohol and the Human Body: An Introduction to the study of the subject and a contribution to National Health' (1908). Their view was that paternal alcohol consumption affected the baby's ability to suckle. However, according to Horsley and Sturges, this apparently only affected female children 'The rule is that if the father is a drunkard, the daughter loses her power of suckling' (p334). This text also touches on the possible intergenerational aspects with a suggestion of heredity, 'When a woman is unable to suckle, it is almost without exception that her daughter cannot do so, and the power is lost for all the next generation' (op cit).

Some of the original work in this area by Little et al. (1989) reported that, after controlling for gestational alcohol consumption, 'motor development was significantly lower in infants exposed regularly to alcohol in breast milk' (1989.425). Other studies have suggested alcohol changed the smell and taste of breast milk and may affect the baby's willingness to drink. (Mennella and Beauchamp, 1991). Alcohol does adversely affect the 'let down' reflex and reduces the amount of milk the baby will receive at the next feed. The quality of the milk is not affected but the amount available to the baby is reduced. When the mother drinks alcohol at the evening meal, the late-night feed is affected - with the result that the baby will wake up hungry, and earlier.

Other research suggests babies (4-11 weeks old) who were breastfed soon after the mother had been drinking, were found to have fewer hours sleep, were restless and cried more (Schuetze et al., 2002). Mennella and Garcia-Gomez (2001) found the disturbed sleep continuing for about three and a half hours after the feed. This study did show a dose response in that the higher the maternal blood alcohol concentration (BAC) the more episodes of distressed crying were evident in the baby.

Most of the evidence for breastfeeding is positive in terms of bonding. An Australian study on antenatal bonding used maternal substance use and mental health as predictors of postnatal bonding. (Rossen et al., 2016) reported: 'Substance use had no association with bonding postpartum' (2016.620). The authors note that the levels of consumption in pregnancy were small, and frequency of drinking was low. They go on to say that, in their study, stress and depression in pregnancy had a greater impact.

Two Scottish studies addressed the idea of whether knowledge and attitudes around alcohol affecting the infant had an impact on maternal behaviour in relation to breastfeeding. The results were mixed. (Dungy et al., 2008) included 49 women in an area of deprivation in Glasgow. The second study by Shaker et al. (2004) included 108 couples and found, not surprisingly, that women who breastfed had more positive views on the benefits of breastfeeding. Interestingly, they also found: 'Mothers of formula-fed infants were more likely to think that women who occasionally drink alcohol should not breastfeed' (2004. 260).

Attitudes towards whether alcohol consumption affected decisions to breastfeed are complex and varied. One factor that was reported by many studies was the myths surrounding breastfeeding and alcohol and how that impacts on maternal feeding practices. It used to be culturally believed wisdom that a glass of Guinness or Sweetheart Stout before the 6pm feed would help relax the mother and make feeding easier. By contrast evidence now shows that having a drink before breastfeeding inhibits the 'let down reflex' and reduces the amount of breast milk available to the baby.

If a mother who is breastfeeding wants to drink, then the current advice is to wait 2 hours after drinking before feeding the baby. However, this is a standard 'US drink' measure of 14 gms. In the UK, a large glass of wine equals just under two US drinks. This would suggest that a 3.5-hour gap between finishing her drink and breastfeeding would be more appropriate advice in the UK. The mother can either pump and store breast milk prior to drinking or wait for 3.5 hours afterwards. Yet, 3.5 hours is a long time and could well cause problems for either the mother or the baby in terms of feeding patterns. For a review of the issues on alcohol and breastfeeding, see (Greiner, 2019).

Up until this point, the main focus of this review has been on how best to identify women who may be drinking alcohol just before, or during, pregnancy. It has been on how to engage with them to achieve the healthiest outcomes possible for them and their babies. A key aim is to prevent alcohol-affected pregnancies and, thereby, reduce the incidence of Fetal Alcohol Spectrum Disorders.

By estimating that 172,000 children, young people and adults have FASD, the Scottish Government is implicitly conceding that FASD prevention has not been as successful as it could, and should, be throughout Scotland. That many people having FASD makes it inevitable that most, if not all of them, will have encountered community nurses.

However, 'seeing' those affected (across the age spectrum) does not guarantee that their FASD will be recognised and responded to properly. The QNIS/HPBL survey (2022) of community nurses and midwives revealed that awareness of FASD within their practice was lacking and therefore appropriate treatments and referrals are not being made. The good news is that the respondents are keen to both learn more and do more in relation to FASD.

The next section describes some of the physical and behavioural aspects of this spectrum disorder. It explores what FASD means for Scotland's health, education and justice systems. It considers identification, diagnosis and the long-term implications.

Section Three

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Fetal Alcohol Spectrum Disorder (FASD)

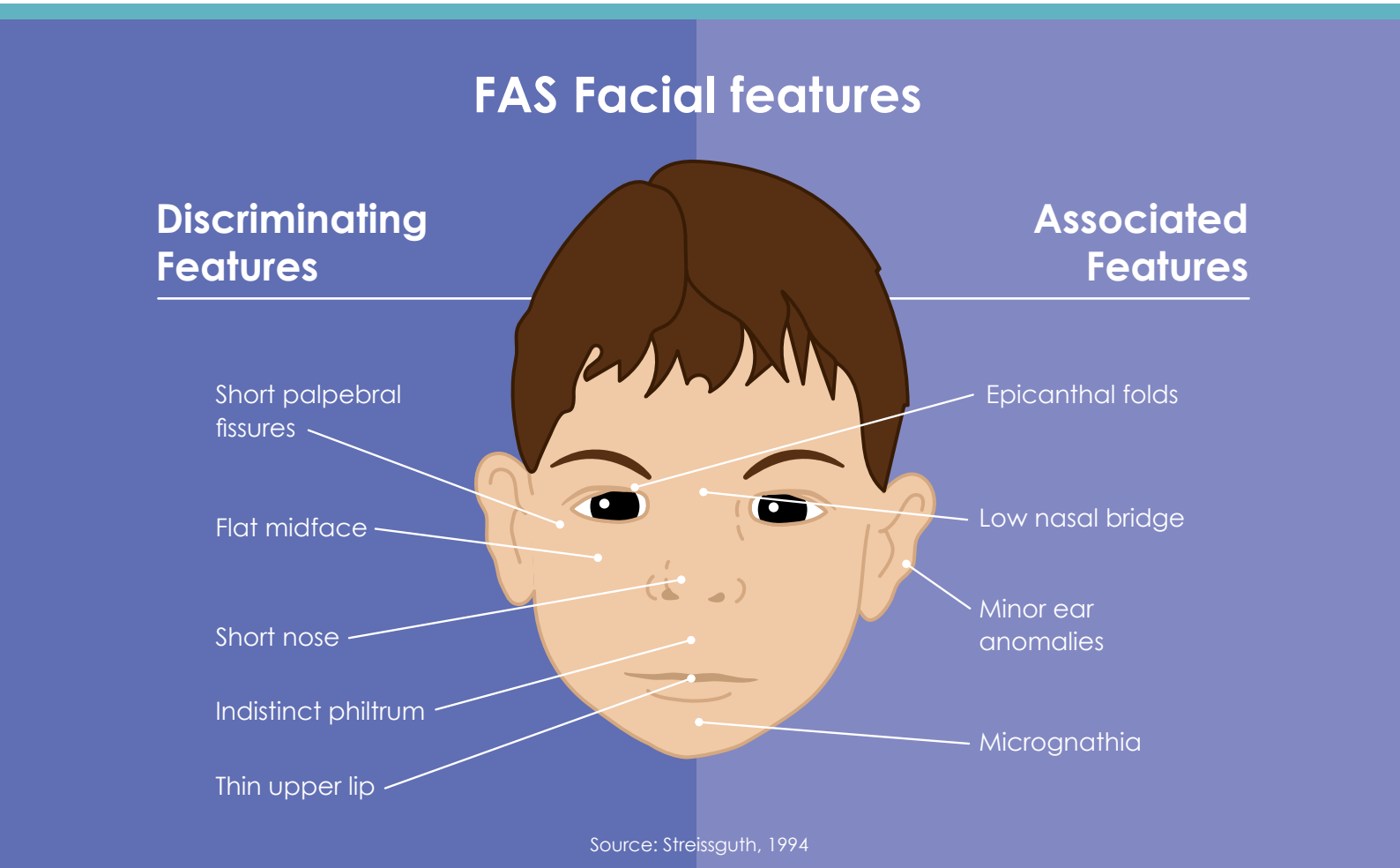
The diagnostic criteria for FASD are now well established (Jones and Smith, 1973; Astley et al., 2000a, 2000b; Charness 2022).

The most frequently used diagnostic tool comes from North America and is known as the 4-digit code (Astley and Clarren, 1996). The four areas include:

- Growth - including height, weight and head circumference
- Specific FASD facial features - including short palpebral fissures, absent philtrum, narrow upper lip, receding forehead and chin
- Brain domains
- Maternal drinking history

Recently there has been debate about the usefulness of including the second of these categories (facial dysmorphologies) in the diagnosis. That is because the presence or absence of facial features is a matter of timing. For the facial features to be present, the drinking had to take place at the time these specific features are being developed, i.e., gastrulation, defined as beginning in week 3 continuing to week 8 of embryonic development (Charness, 2022; Muhr and Ackerman, 2022). If a woman is drinking in the binge pattern, then she may not drink during the first seven days of the gastrulation period of foetal development. However, her subsequent alcohol consumption over the next five weeks, sometimes even before she is aware she is pregnant, may have an impact on the baby.

The question of how easy it is to identify these specific FASD facial features remains. It may not be a question of presence or absence of facial features but rather the ease of identifying them (Suttie et al., 2013; Muggli et al., 2017; Charness, 2022). Use of 3D imaging has now made it possible to differentiate between children with a history of prenatal alcohol exposure (but no visible, distinct FASD related facial features) and those with no such alcohol history. In other words, comparisons of controls from a general population against children with a known history of PAE (even if the facial features are not obvious to the naked eye), are clear with 3D imaging and can be identifiable at 12 months age (Muggli et al., 2017).



Source: Streissguth, 1994

Another measure in the 4-digit code, the palpebral fissure length (PFL), is usually measured with a ruler but it is not easy to measure. It can be challenging to hold a wriggling baby still long enough for careful measuring. Astley has quite recently acknowledged that many errors occur with clinician measurements, and that the only accurate way to measure the classic palpebral fissure length is with the use of photographic analysis. Astley states that the use of the traditional ruler is not accurate enough 'Direct measurement of the PFL with a ruler is very prone to error' (Astley, 2015.e9).

To further show the complexity of this seemingly simple measure, questions have been raised about the accuracy of 'normative' measures used as comparison for palpebral fissure length (Clarren et al., 2010). In other words, is the comparison measure that is being used an accurate one? A recent UK study by Howe et al. (2019) focussed on low to moderate drinking and matched this with maternal self-report questionnaires, the maternal genotype and high-resolution facial images. They concluded 'There is no strong evidence, in a sample representative of the general population, for an effect of prenatal alcohol exposure on normal-range variation in facial morphology' (2019.42). This raises questions over the significance of levels of alcohol consumption. Is it any amount of alcohol or only heavy drinking that is the issue?

The children in the Howe et al. study (2019) were 15 years old. It is well established that, as children grow older, these facial features so prominent in babies become less and less obvious. Nevertheless, recent results from a follow-up German study (Maschke et al., 2021) may show promise for identifying older children through facial analysis software. They used meconium biomarkers from birth to identify babies who had been prenatally exposed to alcohol, and facial photographic analysis software on adolescents aged 12 - 14 years-old. This research concluded that meconium was a robust measure for identifying PAE. However, as noted earlier, this can only identify PAE in the second and third trimester.

The potential benefits of using facial photographic software in the identification and diagnosis of FASD in older children is an interesting technological development. We now live in a world where soon facial features may be identified using apps on smartphones (Charness, 2022). However, until these technologies are employed by the majority of clinicians, the cost of 3D imaging technology remains out of range for most NHS budgets.

Although comparison of these studies and new technologies can seem like intellectual debate, there is a real-life impact. Many training courses persist in stating the importance of considering identifying facial features (including small palpebral fissure measurements, reduced or absent philtrum and thin upper lip) as a cardinal/ sentinel sign of PAE. They often suggest these can been seen by simply looking at the infant or measured by using charts. Unfortunately, it has become more and more apparent that confusion over how frequently facial features are identifiable is having a negative impact on babies and children, often being the reason, they fail to receive an accurate diagnosis.

FASD are spectrum disorders. Relying on visible facial features as a diagnostic criterion means that most children with neurodevelopmental harm related to pre-natal alcohol exposure will not be identified. Not being diagnosed translates into not getting the services and support they need. Around 90% of children with FASD do not present with the sentinel facial features defining the condition. Yet, many parents continue to hear 'he/she doesn't have the facial features, so it's not FASD' from misinformed health professionals. This has serious implications for identifying, treating and providing services for alcohol affected babies, children, and adults.

As seen in the examples above, diagnosis can be complicated, ranging as it does across the lifespan (McLachlan et al., 2015; Cook et al., 2016). Since first discussed in 1996 (Institute of Medicine) there have been a number of changes to the diagnostic criteria, mainly related to clarification of different aspects. More recently, the term Fetal Alcohol Spectrum Disorder was viewed as 'an umbrella term – rather than a diagnoses. This has since changed and FASD is now the accepted diagnosis for alcohol-affected or, more recently referred to as neurodevelopmentally impaired – children, young people and adults. In the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), FASD are recognised for the first time under the heading, Neurobehavioral disorder associated with prenatal alcohol exposure (ND-

PAE). For a clear discussion on the strengths and weaknesses of the different diagnostic terms, see (Kable et al., 2016).

Given how often a maternal alcohol history is either inaccurate, or missing altogether, there is a major lack of consistency among different diagnostic systems (Coles et al., 2016). As noted in Scotland's SIGN 156 Guideline: 'There are a total of 256 diagnostic codes arranged into 22 diagnostic categories in the 4-digit diagnostic code system' 2019.4). Seven of these 22 categories include 'alcohol exposure unknown'. This is particularly relevant for looked after, fostered or adopted children, since information on maternal alcohol consumption may not be available (Lange et al., 2013; Marcellus and Badry, 2021).

There has been much debate over the impact of the diagnosis of FASD. In the diagnostic term 'fetal' is problematic because it implies this is a neurodevelopmental condition that children will grow out of, but we know this is not the case.

The term 'disorder' can be problematic as it has negative connotations for many people. It may be worth exploring related discussions about Post-Traumatic Stress Disorder (PTSD) (Sagalyn, 2011). By moving to Post Traumatic Stress Syndrome (PTSS) and then Post Traumatic Stress Injury (PTSI), the term 'disorder' has been replaced. The term 'Fetal Alcohol Spectrum Injury' (FASI) would remove the stigma of this being a 'disorder'. However, as with all debates about terminology, there are pros and cons. A major consideration against this inclusion of 'injury' in the title is the risk of stigmatising maternal behaviour even more.

Whatever the diagnostic term used, evidence has shown the earlier the diagnosis, the better the outcome. Debate about the robustness of the diagnosis is not a good reason for stopping the attempt to clarify diagnosing this condition. As noted succinctly by Hanlon-Dearman (2021) early assessment and diagnosis allows for '... activation of appropriate referrals, optimizing medical management through diagnosis and management of co-morbid conditions, communication of the child's needs and anticipatory guidance with families and other providers, promotion of developmental and behavioural strategies with home and community, prevention and mitigation of future disabilities, prevention of future alcohol-affected children, and the development of a circle of support around the child and family.' (2021.88)

A more detailed consideration of these topics and of methods to identify the condition are well covered in the Scottish resources SIGN 156 and the NES (NHS for Education Scotland) eLearning resource on FASD. The links to them are in the Useful Websites section of this report.

What are the difficulties experienced by people diagnosed with Fetal Alcohol Spectrum Disorder (FASD) at different ages? Prenatal alcohol exposure affects the physical, psychological, behavioural and emotional dimensions of the person's life. The following section has been developed and refined over the years not only by such organisations as the original FAS/FAE Support Network Vancouver, but also by listening to parents, carers, siblings, health professionals, researchers and perhaps most importantly, the people who live with FASD every day.

Physical aspects

Source: FAAST.ed.ac.uk

FASD requires multidisciplinary assessment

FASD is a whole body diagnosis, and can affect the brain, central nervous system and physical development. Features include:

A 'patchy' cognitive profile with a 'disorganised' brain

3 or more affected brain areas of assessment/domains indicating CNS impairment (>2SD below the mean)

High variability from individual to individual

The complex comorbidities present with FASD are now recognised (Burd, 2016; Popova et al., 2016; Himmelreich et al., 2020; Del Campo and Jones, 2017). The physical problems experienced by many people with FASD have been identified, in part, by a group of young people with FASD.

Apart from the findings, the story is interesting and instructive about not underestimating what many young people with FASD can achieve. A group of them in Canada talked amongst themselves about the physical problems they experienced.

One of the young people said he had to leave as he had an appointment with his family doctor to get treatment for 'yet another' ear infection. Three of the other young people said: 'I have a lot of those too'. They began to compare medical histories and were surprised how many of them experienced similar physical problems. They decided to find out about other young people with FASD.

They thought given the age range they were studying the best way to do this was by using

the internet. With the help of Professors Joanne Weinberg and Ed Riley, and Jan Lutke who kept it all running smoothly these young people designed an online questionnaire. Their aim was to explore the idea of FASD being more than the learning and behavioural problems always talked about, or even the underlying neurological problems associated with FASD. Rather, they wanted to explore what they called a 'whole body diagnoses. This became 'the first extensive exploration of the broad health issues of young people and adults with FASD'. (Himmelreich et al. (2020. 191). All the information on physical aspects of FASD in the following section of this review came from this study.

The group of Canadian young people with FASD curious about a 'whole body diagnoses compared the frequency of many conditions in people with FASD to the general population of Canada.

The survey contained 260 items grouped into 26 areas. These included such categories as: Auto immune and endocrine disorders, cardiac problems and difficulties involving bones, muscles and joints. Problems with vision and hearing were also included, along with other sensory problems, seizures, sleep disorders, problems with 'executive functions' of the brain and mental health. See below for some of their findings;

CONDITION: Auto Immune Disorders	Times higher than general population
Rheumatoid Arthritis	12
Celiac Disease	4
Crohn's Disease	4

CONDITION: Other Immune System Conditions	Times higher than general population
Asthma	4
Allergies (any)	1
Carrying an Epi-pen	4
Chronic Sinusitis	3
Chest Infections	2
Chronic Ear Infections (adults)	143

CONDITION: Problems with Hearing	Times higher than general population
Hearing loss as children	58

CONDITION: Other Sensory Problems	Times higher than general population
Acute Sense of Smell	55
No sense of smell	9
Doesn't like the texture of food	54.2%*
Do not often feel hunger	35.2%*
Seizures Disorders	21
Migraine headaches	2.4

**No comparable number for the general population. This is the % of respondents reporting this variable*

CONDITION: Sleep Disorders	Times higher than general population
Problems Falling Asleep	7-14
Problems Staying Asleep	6-11
Sleep Apnoea	6

CONDITION: Cardiovascular Problems	Times higher than general population
Congenital Heart Defects	23
Child Heart Surgery	15
Hypertension (ages 18-44 years)	2
Supraventricular Tachycardia	27

CONDITION: Bones, Muscles, Joints	Times higher than general population
Scoliosis	7
Joints always hurt, 'make a noise'	3
Osteoarthritis	4
Gout	10
Cleft lip and/or palate	26

CONDITION: Problems with Executive Functioning of the Brain	% of Respondents reporting the variable
Problems with Short Term Memory	79.8%
Problems with Long Term Memory	69.3%
Problems Paying Attention	88.3%
Problems Making Decisions	86.0%
Difficulty with judgement	80.7%
Difficulty understanding what people mean when they speak	68.8%
Difficulty understanding what they read	68.3%

More recent work is beginning to report that young people with FASD are developing diseases such as arthritis, previously thought to be only present at an older age. For instance, consider the reports from parents and carers who were told by health professionals that their 21-year-old with FASD, now in a wheelchair because walking is so painful, cannot have arthritis 'because she is too young' (Personal Communication).

A concern has even been raised about the possibility of early onset dementia among FASD-affected people in their thirties (Clarren: Personal Communication). According to the Himmelreich et al. study (2020), premature menopause is 58 times higher than in the general population.

Epigenetic evidence suggests inflammatory processes are linked to autoimmune conditions and infections, which can be severe and longer lasting (Popova et al., 2016; Himmelreich et al., 2020). As noted above, a good example of this is the frequent occurrence and severity of ear infections.

Confusing this picture (and adding to potential misunderstandings between the young person with FASD and health professionals) is the issue of heightened sensitivity, or lack of sensitivity, to pain. Many of these young people do not experience pain in the way health professionals recognise. This may lead health professionals to ask themselves: 'Can it be that serious if he/she is not feeling much pain?' However, numerous ear infections in this subpopulation are often undiagnosed and, therefore, untreated. This may eventually lead to hearing loss.

Undiagnosed and untreated hearing impairment can lead to learning and behavioural problems at school. Often, these children are seen and treated as lazy or inattentive, when the reality is that they are not hearing whatever is being said. Sadly, some children and young people with FASD simply stop trying and just accept the teacher's view of them. As with any spectrum, there are major variances in what people with FASD perceive - one size does not fit all. An individual's level of pain is an extremely personal sensation. Yet, for people with FASD, their own experiences are too often dismissed.

For FASD-affected children entering the education system, life can become fraught, as is also true for their parents/carers and teachers (Blackburn 2021; Millar et al., 2014; Kully Martens et al., 2012; Olswang et al., 2010). Any checks that can be carried out to ensure hearing and vision are as good as possible, along with actions taken to improve a student's sensory experience at school, would be of real benefit.

Taking another example of inflammatory processes, there may be long term effects to viral infections such as 'flu' (McGill et al., 2009; Carpenter et al., 2014; Lussier et al., 2021). How people enduring Long Covid are being impacted is still to be determined.

As reported in the Himmelreich et al. study, sleep problems are very common in people of all ages with FASD. Around 85% of children between the ages of 4 and 12 years of age experience serious sleep disruption (Chen et al., 2012). Frustration, exhaustion, and lack of sleep can heighten the inherent risks/difficulties of FASD. If the child isn't sleeping, then the parents, or even the siblings, can be adversely affected too. A common concern raised by parents and carers is how many health professionals do not take concerns and complaints about years of sleepless nights to be a serious problem.

Potential FASD Behavioural Indicators by Age Group

Beyond the bodily manifestations of FASD, the behavioural dimensions are lifelong and life-altering. For instance, throughout life, a failure to grasp, and be influenced by, the concept of cause and effect can be frustrating for young people themselves. The same is often the case for their parents/carers, siblings and, as they grow older, their teachers and work colleagues. Telling a child with FASD how to tie their shoelaces isn't done just once or twice, but over and over and over again. For them, and the person trying to teach them, this leads to frustration and exhaustion.

There are myriad ways in which behaviour is impacted by FASD. In part, that is a function of it being a spectrum. But it also varies by age.

Birth to 36 months

- May have been diagnosed as 'failure to thrive' (one of many diagnoses given over time).
- Difficulties with feeding.
- Difficulties in establishing a regular sleeping pattern.
- Irritability very active/hyperactive.
- Frequent bouts of illness.
- Delay in reaching developmental milestones.
- Indiscriminate; people are interchangeable.

3 to 5 Years

- Easily overwhelmed.
- Frequent and lengthy temper tantrums.
- May react in a physically aggressive manner.
- Reacts badly to and resists change.
- Unable to learn from experience.
- Accident prone.
- Fearless/unable to comprehend danger

6 to 10 Years

- Concrete thinkers – tell a 7-year-old with FASD to 'pull your socks up' and they don't hurry up, instead they will do exactly what you say - pull their socks up.
- Visual memory better than auditory memory.
- Information seems to 'slip in and out', e.g., remembers today, forgets tomorrow and remembers again next week. Imagine how this is interpreted by teachers?
- Difficulty separating fact from fantasy.
- Mood swings.
- Difficulty with self-regulation.
- Problems with planning and the sequencing needed in a lot of tasks.
- Needing constant reminders for basic living tasks.
- Confabulating - making up stories to explain the gaps in their memory.

10 to 14 Years

- Initially may be seen as intelligent, based on language skills.
- Lots of words but quantity masks quality.
- Speech problems, e.g., stammering.
- Gets lost quickly in conversation and loses interest.
- Trouble following directions.
- Little understanding and adherence to social norms.
- Increased risk of alcohol/drug use.
- Difficulty in reading social cues.
- Falling significantly behind at school.

14 to 18 Years

- Minimal sense of personal space or boundaries.
- May be sexually inappropriate/does not understand risks.
- Overly affectionate with people s/he does not know well.
- May be teased or bullied by other adolescents.
- May, in turn, bully or frighten others.
- Moves through extremes of behaviour in a short space of time.
- May be diagnosed as having a 'Conduct Disorder'.
- Burns even patient people out.

Adulthood

- Judgement and critical thinking are poor.
- Lacks social skills; either aggressive or withdrawn.
- Blames others for their own mistakes.
- Involved in criminal activity, usually low level and repetitive.
- Difficulty in keeping a job.
- Abusive relationships.
- Mental health problems such as:
- Depression
- Anxiety

It is crucial to remember, time and time again, this is not wilful 'bad behaviour'. Rather, it is brain damage. Seeing a young person with FASD banging his fists against his head and repeating over and over again 'I'm stupid, stupid, stupid', it becomes clear that the frustration is not only with the parents, carers, siblings, and teachers, but that it is felt most powerfully within the young people themselves.

An example of this is the young boy who had an appointment with the school counsellor. His mother put a note in his school bag reminding him of this appointment at 9.45. Later that afternoon, the counsellor phoned the mother and said he didn't come for the appointment. When her child got home, she asked what happened. 'Did you lose your watch?' (a not uncommon occurrence), 'No, but you said 9.45. I looked at my watch and it said 9.35 then, when I looked again, it said 9.50. 9.45 never came'.

Such behaviours are repeated day-in and day-out, year-in and year-out. A diminished capacity to 'learn from experience' is a hallmark of a problem with the 'executive functions' of the brain. In turn, impaired execution functions are characteristic (to varying degrees) of children, young people and adults with FASD.

Being a neurodevelopmental condition means that programmes such as behaviour reward may be less successful for people with FASD. It is important to remember however, it is not because the parent is doing it wrong or not trying hard enough.

If these types of interventions are tried, the reward for positive behaviour must be given immediately. Telling a child with FASD that if they behave well all week, they can go on the school trip next week, will not work. The reward is too far away for them to connect with behaviour today. Add this to the tiredness which accumulates over the week, and many children with FASD will start to become more disruptive or withdrawn by Friday classes.

Along with noting frustrations about poor time management, everyday living skills and impulsivity; parents and carers will also describe their children's strengths. They describe their resilience, a sense of humour, compassion and caring, and a willingness to learn and work hard.

Another problem for the parents is that their child may manage to behave quite well at school, but when they get home, the pressure cooker they have been kept under control at school is released. It is certainly true that many teachers or health care providers will say to parents 'Oh, he always behaves well here'. That's great, but it is important they do not disbelieve the parent's far more dysregulated picture of the child's behaviour at home. It is also vital that the health professional does not interpret this as the parent not parenting well. Parents have enough to cope with; they do not need or benefit from negative, blaming messages.

A classic example of why FASD distorts 'normal' home routines involves bedtime. Telling most children to 'get ready for bed' is simple. By contrast, for many children with FASD, that simple instruction actually means:

1. Going into the bedroom
2. Taking off their clothes
3. Putting on their PJs
4. Going to the toilet

5. Washing their hands
6. Washing their faces
7. Cleaning their teeth

Not one message, but seven. And usually, they all are supposed to be carried out in order.

Adults with FASD involved with the Criminal Justice System

Difficulties with executive functions of the brain have profound and enduring consequences for people affected by FASD. An inability to:

- control impulses
- plan actions
- anticipate reactions
- learn from experience

- can all cause problems throughout every situation and stage of life. And yet, it matters in some circumstances more than in others.

Not understanding the concept of cause and effect can sadly lead to involvement with the criminal justice system. As noted by Popova et al. (2015), individuals affected by FASD are 19 to 40 times more likely to become involved in the criminal justice system. As with so many aspects of this neurodevelopmental condition, the relationship between FASD and the criminal justice is complex.

The legal system wants a simple diagnosis, clear cut and unequivocal. An FASD diagnosis is not like that because it is complex and varied across this spectrum. In addition, the problems encountered by young people with FASD often change over time.

Much of the work carried out on this topic comes from the US and Canada. However, North American justice systems often differ from those in other countries. A recent review by an Italian group provides a good overview (Sessa et al., 2022), as does an excellent report by the Chief Science Advisor for the Justice Sector to New Zealand's Prime Minister (Lambie, 2020).

An example of how court systems and young people with FASD clash is highlighted in the story of a young woman who had been arrested and charged with shoplifting many times. When she appeared before the judge, he asked why she was back in his court yet again for shoplifting. She always stole from the same shop, and he couldn't understand this. She seemed surprised, saying: "But I didn't steal from that store. I stole from a different one". (Personal Communication).

To health professionals and those in the criminal justice system who are unfamiliar with FASD, that story is not believable. They are likely to interpret the young woman as being cheeky and disrespectful. However, she genuinely thought the situations were different. She simply couldn't fathom that just because a behaviour was illegal in one situation that didn't mean it was also illegal in any situation. (Cox et al., 2006; Brown et al., 2011; Douglas et al., 2012; Douds et al., 2013; Mutch et al., 2016; Pei et al., 2018).

People with FASD are highly suggestable and they confabulate. Their pressing need to please means they will give the answers they think the police or courts want to hear, which may be far from the objective truth. In general, young people with FASD differ from other people involved in the criminal justice system because they tend not to escalate from minor crimes to more serious ones. Indeed, if they are imprisoned, then it is often because they have not been attending regular contacts with the person designated by the court.

Some criminal justice systems are acknowledging the complexities here and putting training and support in place.

Even behaving in a way that their parents taught them (and they remembered) can get a young person with FASD in trouble. Take Jason (currently on probation) who is walking along the street when he sees two men struggling to lift a very heavy container onto the back of a lorry. His parents taught him to be helpful, so he responded by helping them lift the container onto the lorry. Unfortunately, the two men were stealing a federal post box! Jason was now in trouble again because his 'helping' was considered a breach of his probation.

The ideal would be a criminal justice system flexible enough to allow the judge leeway to decide on how best to handle such a situation. Scotland's judicial system has more leeway than many. However, people with FASD in Scotland rarely have an official diagnosis that the judge or justice system can take into account as a mitigating factor.

In a strange twist, children with FASD are often described as 'innocent victims' of alcohol exposure while a foetus. This is most likely to occur when the mother is blamed as the 'guilty party'. Ironically, even though FASD cannot be cured or outgrown, affected adolescents and adults are usually deemed responsible for their own behaviour and are labelled as deviant, wilful wrong doers (Dej, 2011). 'Fetal' being in the name of this condition neither implies it only exists while still a child, nor that those affected have become 'bad' instead of remaining neurodivergent.

Life Expectancy of People with FASD

A recent study carried out using a FASD patient record database in Alberta, Canada (Thanh and Jonsson, 2016) reported startling and concerning results. The average life expectancy of people with FASD was 34 years.

The leading causes of death were classified as 'external' causes, i.e.:

- suicide - 15%
- accidents - 14%
- poisoning by alcohol or illicit drugs - 7%
- nerve problems – 8%
- respiratory problems - 8%
- congenital malformations - 7%
- disease of the circulatory system - 4%
- mental and behavioural disorders - 4%

Very early onset dementia could be related to the initial cognitive deficits experienced by some on the FASD spectrum (Moore and Riley, 2015)

Life expectancy for people with FASD is an area in which little research has been completed. One reason is the extent of undiagnosed or misdiagnosed cases of FASD. Knowing much more about who has FASD is the prerequisite for better understanding their lives and deaths.

Effects on Parents, Carers and Siblings

Two studies from North Dakota showed disturbing results (Burd et al., 2008) The findings note: "The diagnosis of an FASD appears to represent a common and under-appreciated risk marker for mortality in diagnosed cases of FASD and their siblings" (2008.222). A related study (Li et al., 2008) also addressed mothers of children with FASD and reported: "FASD is an important risk marker for increased familial risk of premature mortality in the affected child, siblings, and the mother".

There were issues and limitations in these two studies acknowledged by the authors. Both studies included only that state's population, using the North Dakota FASD Registry. Whether the results would be similar in other locations is unknown. North Dakota is a mainly rural state with the largest minority group comprised of Native Americans.

Causes of death were unknown for some of the siblings. They may have also been affected by prenatal alcohol exposure. Some of the mothers will have had a serious alcohol problem affecting their health and longevity. Nevertheless, these are important studies, and more attention needs to be paid to the health of siblings, as well as other family members and carers. The point of raising this topic is to emphasis the reality that FASD is a condition that affects whole families and can also affect more than one generation. This is the case even though no 'FASD gene' has been identified. As succinctly concluded by Flannigan et al. (2022): "Fetal Alcohol Spectrum Disorder represents the intersection of complicated biological, family, community, and societal circumstances that increase risk for social inequity, intergenerational trauma, and health disparity" (2022. 5).

Many families impacted by FASD describe negative societal attitudes toward them that influence increased chronic stress and isolation for them and their child (Paley et al., 2006; Rutman and Van Bibber, 2010; Bobbitt et al., 2016; Domeij et al., 2017). Accordingly, self-care for parents and carers of people with FASD is a vital, but often overlooked, concern (Kautz et al., 2020). The necessity for supporting parents, carers and siblings is crucial and is starting to be recognised and responded to by parent/peer support groups (Black, 2021).

Very little research exists on siblings of children with FASD, but useful information is found in the work of Leedham et al. (2020) into siblings of young people with autism. Their conclusions fit well with the anecdotal evidence and frequent experiences of siblings of young people with FASD. They conclude: "Findings suggest a sense of agency, understanding Autistic Spectrum Condition (ASC), time spent alone with parents, supportive environments and the chance to relate to other siblings as protective factors in facilitating positive

psychological wellbeing for siblings of autistic people" (2020.1).

It is increasingly realised that key family members (biological or de facto) should be invited and integrated into the 'team' around a person with FASD. Most successful services use a person-centred approach, and this is generally appreciated by the family members involved. Sometimes, they complain that the medical terminology some health professionals use creates a barrier amongst those who need to work together for the benefit of the FASD-affected person. In Canada, where work in this area has been going on for a long time, families recommended changes needed (Alberta FASD Cross Ministry Committee, 2020). These included:

- better accessibility of services
- additional services and support
- improved communications between all parts of the team
- reduced time between seeing health professionals (especially during the diagnostic process)

Unsurprisingly, greater FASD awareness and training were also listed. Although Canadian, these recommendations are now being echoed in Scotland.

The inclusion of parents/families can be central to the success of any FASD diagnosis, treatment, and support activities. Being asked: 'What is life like for you right now?' then having that person take the answer seriously can be life changing. The reaction can be along the lines of: 'At last someone is truly listening to me, rather than telling me what I am doing wrong or describing techniques that I have tried over and over again with no success'.

Giving credence to the views and lived experience of people affected by FASD and their families is not just polite, it is essential to understanding what's true and what to do. Take the case of an adoptive family who found out about the birth mother's drinking history. They asked the health professional whether this fact could help explain some of their child's problems, such as failure to thrive. Imagine their reaction on being told: 'No matter what the mother did when she was pregnant, it couldn't account for this child's problems. You are just not feeding him enough' (Personal Communication). It remains a real possibility that the birth mother drinking heavily during pregnancy was causally related, especially since she recently died from alcohol-related causes. Who benefits - while struggling to help their adoptive child - from their concerns being dismissed and instead being told they are bad parents?

Diagnosis or label?

A good example of the implications of these two words was witnessed when visiting a clinic in Vancouver. A little boy with FASD was being cared for by his grandparents as his mother had died a year earlier from alcohol-related problems. The child's grandmother wanted a diagnosis because she felt it could help get access to services. His grandfather did not want a diagnosis because he believed nothing would change, except that his grandson would be stigmatised and bullied even more at school (Personal Communication).

In addition to the stigma experienced by the parents, carers and siblings of young people with FASD, it is also felt painfully by the child, adolescent or adult with FASD. One way of ameliorating this problem is through the use of appropriate language. There are a number of language guides that have been created to help health professionals, teachers and other involved adults (CanFASD. 2016; FASD Hub, 2019; Seashell and the National Organisation for FASD. 2020). The CanFASD network has recently (2022) updated their guidelines for writing and talking about FASD, which may be helpful when discussing the issue with colleagues. Details are in the 'Useful Weblinks' section.

Conclusive Evidence or Moral Panic?

We still live in a world where there is ongoing debate about whether use the word 'fetal' in the diagnosis is misleading. This is not a condition that only affects babies. People with FASD do not 'grow out if it'. There is also still debate about whether alcohol is the sole casual factor for this condition. Therefore, the question occasionally arises about whether either 'fetal' or 'alcohol' should explicitly be in the name/diagnosis? It has long been said 'Do not name a new condition after what you think causes it, as subsequent evidence may well change that'. It is believed by some that focussing on solely on alcohol, could have the effect of inducing 'moral panic' (Armstrong and Abel, 2000; Golden, 2000; Bell et al., 2009; Rizzo and Racine, 2017).

Yet, focussing on alcohol as being the only variable that matters is still used by governments across the world. Why? On the one hand, there are no credible recorded cases of a person having FASD who was not exposed to any alcohol at any time during pregnancy. On the other hand, it is convenient for governments to be able attribute full responsibility to individual women and, thereby, avoid their responsibility for addressing such contributing, structural causes as social inequalities and poverty.

A 2013 article by May et al. noted the complexity of concentrating on one factor - alcohol – over many others. These authors highlighted 'the complex relationships between alcohol use, maternal health, nutrition, social environment, biological, and genetic influences on child development' (2013.323). In a thoughtful article by Price and Kelly (2015), the authors conclude 'political inactions and dire social need are the primary drivers in the FASD field' (2015.424). Few would disagree that alcohol use in pregnancy is fundamentally a public health issue.

These examples are provided to show the complexity of making this diagnosis. There is no 'one size fits all' for any spectrum disorder. Larger societal factors, such as maternal nutrition, socio economic status (SES) and stable home environments, play major parts. The evidence that FASD usually exists alongside other neurodevelopmental conditions underscores the complexity of making a diagnosis. By definition, co-morbidities have different causes and manifestations, and this only strengthens the need for good preconception and postnatal care and support. The manner in which public health has previously, and is still, dealing with FASD has been defined by some critics as a 'moral panic', i.e., being unnecessarily alarmist by exaggerating the risks of prenatal alcohol exposure. It would be unwise to dismiss such criticism. There is no credible evidence proving that 'If the mother only drank one glass, it could still harm her baby. We may not see any effect yet, but we will as the child becomes older'. Such claims are based primarily upon a desire to 'prove' not only that FASD exists, but also that the responses to the risk should be extreme.

As noted earlier in relation to screening tools, exaggerating the risks of prenatal alcohol beyond the evidence (and conflating any drinking and heavy problem drinking) will backfire. Health and public health professionals, as well as members of the general public, might feel inclined to dismiss the whole idea of prenatal alcohol exposure being risky for the unborn child.

That would be wrong, too. FASD is real, is potentially preventable, and does matter in the lives and life chances of those who are affected. Mass media also bears some responsibility here. It is commonplace to see 'debates' about alcohol during pregnancy that pit two extreme positions against each other; neither of which is supported by the evidence.

Care needs to be taken not to return to the idea that the woman is simply the vehicle for the unborn child. The woman has rights of her own and they should be respected. Not recognising or disrespecting these rights may lead to problems in the woman's relationship with health professionals.

Both human and animal models provide compelling evidence that heavy prenatal alcohol exposure can have a causal relationship with lifelong, adverse impacts upon the baby. Even so, there are many variables involved, some of which may not yet be known. As Donald Rumsfeld, White House Chief of Staff during the George W Bush administration famously said 'There are known knowns, things we know that we know; and there are known unknowns, things that we know we don't know. But there are also unknown unknowns, things we do not know we don't know' (Rumsfeld 2002). He was laughed at, but he was right.

Recognising the gaps, the contradictions and uncertainties, is simply acknowledging the facts. They do not weaken the case for preventing or for responding well to FASD. Being careful not to exaggerate or make false claims reduces the risk of people dismissing FASD as 'moral panic' or 'just another way to see women's prime role in life as having children'.

New technology and robust clinical, public health and social science work are ongoing. Cognitive dissonance can occur when we encounter ideas and views that do not conform to one's existing world view. This can happen when exploring the research evidence in the fields of prenatal alcohol exposure and FASD. People struggle until they can fit them into the box they create; the one making people most comfortable. In other words, the

place that reduces cognitive dissonance.

It is commonplace for people to fall prey to 'confirmation bias'; that is, only 'finding' the evidence that fits their current opinions and world view. This report is intended to help readers consider and stay with discomfort while exploring ideas previously unknown or dismissed out of hand.

At this point in time, the honest statement is 'With small amounts of alcohol during pregnancy, we just don't know the impacts yet – so, until we do, the wisest decision is to stop drinking'. This is simply an application of public health's 'Precautionary Principle'. Alcohol during pregnancy may be a risk, but the outcome, positive or negative, for an individual pregnancy is not a certainty either way. Even for some women that drink heavily or have an unhealthy binge drinking pattern - not every baby of theirs is guaranteed to have FASD.

There is still work to be carried out in this field. Moving too quickly in directions that the evidence does not warrant would be a mistake. One example of this is unnecessarily referring women for alcohol brief interventions i.e., alcohol treatments. A sensitive, careful discussion with her about drinking and the wisdom of stopping until after her baby's birth may be all that is needed.

Published research on alcohol in pregnancy may be distorted or exaggerated by the media to fit their own views and agendas. Researchers must guard against extrapolating beyond the results of their study population (Lee et al. ,2016). The reality is it may never be possible to measure the effects of low levels of alcohol consumption as beyond a certain point there are far too many other variables which may have a greater impact on foetal health.

Section Four

THE QUEEN'S NURSING INSTITUTE SCOTLAND

Opportunities for Prevention

Some evidence suggests that women who abstained from consuming alcohol during pregnancy, or were light drinkers' pre-pregnancy, did not change this behaviour after childbirth. It also suggests that women who were drinking more heavily are at risk of increasing their drinking again after the birth of the child. For instance, one of the few studies that followed up women over a 21-year period of their reproductive life course (Tran et al., 2014; Tran et al., 2015) found heavier drinkers apparently consumed moderate levels of alcohol while breastfeeding.

Results from the Tran et al. studies also showed a 'high level of stability for abstainers and low-stable drinkers, but changeability for moderate and heavy-escalating drinkers over their reproductive life course' (2015.45). Drinking started to increase in the moderate drinking group but remained at a moderate level in the three follow up interviews at 5, 14 and 21 years. In the heavy-escalating group, the results were markedly different. By the time the child was around 5 years-old, this group of heavier drinkers markedly increased their drinking to the UK equivalent of 24 units a week. This would place these women at increased risk of developing an alcohol-related health problem. Furthermore, any subsequent children would be at higher risk.

Other work has highlighted the importance of looking out for issues, such as depression in new mothers, as a factor in increasing alcohol consumption (Liu et al. 2014). In all these cases, community nurses (with their ability to follow up with women beyond the initial postpartum period) have an opportunity to identify needs and opportunities to provide early intervention. research also shows the importance of interconception education, counselling and care in advance of any subsequent pregnancy. Evidence has been available for many years now that if a woman who has had one FASD-affected child continues to drink, each subsequent baby of hers will be more severely affected.

Attitudes of Health Professionals

As previously noted, the attitudes of health professionals are of key importance in developing a relationship with the women in their care. However, one aspect of practice often not addressed is the issue of secondary traumatisation of health professionals working with patients who have life histories of trauma in its many forms.

It can be difficult and stressful for any health professional, including community nurses and midwives, to become aware of these stories. (Read more about this here on the QNIS website).

The reality is that some health professionals will have their own personal histories of trauma. In a U.S. study by Butler et al. (2018), graduate clinical social work students reported substantial levels of adverse childhood experiences (ACEs) in their own lives. These included close family members experiencing psychiatric illness, parental divorce and alcohol or other substance misuse.

Working with parents and carers of children living with FASD can increase stress for community nurses, midwives and other health professionals. This is especially true when they can see the pressing need for services, which at this point do not exist. The Queens Nursing Institute Scotland has been a leader in self-care among professionals, e.g., the 'Booklet' (available here) and Capacitar could benefit many health professional organisations and their staff members. They can become examples of positive role modelling for professionals and, by extension, for their patients.

Assisting Community Nurses and Midwives

Almost without exception, surveys of nurses and midwives have reported that more initial education, continuing professional development and other training around alcohol, preconception health, pregnancy and FASD would be both beneficial and well-received (Butler et al. 2016; Howlett et al., 2017b; Coons et al., 2017; Schölin and Smith, 2019; Howlett et al., 2019a, 2019b; Schölin et al., 2019; QNIS/HPBL, 2022). As concluded in the recent study by Schölin and her colleagues "Findings suggest that interventions aimed to improve midwives' knowledge, skills and clinical confidence to deliver alcohol advice appropriate for the level of risk of the woman's drinking may facilitate midwives' practices" (Schölin et al., 2019.6).

The topic of alcohol is often seen as fraught by health professionals. Yet, when women are asked how they feel about being questioned about their drinking, most say they are okay with it, if it's perceived as non-judgemental. Some even welcome it, especially if they believe the information can help other women. Even women who have given birth to a baby with prenatal

alcohol exposure (PAE) will say they would not have minded being asked about their drinking and would have welcomed information about the effects of alcohol. However, it must be borne in mind that although some women would not have minded being asked, they are now looking back through a different lens; one which includes caring for a child with complex needs.

As with all health professionals, community nurses and midwives may benefit from sharing experiences on how to engage positively with those patients previously labelled as 'difficult'. This is ideally done in triads or peer groups designed to encourage learning from each other. The newer or less experienced can learn from the more experienced about what has and hasn't worked well. When these situations feel safe enough to participants, difficult issues can be more readily explored, and important lessons learned.

It is interesting to note that in the FASD survey by QNIS/HPBL (2022) of an illustrative sample of Scotland's community nurses and midwives, the largest group of respondents had been employed for 25 years or more, and almost 90% are employed within the NHS. This wealth of experience is an advantage. Even so, those employed for 5 years or less have an important part to play in confirming or questioning the conventional wisdom.

In asking about drinking, as in any therapeutic interaction, what matters is the relationship. Community nurses develop good professional relationships with their patients in different areas and at different ages. They can develop close, positive relationships that enable the collaborative, non-judgemental approach necessary for asking sensitive questions. Community nurses also have a much broader view of the woman's life beyond the fact she is pregnant or planning a pregnancy. They see, for example, if she has a history of poverty, domestic abuse or child abuse. They may even know the parents, partners and relatives of the woman with whom they are now working.

This opportunity to view any situation in a more holistic way is very valuable. To be able to connect the multitude of problems some pregnant women experience is necessary to provide appropriate help (Schölin and Fitzgerald, 2019). And yet, some health professionals feel ill-prepared to engage confidently and competently in such potentially sensitive conversations. CPD (Continuing Professional Development) and assistance in mapping out the complete picture and identifying priority areas can reduce the sense of being overwhelmed and powerless.

One thing learned through Covid-19 is that online webinars, weblinks, and even YouTube videos, can be of great value in learning. They can be particularly useful when geography and pressure of time makes gathering everyone getting together in one room unfeasible.

Respondents to the recent QNIS/HPBL survey (2022) suggested a few possibilities as to methods of future training. These included a series interactive webinars and podcasts that allow discussion. The idea of courses with completion certificates was also suggested as a good way forward. This useful survey also noted desired topics, such as knowledge of FASD in children under 5 years-old, FASD-affected adults, the care of women with alcohol-related problems, as well as help with trauma-informed care.

Initial education and CPD on general alcohol issues, and taking alcohol histories, in particular, has consistently been reported as necessary to reduce of prenatal alcohol exposure and FASD. Schölin et al. (2019) revealed that most UK midwives they surveyed received fewer than 4 hours training in this area, with some having received no training at all.

The QNIS/HPBL (2022) survey asked substantive questions about FASD and found the level of knowledge was mixed:

- 98% of responding community nurses and midwives agreed it was 'False' that 'FASD only affects children and young people because people grow out of it'.
- Over 60% did not know that 'Only about 10% of people affected by prenatal alcohol exposure have unusual facial features or other visible indicators of FASD'.
- Only 25% of respondents did not believe that the false assertion that 'people can have either FASD or ADHD but not both'
- Around 30% were unsure whether all people with FASD 'have a lifelong

neurodevelopmental disorder affecting many areas of their lives'.

The need for a holistic view and continuing professional development on alcohol during pregnancy and FASD is now clear. Alcohol is a lifestyle issue which, if and when addressed compassionately and well, may help woman in a number of situations. It could help a woman living with domestic abuse feel less lonely; a woman with a party lifestyle feel she can change without becoming isolated; or a woman who does not want to be pregnant feel able to talk about her true emotions.

The holistic view of the pregnant woman's context and circumstances increases the chances of helping and supporting her toward a healthier pregnancy and a better life for herself, her baby and her partner.

Another key to success in dealing with alcohol, pregnancy and FASD is for health professionals to have a well-developed set of listening skills. This includes not only active listening, but also showing the woman she is being heard. There are significant benefits in embedding such skill development within initial education and CPD.

Health professionals' awareness of their own attitudes towards drinking in pregnancy matters. If negative, these attitudes can discourage the woman from being honest in answering alcohol-related questions. Disguising negative attitudes is difficult and women can usually discern them.

The attitudes of professionals are conveyed not only in the words used, but also in tone of voice and body language. People are sensitive to the messages they perceive from providers' facial expressions and other non-verbal clues, especially when they are already nervous or uncomfortable.

The tried and tested ways of education and skill development, such as face-to-face lectures, discussion of vignettes and the use of triads are still relevant. They can enhance both competence and confidence. Effective, critical self-assessment and self-reflection are important in enabling personal and professional growth, learning and improving practice.

Community nurses and midwives are generally principled pragmatists, who may welcome the opportunity to discuss such questions as:

- How do we as health professionals perceive women who drink in pregnancy and how may this effect our interactions and relationships with these women?
- Are there differences in how women are perceived by health professionals when measured by whether the women drink alcohol at all? If so, whether they are light drinkers or heavy drinkers?
- Do these classifications (light or heavy) make a difference in the way they are treated?
- Are health professionals more likely to continue asking about drinking on subsequent clinic appointments if the women are viewed as heavy rather than light drinkers? Why or why not?
- How does referral for an Alcohol Brief Intervention (ABI) affect the woman?
- How does referral for an ABI affect her relationship with the midwife or the practitioner making the referral?
- How does including 'referral to an ABI' in a woman's case notes affect her care in subsequent pregnancies?

As any competent therapist knows, words can be guarded, but tone, body language and facial expressions will give away the underlying attitudes every time. The best way to make progress is for professionals to honestly acknowledge, examine and, if necessary, adjust their own beliefs and value systems. Learning sessions where it feels safe to do so should become the norm.

There has always been debate about combining the issues of alcohol, tobacco and illicit substances in relation to pregnancy. However, there are differences among these three issues. Alcohol and tobacco are legal, while, by definition, 'illicit' substances and street drugs are not. Legality does not eliminate the issue of stigma. A study among aboriginal/indigenous women in Canada (Salmon et al. 2007) reported that the stigma there around FASD is now so strong that women are increasingly

likely to admit abusing any drug other than alcohol.

Hicks et al. (2014) noted the relationship between smoking and drinking continuing into pregnancy. An option suggested in several studies is to combine alcohol reduction efforts with existing smoking cessation programmes. For example, Beenstock et al. (2012) noted midwives' confidence in addressing smoking and encouraging pregnant women to stop.

However, there are differences. The proportion of the general population who smoke is low compared to those who consume alcohol. A tipping point has been reached where delineating smoke-free zones elicits little negative reaction. Growing public awareness of the harmful effects of second-hand smoking (especially on babies and children) contributed toward the public health success in reducing tobacco use.

Research has shown overwhelmingly for many years that there are many harms and few benefits from smoking tobacco. Among many others, the World Health Organisation (WHO) has now acknowledged and started acting on the issue of harm to others related to drinking alcohol.

An interesting result from the recent Scottish survey (QNIS/HPBL 2022) was that the community nurses and midwives talked most often with their patients about smoking. Alcohol came next on the list and illicit drugs were least frequently discussed.

One thing is clear. Until we know whether there are potential risks of small amounts of alcohol during pregnancy, reducing the risk of prenatal alcohol exposure can best be accomplished by increasing and improving preconception (including interconception) health, education and care. This speaks to the strengths of community nurses and midwives, given their opportunities and their ability to develop open, honest, trusting relationships with people of childbearing age. This is crucial, whether the prospective parents' preference is to avoid, delay or prepare well for pregnancy (HPBL, 2022).

Acknowledging the trauma of the Covid-19 pandemic years is important, as are its FASD-related implications (Sher. 2020). The restrictions and increased pressures brought by the Covid-19 pandemic led to exhaustion and burnout for many nursing professionals. The impressive response to the Scottish survey (QNIS/HPBL, 2022) confirmed that FASD prevention, identification and services/ support is an area community nurses and midwives do see as relevant and important.

The essential finding is that, even in these turbulent times, they want to learn more and do more about FASD. This echoes other studies (national and international) that highlight the need for information and skills enabling community nurses, midwives and other professionals to feel more comfortable, and competent, in addressing the issues surrounding alcohol in pregnancy.

Recommendations

These recommendations are divided into two sections:

1. recommendations for Scotland's Coalition for Healthier Pregnancies, Better Lives

2. broader recommendations for the future of alcohol and pregnancy FASD services in Scotland.

Queens Nursing Institute Scotland & Healthier Pregnancies, Better Lives

Encourage and facilitate continuing professional development to:

- increase knowledge and understanding of patterns of alcohol consumption in women in Scotland

- strengthen knowledge and understanding of how best to introduce, conduct and make good, use of alcohol-related conversations with women at the preconception, interconception and pregnancy stages

- create and facilitate opportunities for reflection, peer discussions and support among community nurses and midwives in their practices around alcohol, pregnancy and FASD

- develop ways of improving listening skills and self-reflections about relevant attitudes

- explore and put into practice greater involvement of the partner's role in improving pregnancy and birth outcomes

- increase awareness, and encourage

implementation, of effective strategies for preventing, identifying and supporting individuals/families affected by FASD

The actions recommended above will result in:

- increased confidence and competence
- improved communication with effective support networks within and beyond the community nursing and midwifery workforce in relation to alcohol, pregnancy and FASD
- QNIS/HPBL enhancing its reputation and performance as a valuable, accurate, widely known and respected information source on alcohol, pregnancy and FASD

Ideally, this would be done in two stages:

1. A 'Training the Trainers' initiative
2. Rolling out CPD opportunities, both virtually and in different geographical areas, to reach a cross-section of community nurses and midwives throughout Scotland.

Given the sensitivity and complexity of media coverage of these topics, it is recommended to have at least one identified person in each geographical area with media training. Any media interest in FASD in local areas could be routed to this designated person. This may help prevent further misinformation.

It is recommended that a list of experienced and knowledgeable people who are willing to talk with the media be compiled and maintained by HPBL. A further list of peers, experts and people with lived experience should be created and used to act as consultants to community nurses and midwives.

Recommendations for Scotland

- Development of a national data base on FASD. This could use the Community Health Index (CHI) identification number to link data on health, including vision, hearing, dental services and education of those affected. Ideally, this would also include criminal justice, but it is understood that great care needs to be taken with confidentiality. Who has control over, and access to, these data must be carefully monitored.
- Preconception education and counselling to reduce the risk of alcohol-exposed pregnancies should be introduced (and adequately resourced) within initial education and CPD programmes serving all relevant professional groups.
- Integrate information on alcohol consumption and pregnancy into all 'well woman' clinic settings.
- Integrate information on alcohol consumption and sexual health into clinics serving men/partners.
- Preconception and FASD training of mental health and addiction workers must become standard. Health professionals and others working in substance misuse/addiction services are most likely to be in contact with the women at highest risk. It is vital that they are knowledgeable on this issue. They will already be seeing patients who may have drunk heavily during their pregnancies and have children and young adults with FASD. Furthermore, in terms of prevention, they are in a good position to highlight options/choices to avoid additional pregnancies, if continuing to drink.
- Situate services for people with FASD within general neurodevelopmental clinics, rather than as isolated 'silos' would be cost effective. After upskilling staff, this would identify more babies, older children, young people and adults with FASD.
- Enlist the help of self-help groups such as Alcoholics Anonymous, who can be valuable colleagues in this work. AA groups can offer a great deal of non-judgemental support to members who may be struggling with young children at home, especially those experiencing the impact of undiagnosed FASD. AA groups will also have adults with undiagnosed FASD amongst their membership.
- Develop mutually beneficial relationships with responsible mass and social media at the local, regional and national levels to encourage the accurate portrayal of people FASD, and the surrounding issues. A serious and concerted shift must occur within Scottish Government and grant-giving bodies

to develop longer term funding for FASD prevention, diagnostic and post-diagnosis services, supports and research. It is highly desirable, and not impossible, for ten-year plans to be developed and implemented to ensure continuously improving outcomes/ services.

- Further scoping exercises should be carried out, analysed and used as the basis for actions to identify and subsequently close the gaps in service provision across disciplines, professions and agencies. This will enable a further structured plan to be developed to ensure joined up services for people with, or at risk of, FASD.

- A major, long-term investment in FASD prevention, bespoke for Scotland. Given the human and financial costs to the nation from prenatal alcohol exposure, this would be a wise and long overdue strategy. The Australian Government's multi-year, national, $27 million investment in FASD prevention (with more allocated for FASD services and support) is a precedent worth emulating in Scotland.

Useful Web Links

The SIGN 156 Guidelines

https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol

The SIGN 156 guidelines for parents and carers

https://www.sign.ac.uk/media/1145/pat156_fasd.pdf

The Scottish Government's 2020 eLearning resource on FASD. Access to NHS Education Scotland (TURAS)

https://www.qnis.org.uk/invisible-not-inconsequential-fasd/

FASD Hub

FASD Hub Scotland is funded by the Scottish Government and managed by Adoption UK in Scotland. The FASD Hub supports all parents and carers (adoptive, biological, fostering and kinship) who parent an individual with a history of prenatal alcohol exposure, with or without a FASD diagnosis. The service extends to provide a point of reference for those working across the Third Sector, Education and those in Social Work supporting adoptive, fostering and Kinship carers.

Services include an advice Line, training, 1:1 support, online peer support groups, a website containing factsheets and resources and training for parents, carers and those who support them. Further details can be found at https://www.fasdhub.scot

The Fetal Alcohol Advisory and Support Team (FAAST)

The Fetal Alcohol Advisory and Support Team (FAAST provide 'resources, consultation and training services for professionals working in the health and social care sectors'.
https://www.faast.ed.ac.uk

UK Organisations

The National Organisation for FASD

An organisation 'dedicated to supporting people with Fetal Alcohol Spectrum Disorder (FASD), their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy'. Its 2022 publication – The Time is Now – is a comprehensive report sharing the findings and contributions from a series of UK-wide 'roundtables' on FASD.
https://nationalfasd.org.uk

FASD UK Alliance

This coalition includes most of the UK organisations for FASD
https://fasd-uk.net

University of Salford and NHS website

Resources for 'helping parents to go alcohol free'
https://www.drymester.org.uk

International Organisations

CanFASD

The CanFASD is a Canadian organisation whose mission 'is to produce and maintain national, collaborative research designed for sharing with all Canadians, leading to prevention strategies and improved support services for people affected by Fetal Alcohol Spectrum Disorder'.
https://canfasd.ca

This site also provides 'clear and evidence-informed information for clinicians, including short videos with trauma-informed language recommendations on talking with women about alcohol use in pregnancy.
http://bccewh.bc.ca/webinars-and-media/webinars

FASD Hub Australia

The mission of this Australian organisation is 'To be the leading source of high quality, evidence-based content about alcohol and pregnancy and FASD in Australia'
https://www.fasdhub.org.au/

NOFASD Australia

This Third Sector organisation is funded by the Australian Government and brings together a wide range of practitioners, stakeholders and experts.
https://www.nofasd.org.au/

FARE Australia

This charity is similar to Alcohol Focus Scotland. It also is the organisation leading the national FASD prevention campaigns.
https://fare.org.au/

One Key Question for Preconception Care

For information on Michele Stranger Hunter's one key question for preconception care
https://powertodecide.org/one-key-question

Language guides for working with parents, carers and young people with FASD

FASD Hub Language Guide

https://www.fasdhub.org.au/fasd-information/resources/language-guide

CanFASD 2022 Guidelines for Writing and Talking about FASD

https://www.canfasd.ca/common

FASD: Preferred UK Language Guide produced by Seashell and The National Organisation for FASD

https://nationalfasd.org.uk/wp-content/uploads/2020/11/Seashell_NationalFASD_FASDLanguageGuide.pdf

UK Government Information website on alcohol screening tools and brief intervention strategies

https://www.gov.uk/government/publications/alcohol-use-screening-tests

Scottish Government Toolkit on Trauma Informed Practice

https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland

Reference List

Abernethy, C., McCall, K.E. and Cooper, G. et al.. (2018) 'Determining the pattern and prevalence of alcohol consumption in pregnancy by measuring biomarkers in meconium',
Archives of Disease in Childhood: Fetal and Neonatal Edition, 103, pp216–F220. doi:10.1136/archdischild-2016-311686

Adkison, S.E., Grohman, K. and Colder, C.R. et al.. (2013) 'Impact of fathers' alcohol problems on the development of effortful control in early adolescence'. Journal of Studies on Alcohol and Drugs. 74(5), pp674-83. doi:10.15288/jsad.2013.74.674

Alberta FASD Cross Ministry Committee (2020) 'The Patient's FASD Journey' Alberta, Canada.

American College of Obstetrics and Gynecology Committee (2015) 'Alcohol Abuse and Other Substance Use Disorders: Ethical Issues in Obstetric and Gynaecologic Practice: Opinion No. 633, Obstetrics & Gynaecology, 125(6), pp1529-1537.
doi: 10.1097/01.AOG.0000466371.86393.9b

Anderson, A.E., Hure, A.J. and Kay-Lambkin, F.J. et al.. (2014) 'Women's perceptions of information about alcohol use during pregnancy: A qualitative study'. BMC Public Health, 14, page1048.

Arch, J.J. (2013) 'Pregnancy-specific anxiety: which women are highest and what are the alcohol-related risks?' Comprehensive Psychiatry. 54(3), pp217–28.

Armstrong, E.M. and Abel, E.L. (2000) 'Fetal alcohol syndrome: the origins of a moral panic' Alcohol & Alcoholism, 35(3), pp276–282

Astley, S.J. (2015) 'Palpebral fissure length measurement: accuracy of the FAS facial photographic analysis software and inaccuracy of the ruler'. Journal of Population Therapeutics and Clinical Pharmacology', 22(1), pp9 - e26.

Astley, S., Bailey, D. and Talbot, C. et al. (2000a) 'FAS primary prevention through FAS diagnosis 1. Identification of high-risk birth mothers through the diagnosis of their children' Alcohol and Alcoholism, 35(5), pp499-408.

Astley, S., Bailey, D. and Talbot. C. et al. (2000b) 'FAS primary prevention through FAS diagnosis 11: A comprehensive profile of 80 birth mothers of children with FAS' Alcohol and Alcoholism ,35(5), pp509-519.

Astley, S.J. and Clarren, S.K. (1996) 'A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome'. Journal of Paediatrics, 129, pp33–41.

Autti-Ramo, I., Loimu, L. and Hoyme, H.E. (2007) 'Relationship between dysmorphic features and general cognitive function in children with fetal alcohol spectrum disorders. American Journal of Medical Genetics, 2923, pp2916 - 2923.

Bailey, J.A., Hill, K.G. and Hawkins, J.D. et al. (2008) 'Men's and women's patterns of substance use around pregnancy' Birth, 35(1), pp50-59.

Bakhireva, L., Leeman, L. and Roberts, M. et al. (2021) 'You Didn't Drink During Pregnancy, Did You?' Alcoholism Clinical and Experimental Research. 45(3), pp543–547.

Balachova, T., Sobell, L.C. and Agrawal, S. et al.. (2018) 'Evaluating alcohol use among Russian women at risk for an alcohol exposed pregnancy: A comparison of three measures of alcohol use' Journal of Ethnicity and Substance Abuse, 17(3), pp324-334.

Banwell, C. and Bammer, G. (2006). 'Maternal habits: Narratives of mothering, social position and drug use'. International Journal of Drug Policy, 17(6), pp504–513. https://doi.org/10.1016/j.drugpo.2006.09.005

Beenstock, J., Sniehotta, F.F. and White, M. et al. (2012) 'What helps and hinders midwives in engaging with pregnant women about stopping smoking? A cross- sectional survey of perceived implementation difficulties among midwives in the North East of England' Implementation Science, 7(36)

Bell, E., Andrew, G., Pietro, N. D., et al.. (2016). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies'. Public Health Ethics, 9, pp65–77. doi:10.1093/phe/phv012

Bell, K., McNaughton, D. and Salmond A. (2009) 'Medicine, morality and mothering: public health discourses on foetal alcohol exposure, smoking around children and childhood overnutrition' Critical Public Health, 19(2), pp155–170.

Bennett, R. and Bowden, C. (2022) 'Can routine screening for alcohol consumption in pregnancy be ethically and legally justified?' Journal of Medical Ethics, 0.1-5 doi:10.1136/medethics-2021-107996

Blackburn, C. (2021) 'Identifying the child with FASD in the education system' In Prevention, Recognition and Management of Fetal Alcohol Spectrum Disorders' Mukherjee R.A.S. and Aiton N (Eds) Springer Nature Switzerland, 9, pp103-118.

Borschmann, R., Becker, D. and Spry, E. et al. (2019) 'Alcohol and parenthood: An integrative analysis of the effects of transition to parenthood in three Australasian cohorts' Drug and Alcohol Dependence' 197, pp326-334

Bortes, C., Geidne, S. and Eriksson, C. (2015) 'Preventing Alcohol Consumption during Pregnancy: A Randomized Controlled Trial'. Health, 7, pp289-299.

Bos, A.E.R., Pryor J.B. and Reeder, G.D. et al. (2013) Stigma: Advances in theory and research, Basic and Applied Social Psychology, 35(1), pp1-9. DOI: 10.1080/01973533.2012.746147

Bottorff, J., Poole, N. and Kelly, M et al. (2014). 'Tobacco and alcohol use in the context of adolescent pregnancy and postpartum: A scoping review of the literature'. Health and Social Care in the Community. 22, pp 561–574. doi:10.1111/hsc.12091

Bradry, D. and Hickey, J. (2018). I am a caregiver! For a person with FASD: Caregiver resource guide. Retrieved from: https://canfasd.ca

British Medical Association (BMA) (2016). 'Alcohol and pregnancy: Preventing and Managing Fetal Alcohol Spectrum Disorders' London. British Medical Association

Brown, N.N., Gudjonsson, G. and Connor, P. (2011). 'Suggestibility and fetal alcohol spectrum disorders: I'll tell you anything you want to hear'. The Journal of Psychiatry Law, 39(1), pp39-71. doi:10.1177/009318531103900103

Bruckner, H., Martin, A. and Bearman, P.S. (2004) 'Ambivalence and pregnancy: adolescents' attitudes, contraceptive use and pregnancy'. Perspectives on Sexual and Reproductive Health., 36(6), pp248-57. doi: 10.1363/psrh.36.248.04.

Burd, L., Marilyn, G. and Klug, M.G. et al. (2008) 'Mortality rates in subjects with Fetal Alcohol Spectrum Disorders and their siblings' Birth Defects Research. Clinical and Molecular Teratology, 82(4), pp217-223.

Burd, L. (2016) 'Fetal alcohol spectrum disorder: complexity from comorbidity' Lancet, 387(10022), pp926-927. DOI:https://doi.org/10.1016/S0140-6736(15)01346-X

Burns, E., Gray, R. & Smith, L. A. (2010) 'Brief Screening Questionnaires to Identify Problem Drinking during Pregnancy: A Systematic Review'. Addiction, 105(4), pp601–14.

Butler, L. D., Carello, J., and Maguin, E. (2016). 'Trauma, stress, and self-care in clinical training: Predictors of burnout, decline in health status, secondary traumatic stress symptoms, and compassion satisfaction'. Psychological Trauma: Theory, Research, Practice, and Policy. 9(4), pp416–424.

Butler, L.D., Maguin, E. and Carello J. (2018) 'Retraumatization mediates the effect of adverse childhood experiences on clinical training-related secondary traumatic stress symptoms'. Journal of Trauma & Dissociation, 19(1), pp25-38

Cannon, M.J,, Guo, J. and Denny, C.H. et al.. (2015) 'Prevalence and characteristics of women at risk for an alcohol-exposed pregnancy (AEP) in the United States: estimates from the National Survey of Family Growth'. Maternal Child Health Journal.19(4), pp776-82.

Carpenter, B., Blackburn, C. and Egerton, J. (2014) 'Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives Routledge London and New York.

Casement, P. (2013) 'On learning from the patient' Routledge Mental Health Classic Editions. London and New York

Charness, M.E. (2022) 'Fetal Alcohol Spectrum Disorders: Awareness to Insight in Just 50 Years' Alcohol Research Current Reviews 42(1), pp1-8. https://doi.org/10.35946/arcr.v42.1.05

Chang, G. (2001) 'Alcohol-Screening Instruments for Pregnant Women' National Institute on Alcohol Abuse and Alcoholism Alcohol Research and Health, 25(3), pp204-209.

Chasnoff, I. J., McGourty, R. F. and Bailey, G. W. et al.. (2005). 'The 4P's Plus screen for substance use in pregnancy: Clinical application and outcomes' Journal of Perinatology, 25, pp368–374

Chasnoff, I. J., Wells, A. M. and McGourty, R. F. et al. (2007). 'Validation of the 4P's Plus screen for substance use in pregnancy validation of the 4P's Plus' Journal of Perinatology, 27(12), pp744–748.

Chen, M.L, Olson, H.C. and Picciano J.F. et al. (2012) 'Sleep problems in children with fetal alcohol spectrum disorders'. Journal of Clinical Sleep Medicine. 8(4), pp421-429.

Chiodo, L.M., Delaney-Black, V. and Sokol, R.J. et al. (2014) 'Increased cut-point of the TACER-3 screen reduces false positives without losing sensitivity in predicting risk alcohol drinking in pregnancy'. Alcoholism Clinical and Experimental Research, 38, pp1401–1408.

Chiodo, L.M., Cosmian, C. and Pereira, K. et al. (2019) 'Prenatal alcohol screening during pregnancy by midwives and nurses'. Alcoholism: Clinical and Experimental Research, 43(8), pp1747-1758.

Clarren, S.K., Chudley, A.E. and Wong, L. et al. (2010) 'Normal distribution of palpebral fissure lengths in Canadian school age children' Canadian Journal of Clinical Pharmacology, 17(1), pp67-e78.

Coles, C.D., Gailey, A.R. and Mulle J.G. (2016). 'A comparison among 5 methods for the clinical diagnosis of fetal alcohol spectrum disorders'. Alcoholism: Clinical and Experimental Research, 40(5), pp1000–1009.

Conderelli, R.A., Calogero, A. E. and Vicariet E. et al. (2015) 'Chronic consumption of alcohol and sperm parameters: our experience and the main evidences' Andrologia, 47, pp368 – 379.

Conner, K.E., Bottom, R.T and Huffman, K.J. (2020) 'The impact of paternal alcohol consumption on offspring brain and behavioral development'. Alcoholism Clinical and Experimental Research ,44(1), pp125-140. doi:10.1111/acer.14245

Cook, J.L., Green, C.R. and Lilley, C.M. et al.. (2016) 'Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. Canadian Medical Association Journal.1883, pp 191–197.

Coons et al. (2017) 'Health Care Students' Attitudes About Alcohol Consumption During Pregnancy: Responses to Narrative Vignettes' Global Qualitative Nursing Research, 4, pp1-18.

Cooper, D. L., Petherick, E. S. and Wright, J. (2013). 'The association between binge drinking and birth outcomes: results from the Born in Bradford cohort study' Journal of Epidemiology and Community Health, 67(10), pp821-828.

Corrigan, P.W., Shah, B.B. and Lara, J.L. et al. (2018) 'Addressing the public health concerns of Fetal Alcohol Spectrum Disorder: Impact of stigma and health literacy'. Drug and Alcohol Dependence, 185, pp266–270.

Cox, L.V., Clairmont, D. and Cox, S. (2008) 'Knowledge and attitudes of criminal justice professionals in relation to Fetal Alcohol Spectrum Disorder'. The Canadian Journal of Clinical Pharmacology. 15(2), pp306 - e313.

Crawford-Williams, F., Steen, S. et al. (2015) 'If you can have one glass of wine now and then, why are you denying that to a woman with no evidence?' Journal of the Australian College of Midwives, 28(4), pp329-335.

Dawson, D.A., Das, A. and Faden, V.B. et al. (2001). 'Screening for high and moderate risk drinking during pregnancy: A comparison of several TWEAK based screeners'. Alcoholism: Clinical and Experimental Research, 25(9), pp1342–1349.

Del Campo, M. and Jones, K.L. (2017) 'A review of the physical features of the fetal alcohol spectrum disorders'. European Journal of Medical Genetics. 60(1), pp55-64. https://doi.org/10.1016/j.ejmg.2016.10.004.

Dej, E. (2011). What once was sick is now bad: The shift from victim to deviant identity for those diagnosed with fetal alcohol spectrum disorder. Canadian Journal of Sociology, 36, pp137–160.

Doi, L., Cheyne, H. and Jepson, R. (2014). 'Alcohol brief interventions in Scottish antenatal care: a qualitative study of midwives' attitudes and practices'. BMC Pregnancy & Childbirth, 14(1), pp1-27.

Domeij, H., Fahlström, G. and Bertilsson, G. et al. (2018) 'Experiences of living with fetal alcohol spectrum disorders: A systematic review and synthesis of qualitative data' Developmental Medicine and Child Neurology , 60(8), pp1-12.

Douds, A.S., Stevens, H.R. and Sumner, W.E. (2013) 'Sword or shield? A systematic review of the roles FASD evidence plays in judicial proceedings'. Criminal Justice Policy Review. 24(4), pp492-509.

Douglas, H., Hammill, J. and Russell, E.A. et al.. (2012) 'Judicial views of Foetal Alcohol Spectrum Disorder in Queensland's criminal justice system'. Journal of Judicial Administration. 21(3), pp178-188.

Dozet, D., Burd, L. and Popova, S. (2021) 'Screening for Alcohol Use in Pregnancy: A review of current practices and perspectives' International Journal of Mental Health and Addiction https://doi.org/10.1007/s11469-021-00655-3

Drabble, L, Poole, N. and Magri, R. et al.. (2011) 'Conceiving risk, divergent Responses: Perspectives on the evolution of the construction of FASD in six countries'. Substance Use and Misuse, 46(8), pp943-958.

Dungy, C., McInnes, R.J. and Tappin, D.M. et al. (2008) 'Infant Feeding Attitudes and Knowledge among Socioeconomically Disadvantaged Women in Glasgow' Maternal and Child Health Journal, 12(3), pp313–322.

Edwards, E.P., Leonard, K.E. and Eiden, R.D. et al.. (2001) 'Temperament and behavioral problems among infants in alcoholic families' Infant Mental Health Journal. 22(3), pp374–392. doi:10.1002/imhj.1007

Elek, E., Harris, S. and Squire, C. et al. (2013) 'Women's knowledge, views, and experiences regarding alcohol use and pregnancy: Opportunities to improve health messages. American Journal of Health Education. 44, pp177–190. doi:10.1080/19325037.2013.768906

Ellington, S.R., Flowers, L. and Legardy-Williams, J.K. et al. (2015) 'Recent trends in hepatic diseases during pregnancy in the United States, 2002-2010'. American Journal of Obstetrics and Gynecology. 212(524), pp1-524.e7

Elliot, E.J., Payne, J. and Bower, C. (2006) 'Diagnosis of foetal alcohol syndrome and alcohol use in pregnancy: a survey of paediatricians' knowledge, attitudes and practice'. Journal of Paediatric and Child Health. 1(42), pp698–703.

Esposito, S.D. (2014) 'Pregnancy in patients with advanced chronic liver disease' Clinical Liver Disease 4(3), pp62-68.

Ethen, M.K., Ramadhani, T. A. and Scheuerle, A. E. et al. (2009) 'Alcohol consumption by women before and during pregnancy' Maternal and Child Health Journal, 13, pp274-285.

Ewuoso, C., Hall, S. and Dierickx, K. (2021) 'How do healthcare professionals respond to ethical challenges regarding information management? A review of empirical studies' Global Bioethics. 32(1), pp67–84.

Ewing, J.A. (1984). 'Detecting alcoholism. The CAGE questionnaire'. Journal of the American Medical Association. 252(14), pp1905–1907.

Fealy, G., Casey, M. and O'Leary, D.F. et al. (2018) 'Developing and sustaining specialist and advanced practice roles in nursing and midwifery: A discourse on enables and barriers' Journal of Clinical Nursing, 27, pp3797-3809.

Flannigan, K., Pei, J. and McLachlan, K. et al. (2022) Responding to the unique complexities of Fetal Alcohol Spectrum Disorder' Frontiers in Psychology ,12, pp1-8. https://doi.org/10.3389/fpsyg.2021.778471

France, K., Henley, N. and Payne, J. et al. (2010) 'Health Professionals Addressing Alcohol Use with Pregnant Women in Western Australia: Barriers and Strategies for Communication' Substance Use & Misuse. 45(10), pp1474-1490. Doi:10.3109/10826081003682172

Glass, J. E., Kristjansson, S. D. and Bucholz, K. K. (2013). 'Perceived Alcohol Stigma: Factor Structure and Construct Validation'. Alcoholism: Clinical and Experimental Research, 37(1), pp237-246 https://doi.org/10.1111/J.1530-0277.2012.01887.X

Gibson, L. and Porter, M. (2018) 'Drinking or smoking while breastfeeding and later cognition in children' Pediatrics, 142(2), pp20174266.

Gill, I. and Sharif, F. (2017) 'Out of sight, out of mind? A national survey of paediatricians in Ireland regarding Fetal Alcohol Spectrum Disorders'. Irish Medical Journal. 110(3), pp528.

Gmel, G., Kuntsche, E. and Rehm, J. (2010) 'Risky single-occasion drinking: bingeing is not bingeing' Addiction, 106, pp1037–1045.

Golden, J. (2000) 'A Tempest in a Cocktail Glass': Mothers, Alcohol, and Television, 1977–1996' Journal of Health Politics, Policy and Law, 25(3), pp473–498. https://doi.org/10.1215/03616878-25-3-473

Göransson, M., Magnusson, Å. and Bergman, H.et al. (2003). 'Fetus at risk: Prevalence of alcohol consumption during pregnancy estimated with a simple screening method in Swedish antenatal clinics'. Addiction, 98, pp1513-1520.

Gountas, S. and Gountas, J. (2015) 'How the 'warped' relationships between nurses' emotions, attitudes, social support and perceived organisational conditions impact customer satisfaction' Journal of Advanced Nursing. 72(2), pp283–293.

Goverde, H.J., Dekker, H.S. and Janssen, H.J. et al. (1995) 'Semen quality and frequency of smoking and alcohol consumption-an explorative study' International Journal of Fertility and Menopausal Studies , 40, pp135–138.

Graves, L. (2020) 'Approaching substance use in pregnancy: Giving brief intervention a chance' Journal of Obstetrics and Gynaecology Canada, 42(9), pp1069-1070.

Graves, L., Carson, G. and Poole, N. et al. (2020) 'Guideline No. 405: Screening and Counselling for Alcohol Consumption During Pregnancy' Journal of Obstetrics and Gynaecology Canada, 42(9), pp1158-1173.

Greiner, T. (2019) 'Alcohol and Breastfeeding: A Review' World Nutrition, 10(1), pp63-88.

Gual, A., Segura, L. and Contel, M. et al.. (2002) 'AUDIT-3 and AUDIT-4: Effectiveness of Two Short Forms of The Alcohol Use Disorders Identification Test' Alcohol & Alcoholism, 37(6), pp591–596.

Guzzo, K.B. and Hayford, S.R. (2018) 'Adolescent reproductive and contraceptive knowledge and attitudes and adult contraceptive behavior' Maternal and Child Health Journal, 22, pp32–40.

Haas, D.M., Morgan, A.M. and Deans, S.J. et al. (2005). Ethanol for preventing preterm birth in threatened preterm labor. Cochrane Database of Systematic Reviews 11. Art. No.: CD011445. DOI: 10.1002/14651858.CD011445.pub2.

Hall, S., Ewuoso, C.K. and Dierickx, K. (2017) 'How do healthcare professionals manage ethical challenges regarding information in healthcare professional/patient clinical interactions? A review of concept- or argument-based articles and case analyses' South African Journal of Bioethics and Law, 10(2), pp75-82.

Hammond, P. and Suttie, M. (2012) 'Large-Scale Objective Phenotyping of 3D Facial Morphology' Human Mutation, 33(5), pp817–825.

Hanlon-Dearman, A., Green, C.R. and Andrew, G. et al. (2015) 'Anticipatory guidance for children and adolescents with Fetal Alcohol Spectrum Disorder (FASD): practice points for primary health care providers'. Journal of Population Therapeutics and Clinical Pharmacology. 22(1), pp27–56.

Hanlon-Dearman, A. (2021) 'How FASD presents across the lifespan' In Prevention, Recognition and Management of Fetal Alcohol Spectrum Disorders' Mukherjee R.A.S. and Aiton N (Eds) Springer Nature Switzerland, 8, pp85-102.

Hard, M., Einarson, T. and Koren, G. (2001). 'The role of acetaldehyde in pregnancy outcome after prenatal alcohol exposure'. Therapeutic Drug Monitoring, 23(4), pp286-292.

Hatch, S. and Dohrenwend, B. (2007). Distribution of traumatic and other stressful life events by race/ethnicity, gender, SES and age: a review of the research. American Journal of Community Psychology, 40(3-4), pp313-32.

Healthier Pregnancies, Better Lives. HPBL (2022). The Queens Nursing Institute Scotland. Healthier Pregnancies, Better Lives blogs. Available at: https://www.qnis.org.uk/healthier-pregnancies-better-lives-blogs

Healthier Pregnancies, Better Lives. QNIS/HPBL (2022) 'FASD Survey of community nurses and midwives in Scotland' Queens Nursing Institute Scotland. Available at: qnis.org.uk

Heeb, J-L. and Gmel, G. (2005) 'Measuring alcohol consumption: a comparison of graduated frequency, and weekly recall diary methods in a general population survey' Addictive Behaviors, 30, pp403-413.

Hellmuth, J.C., Gordon, K.C. and Stuart, G.L et al. (2013) 'Risk factors for intimate partner violence during pregnancy and postpartum' Archives of Women's Mental Health, 16(1), pp19-27.

Herring, R., Berridge, V. and Thom, B. (2006) 'Binge drinking: an exploration of a confused concept'. Journal of Epidemiology and Community Health, 62, pp476–9.

Hicks, M., Tough, S. and Johnston, D. et al. (2014). 'T-ACE and predictors of self-reported alcohol use during pregnancy in a large, population-based urban cohort'. The International Journal of Alcohol and Drug Research, 3(1), pp51-61.

Hicks, M., Tough, C. and Premji, S. et al. (2009) 'Alcohol and drug screening of newborns: Would Women Consent?' Journal of Obstetrics and Gynaecology Canada, 31(4), pp331-339.

Hicks, M., Sauve, R.S. and Lyon, A.W. et al. (2003) 'Alcohol use and abuse in pregnancy: An evaluation of the merits of screening' The Canadian Child and Adolescent Psychiatry Review, 12(3), pp77-80.

Hillis, S.D., Anda, R.F. and Dube, S.R. et al. (2004) 'The association between adverse childhood experiences and adolescent pregnancy, long-term psychosocial consequences, and fetal death'. Pediatrics, 113(2), pp320–7.

Himmelreich, M., Lutke C.J. and Travis Hargrove, E. (2020) 'The Lay of the land FASD as a whole-body diagnosis' (Chapter 11 pages 174-190) In Begun A.L and Murray M.M. (Eds) 'The Routledge Handbook of Social Work and Addictive Behaviors' Routledge: London and New York

Hodgson, R., Alwyn, T., John, B. et al. (2002). 'The FAST alcohol screening test'. Alcohol and Alcoholism. 37:1: 61–66.

Homes, A. and Grandison, G. (2021) 'Trauma-Informed Practice: A toolkit for Scotland' Scottish Government and NHS Education Scotland. Available at: https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland

Horsley, V. and Sturge, M.D. (1908) 'Alcohol and the human body: An introduction to the study of the subject, and a contribution to national health' London: Macmillan and Co Ltd

Howe, L.J., Sharp, G.C. and Hemani, G. et al. (2019) 'Prenatal alcohol exposure and facial morphology in a UK cohort' Drug and Alcohol Dependence, 197, pp42-47.

Howlett, H. (2020) 'An antenatal alcohol service evaluation of the north-east of England and north Cumbria'. Journal of Public Health ,42(2), pp374-387.

Howlett, H., Abernethy, S. and Brown, N. W. et al. (2017a) 'How strong is the evidence for using blood biomarkers alone to screen for alcohol consumption during pregnancy? A systematic review'. European Journal of Obstetrics Gynecology and Reproductive Biology, 213, pp45-52.

Howlett, H., Gray, W. K. and Dismore, L., et al. (2017b) 'A survey of attitudes, beliefs and practice regarding alcohol use and screening in pregnancy: an opportunity for support and education?'. Journal of Research in Nursing, 22(8), pp618-633.

Howlett, H., Mackenzie, S. and Gray, W. K., et al. (2018) 'Assessing prevalence of alcohol consumption in early pregnancy: Self-report compared to blood biomarker analysis'. European Journal of Medicine and Genetics, 61(9), pp531- 538.

Howlett, H., Mackenzie, S., Strehle, E. M. et al. (2019) 'A Survey of Health Care Professionals' Knowledge and Experience of Foetal Alcohol Spectrum Disorder and Alcohol Use in Pregnancy'. Clinical Medical Insights: Reproductive Health. 13: 1-10.

Howlett, H., Mackenzie, S. and Gray, W. K., et al. (2020) 'Assessing the prevalence of alcohol consumption in early pregnancy using blood biomarker analysis: a consistent pattern across north-east England?', Journal of Public Health, 429(1), pp74-e80.

Ireland, W.W. (1894) 'Means of preventing and evading insanity' Alienist and Neurologist, 2, pp181-208.

Italian Association for the Study of Liver Disease (2016) 'AFIS Position paper on liver disease and pregnancy' Digestive and Liver Disease, 48, pp120-137.

Jacobs, L. and Jacobs, J. (2014). 'Bad' Mothers have Alcohol Use Disorder: Moral Panic or Brief Intervention? Gender & Behaviour, 12(3), pp5971-5979.

John, B., Newstead, S. and Heirene, R. et al. (2021) 'Does the Fast Alcohol Screening Test Accurately Distinguish Between Harmful and Severely Dependent Tiers of Alcohol Misuse? ' Alcohol and Alcoholism, 56(60, pp737–745 https://doi.org/10.1093/alcalc/agab015

Johnson, K.E., Sobell, M. B. and Sobell, L. C. (2010) 'Using One Question to Identify Women at Risk for an Alcohol-Exposed Pregnancy' Journal of the American Osteopath Association, 110(7), pp381-384

Jones, K.L. and Smith, D.W. (1973) 'Recognition of the Fetal Alcohol Syndrome in early infancy' Lancet, 2, pp999-1001.

Joya, X., Friguls, B. and Ortigosa, S. et al.. (2012) 'Determination of maternal-fetal biomarkers of prenatal exposure to ethanol: A review'. Journal of Pharmaceutical and Biomedical Analysis, 69, pp209–222.

Kable, J.A., O'Connor, M.J. and Carmichel Olson, H. et al. (2016) 'SUBSTANTIVE/THEORETICAL REVIEW Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE): Proposed DSM-5 Diagnosis' Child Psychiatry and Human Development, 47, pp335–346. DOI 10.1007/s10578-015-0566-7

Kaplan, B.J., Leung, B.M. and Giesbrecht, G.F. et al. (2013) 'Increasing the quality of life from womb to grave: the importance of pregnancy and birth cohorts' Applied Physiology Nutrition and Metabolism. 38, pp85–89.

Kautz, C., Parr J. and Christie, L.M. et al., (2020) 'Self-care in caregivers of children with FASD: How do caregivers care for themselves, and what are the benefits and obstacles for doing so?' Research in Developmental Disabilities, 99, 103578

Keller, P.S., Gilbert, L.R. and Koss, K.J. et al. (2011).'Parental problem drinking, marital aggression, and child emotional insecurity: a longitudinal investigation.' Journal of Studies on Alcohol and Drugs.72(5), pp711-22. doi:10.15288/jsad.2011.72.71

Kerr, W.C. and Stockwell, T. (2012) 'Understanding standard drinks and drinking guidelines' Drug and Alcohol Review, 31(2), pp200–205.

Kesmodel, U.S. and Olsen, S.F. (2001) 'Self-reported alcohol intake in pregnancy: comparison between four methods. Journal of Epidemiology and Community Health. 55(10), pp738–45.

Kesmodel, U.S. and Kesmodel, P.S. (2011) 'Alcohol in pregnancy: Attitudes, knowledge and information practice among women in Denmark 2000-2009' Alcoholism:Clinical and Experimental Research, 35(12), pp2226-2230.

Kirillova, G., Reynolds, M. and Kirisci, L. et al. (2014)'Familiality of addiction and its developmental mechanisms in girls'. Drug and Alcohol Dependence. 143(1~), pp213–218. https://doi.org/10.1016/j.drugalcdep.2014.07.032

Kitsantas, P. Gaffney, K.F. and Wu, H. (2015) 'Identifying high---risk subgroups for alcohol consumption among younger and older pregnant women'. Journal of Perinatal Medicine. 43(1), pp43-52.

Kvaale, E. P., Gottdiener, W. H. and Haslam, N. (2013). 'Biogenetic explanations and stigma: A meta-analytic review of associations among laypeople'. Social Science and Medicine. 96, pp95–103. https://doi.org/10.1016/j.socscimed.2013.07.017

Kully-Martens, K., Denys, K. and Treit, S. et al. (2012). 'A review of social skills deficits in individuals with fetal alcohol spectrum disorders and prenatal alcohol exposure: profiles, mechanisms, and interventions'. Alcoholism Clinical and Experimental Research. 36(4), pp568–76.

Lambie, I. (2020). 'What were they thinking? A discussion paper on brain and behaviour in relation to the justice system in New Zealand'. Auckland, NZ: Office of the Prime Minister's Chief Science Advisor

Lange, S., Shield K. and Koren, G., et al.. (2014) 'A comparison of the prevalence of prenatal alcohol exposure obtained via maternal self-reports versus meconium testing: A systematic literature review and meta-analysis'. BMC Pregnancy Childbirth 14, pp127.

Lee, E., Sutton, R.M. and Hartley, B.L. (2016) 'From scientific article to press release to media coverage: advocating alcohol abstinence and democratising risk in a story about alcohol and pregnancy' Health, Risk & Society, 18(5-6), pp247–269

Leedham, A.T., Thompson A.R. and Freeth, M. (2020) 'A thematic synthesis of siblings' lived experiences of autism: Distress, responsibilities, compassion and connection' Research in Developmental Disabilities, 97: 103547.

Leggat, G., Livingston, M. and Kuntsche, S. et al. (2021). 'Changes in alcohol consumption during pregnancy and over the transition towards parenthood. Drug and Alcohol Dependence, 225: 108745. https://doi.org/10.1016/j.drugalcdep.2021.108745

Lemoine, P., Harousseau, H. and Borteyru, J.P. et al. (1968)'Les Enfants de Parents Alcooliques. Anomalies Observees a Propos de 127 Cas,' Ouest Medical ,21, pp476–82.

Li, Q., Fisher, W.W. and Peng, C.Z. et al. (2012) 'Fetal Alcohol Spectrum Disorders: A population based study of premature mortality rates in the mothers' Maternal Child Health Journal, 16, pp1332–1337 DOI 10.1007/s10995-011-0844-3

Little, R.E., Anderson, K.W. and Ervin, C.H. et al. (1989). Maternal alcohol use during breast-feeding and infant mental and motor development at one year'. New England Journal of Medicine. 17(321:7), pp425-30.

Liu, W. and Mumford, E. (2017) 'Concurrent trajectories of female drinking and smoking behaviors throughout transitions to pregnancy and early parenthood' Prevention Science,18:4: 416-427.

Liu, W., Mumford, E. and Petras, H. (2014) 'Maternal Patterns of Postpartum Alcohol Consumption by Age: A Longitudinal Analysis of Adult Urban Mothers' Prevention Science 16:353-363. Doi: 10.1007/s11121-014-0522-y

LoGiudice, J.A. (2012) A systematic literature review of the childbearing cycle as experienced by survivors of sexual abuse. Nurse Women's Health. 20(6), pp582–94.

Loock, C., Elliot, E. and Vitale Cox, L. (2020) 'Fetal Alcohol Spectrum Disorder: Evidence, theory and current insights' (Chap 11:174-190) In Begun A.L and Murray M.M. (Eds) 'The Routledge Handbook of Social Work and Addictive Behaviors' Routledge: London and New York

Lowson, K., Jenks, M. and Filby A. et al. (2015) 'Examining the implementation of NICE guidance: cross-sectional survey of the use of NICE interventional procedures guidance by NHS Trusts' Implementation Science, DOI 10.1186/s13012-015-0283-4

Lussier, A.A., Bodnar, T.S. and Weinberg, J. (2021) Intersection of Epigenetic and Immune Alterations: Implications for Fetal Alcohol Spectrum Disorder and Mental Health. Frontiers in Neuroscience.15:788630. doi: 10.3389/fnins.2021.788630

McBride, N., Carruthers, S. and Hutchinson, D. (2021) 'Reducing alcohol use during pregnancy: listening to women who drink as an intervention starting point'.Global Health Promotion. 19:2: 6-18. doi:10.1177/1757975912441225

McLean, J. and Dean, L. (2020) The Scottish Health Survey 2018 edition; amended in February 2020: volume 1: Main report: A National Statistics Publication for Scotland

McCormack, C., Hutchinson, D. and Burns, L. et al.. (2017). Prenatal Alcohol Consumption Between Conception and Recognition of Pregnancy'. Alcoholism: Clinical and Experimental Research. 41(2), pp369-378.
McDonald, S.W., Hicks M. and Rasmussen, C. et al. (2014) 'Characteristics of Women Who Consume Alcohol Before and After Pregnancy Recognition in a Canadian Sample: A Prospective Cohort Study' Alcoholism Clinical and Experimental Research, 38(12), pp3008-3016.
McDonald, S., Kehler, H. and Bayrampour, H. et al. (2016) Risk and protective factors in early child development: Results from the All Our Babies (AOB) pregnancy cohort Research in Developmental Disabilities, 58, pp20-30.
McGill, J., Meyerholz, D.K. and Edsen-Moore, M. et al.. (2009)' Fetal exposure to ethanol has long-term effects on the severity of influenza virus infections. Journal of Immunology. 182(12), pp7803–7808.

McLachlan, K., Andrew, G. and Pei, J. et al. (2015). 'Assessing FASD in young children:' exploring clinical complexities and diagnostic challenges'. Journal of Population Therapeutics and Clinical Pharmacology, 22(1), pp108–1024.

McLennan, J.D. and Braunberger, P. (2018) 'Caution is needed when adding etiology to mental disorder criteria: The case of neurobehavioral disorder associated with prenatal alcohol exposure'. Journal of the American Academy of Child and Adolescent Psychiatry. 57(11), pp818-819. doi: 10.1016/j. jaac.2018.06.020. PMID: 30392619.

McPherson, N.O. and Grieger, J.A. (2022) 'The science of preconception' International Journal of Birth and Parent Education, 9(2), pp9-14.

Mallard, S.R., Connor, J.L. and Houghton, L.A., (2013) 'Maternal factors associated with heavy periconceptional alcohol intake and drinking following pregnancy recognition: A post-partum survey of New Zealand women' Drug and Alcohol Review, 32(4), pp389–397.

Malta, L.A., McDonald, S.W. and Hegadoren, K.M. et al. (2012) 'Influence of interpersonal violence on maternal anxiety, depression, stress and parenting morale in the early postpartum: A community based pregnancy cohort study' BMC Pregnancy and Childbirth 12(1), p153.

Marcellus, L. and Badry, D. (2021) 'Infants, children and youth on foster care with prenatal substance exposure: A synthesis of two scoping reviews' International Journal of Developmental Disabilities. https://doi.org/10.1080/20473869.2021.1945890

Maschke, J., Roetner J. and Goecke, T. W. et al. (2021) 'Prenatal Alcohol Exposure and the Facial Phenotype in Adolescents: A Study Based on Meconium Ethyl Glucuronide' Brain Science, 11, pp154-174.

Mattson, S. N., Bernes, G. A. and Doyle, L. R. (2019) 'Fetal alcohol spectrum disorders: A review of the neurobehavioral deficits associated with prenatal alcohol exposure'. Alcoholism Clinical and Experimental Research,.43(6), pp1046-1062. Doi:https://doi.org/10.1111/acer.14040.

May, P. A., Gossage, J. and Brooke, L. et al. (2005). 'Maternal risk factors for fetal alcohol syndrome in Western Cape Province of South Africa: A population-based study'. American Journal of Public Health, 95: pp1190–1199.

May, P.A., Tabachnick, B.G. and Gossage, J.P. et al. (2013) 'Maternal Factors Predicting Cognitive and Behavioral Characteristics of Children with Fetal Alcohol Spectrum Disorders, Journal of Developmental & Behavioral Pediatrics.34(5), pp314-325. doi:10.1097/DBP.0b013e3182905587

May, P. A., Hasken, J. M. and Bozeman, R. et al.. (2020). Fetal alcohol spectrum disorders in a rocky mountain region city: Child characteristics, maternal risk traits, and prevalence'. Alcoholism: Clinical and Experimental Research, 44, pp 900–918.

Mengel, M., Searight, R. and Cook, K. (2006). 'Preventing alcohol-exposed pregnancies'. Journal of the American Board of Family Medicine. 19, pp494–505.

Mennella. J.A. and Beauchamp. G.K. (1991) 'The transfer of alcohol to human milk. Effects on flavor and the infant's behavior'. New England Journal of Medicine. 325(14), pp981–985.

Meschke, L. L., Holl, J. and Messelt, S. (2013). 'Older not wiser: risk of prenatal alcohol use by maternal age. Maternal and Child Health Journal, 17(1), pp147-155.

Millar, J., Thompson, J. and Schwab, D. et al. (2014) 'Educating students with FASD: linking policy, research and practice'. Journal of Research in Special Education Needs. 17: pp3–17.

Mizejewski ,G.J. (2010) 'Can prenatal screening for fetal alcohol spectrum disorder be justified? A commentary'. Gynecologic and Obstetric Investigations, 69(2), pp128–130.

Moore, E.M. and Riley, E.P. (2015) 'What happens when children with fetal alcohol spectrum disorders become adults? Current Developments Disorders Reports. 2(3), pp219–27.

Mongan, D. and Long. J. (2015) 'Standard drink measures throughout Europe; peoples understanding of standard drinks and their use in drinking guidelines, alcohol survey and labelling: Technical Report. Available at: https://www.researchgate.net/publication/322273447

Motherisk Commission. (2018). Harmful impacts: The reliance on hair testing in child protection. A report of the Motherisk Commission. Available at: https://www.attorneygeneral.jus.gov.on.ca/english/about/pubs/motherisk/.

Morrison, K., Wolfson, L. and Harding, K. et al. (2020) 'Mothers' Experience of Stigma: Multi-Level Ideas for Action' CanFASD Research Network Canada.

Muhr, J. and Ackerman, K.M. Embryology, Gastrulation. (2022) In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing

Muggli, E., O'Leary, C. and Donath, S. et al.. (2016) 'Did you ever drink more?' A detailed description of pregnant women's drinking patterns' BMC Public Health. 16: pp683 -696.

Muggli, E., Matthews, H. and Penington, A. et al.. (2017) 'Association between prenatal alcohol exposure and craniofacial shape of children at 12 months of age'. Journal of the American Medical Association Pediatrics. 171(8), pp771-780. https://doi.org/10.1001/jamapediatrics.2017.0778.

Mukherjee, R.A., Hollins, S. and Abou-Saleh, M.T. et al.. (2005) 'Low level alcohol consumption and the fetus'. BMJ, 330: pp375–376.

Mukherjee, R.A., Wray, E. and Curfs, L. et al. (2013) 'Estimation of alcohol content of wine, beer and spirits to evaluate exposure risk in pregnancy: Pilot study using a questionnaire and pouring task in England' International Journal of Alcohol and Drug Research, 2: pp71–78.

Mukherjee, R., Wray, E. and Hollins, S.et al.. (2015). What does the general public in the UK know about the risk to a developing foetus if exposed to alcohol in pregnancy? Findings from a UK mixed methodology study. Child Care. Health Development.41, pp467–474.

Mukherjee, R.A. and Ayton N. (Eds) (2021) Prevention, Recognition and Management of Fetal Alcohol Spectrum Disorders' Springer Nature Switzerland

Mullally, A., Cleary, B. and Barry, J. et al. (2011) 'Prevalence, predictors and perinatal outcomes of peri-conceptional alcohol exposure - retrospective cohort study in an urban obstetric population in Ireland'. BMC Pregnancy Childbirth. 11: p27.

Mutch, R.C., Jones, H.M. and Bower, C. et al.. (2016) 'Fetal Alcohol Spectrum Disorders: Using knowledge, attitudes and practice of justice professionals to support their educational needs'. Journal of Population Therapeutics and Clinical Pharmacology. 23(1), pp77-e89.

National FASD (2022), 'The Time Is Now: The national perspective on ramping up FASD prevention, diagnosis and support services

O'Brien, P. (2014) 'Performance measurement: a proposal to increase use of SBIRT and decrease alcohol consumption during pregnancy' Maternal and Child Health Journal, 18(1), pp1-9.

O'Keefe, L., Kearney, P.M. and McCarthy, F.P. et al. (2015) 'Prevalence and predictors of alcohol use during pregnancy: Findings from international multicentre cohort studies' BMJ Open, 5, page 5:e006323. doi:10.1136/bmjopen-2014-0063231

Olswang, L.B, Svensson, L. and Astley, S. (2010) 'Observation of classroom social communication: do children with fetal alcohol spectrum disorders spend their time differently than their typically developing peers? Journal of Speech Language and Hearing Research. 53(6), pp1687–703.

Paley, B., O'Connor, M.J. and Frankel, F. et al. (2006) 'Predictors of stress in parents of children with Fetal Alcohol Spectrum Disorders' Journal of Developmental & Behavioral Pediatrics. 27(5), pp396-404.

Patrick, M.E., Evens-Polce, R. and Wagner, A. et al. (2020) 'High intensity drinking by parental status: Differences by age and sex' Addictive Behaviors, 102, pp1-6.

Parackal, S., Parackal, M. and Harraway J. (2010) 'Warning labels on alcohol containers as a source of information on alcohol consumption in pregnancy among New Zealand women'. International Journal of Drug Policy, 21: pp302–5.

Parkes, T., Poole, N. and Salmon, A. et al.. (2008). 'Double Exposure: A Better Practices Review on Alcohol Interventions during Pregnancy'. British Columbia Centre of Excellence for Women's Health. Vancouver. British Columbia

Payne, J., Watkins, R.E. and Jones, H.M. et al. (2014) 'Midwives knowledge, attitudes and practice about alcohol exposure and the risk of Fetal Alcohol Spectrum Disorder' BMC Pregnancy and Childbirth 14: p377.

Pei, J., Flannigan, K. and Keller, S. et al. (2018) 'Fetal Alcohol Spectrum Disorder and the Criminal Justice System: A Research Summary'. Journal of Mental Health Clinical Psychology, 2(4), pp48-52.

Petersen, I., McCrea, R.L. and Lupattelli, A. et al. (2015) 'Women's perception of risks of adverse fetal pregnancy outcomes: a large-scale multinational survey. BMJ Open, 5:6.

Phillips, D., Thomas, K. and Cox, H. et al. (2007) 'Factors that influence women's disclosures of substance use during pregnancy: a qualitative study of ten midwives and ten pregnant women' Journal of Drug Issues, 37(2), pp357-375.

Plant, M.L. (1984) 'Alcohol consumption during pregnancy. Baseline data from a Scottish prospective study' Alcohol and Alcoholism, 19(2), pp153-157.

Plant, M.L. (1997) 'Women and Alcohol: Historical and Contemporary Perspectives'. London: Free Association Books

Plant, M.L. (2008) 'The role of alcohol in women's lives: a review of issues and responses'. Journal of Substance Use, 13(3), pp155–191.

Plant, M.L. (2021) 'Alcohol-Related Harm in Pregnancy: Public Policy, Attitudes and Recognition' (Chapter 32:pages 431-447). In Prevention, Recognition and Management of Fetal Alcohol Spectrum Disorders' Mukherjee R.A.S. and Aiton N (Eds) Springer Nature Switzerland

Poole, N. A. (2008). 'Fetal alcohol spectrum disorder (FASD) prevention: Canadian perspectives. Ottawa. Public Health Agency of Canada. Available at: http://www.phac-aspc.gc.ca/community nurses and midwives-ps/dca-dea/prog-ini/fasd-etcaf/publications/cp-pc/pdf/cp-pc-eng.pdf

Poole, N. A. and Isaac, B. (2001). 'Apprehensions: Barriers to treatment for substance-using mothers. Centre of Excellence for Women's Health. Vancouver. British Columbia

Poole, N.A. and Greaves, L. (2012) 'Becoming Trauma Informed' Centre for Addiction and Mental Health. Canada

Poole, N. A., Schmidt, R. A. and Green, C et al. (2016). 'Prevention of fetal alcohol spectrum disorder: Current Canadian efforts and analysis of gaps'. Substance Abuse, 10: Suppl.1: pp1–11. doi:10.4137/SART.S34545

Popova, S., Lange S. Shield K et al. (2016) 'Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis' Lancet 387:10022: 978-987.
Popova, S., Lange, S. and Probst, C. et al. (2017) 'Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: A systematic review and meta-analysis' Lancet Global Health, 5, pp290–99.

Popova, S., Dozet, D. and O'Hanlon, G. et al. (2021). Maternal alcohol use, adverse neonatal outcomes and pregnancy complications in British Columbia. BMC Pregnancy Childbirth, 21:p74.

Popova, S., Stade, B. and Bekmuradov, D. et al. (2011). 'What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review'. Alcohol and Alcoholism, 46(4), pp490–497. doi:10.1093/alcalc/agr029

Powers, J.R., Loxton, D.J. and Burns L.A et al. (2010) 'Assessing pregnant women's compliance with different alcohol guidelines: an 11-year prospective study' Medical Journal of Australia, 192: pp690–69.

Powers, J. R., McDermott, L. J. and Loxton, D. J. et al. (2013). A prospective study of prevalence and predictors of concurrent alcohol and tobacco use during pregnancy. Maternal And Child Health Journal, 17(1), pp76-84.

Price, K.J. and Kelly, K.J. (2014) 'Why Ask Why? Logical Fallacies in the Diagnosis of Fetal Alcohol Spectrum Disorder' Ethics & Behavior, 25(5), pp1-9.

Public Health England (2017). Alcohol use screening tests. [online] GOV.UK. Available at: https://www.gov.uk/government/publications/alcohol-use-screening-tests.

Racine, et al. (2018) 'Differential Associations of Adverse Childhood Experience on Maternal Health' American Journal of Preventive Medicine, 54(3), pp368-375. doi: 10.1016/j.amepre.2017.10.028

Raymond, N., Beer, C. and Glazebrook, C. et al. (2009) 'Pregnant women's attitudes towards alcohol consumption'. BMC Public Health, 9: p175.

Rehm, J., Shield, K. and Joharchi, D.N.et al. (2011) 'Alcohol use is an independent risk factor for intentions to engage in unprotected sex'. Addiction, 107, pp51–59.

Reid, N., Dawe, S. and Shelton, D. et al. (2015) 'Systematic review of Fetal Alcohol Spectrum Disorders across the life span' Alcoholism: Clinical and Experimental Research, 39(120), pp2283-2295.

Reid, N., Chen, C-C. and Bernard, A. et al. (2019) 'Understanding contraceptive behaviour to prevent unintended alcohol-exposed pregnancies' Journal of Fetal Alcohol Syndrome Risk and Prevention, 2(1), pp13-22.

Reid, N., Schölin, L. and Erng, M. et al. (2021) 'Preconception interventions to reduce the risk of alcohol exposed pregnancies: A systematic review' Alcoholism: Clinical and Experimental Research, 45(12), pp2414-2429.

Ricci, E., Beitawi, S.A. and Cipriani, S. et al. (2017) 'Semen quality and alcohol intake: a systematic review and meta-analysis' Reproductive BioMedicine Online, 34(1), pp38-47.

Roberts, S. C. M., and Nuru-Jeter, A. (2010). 'Women's perspectives on screening for alcohol and drug use in prenatal care'. Women's Health Issues, 20(3), pp193–200. https://doi.org/10.1016/j.whi.2010.02.003

Roberts, S.C.M. and Pies, C. (2010) 'Complex calculations: How drug use during pregnancy becomes a barrier to prenatal care' Maternal and Child Health Journal, 15(3), pp333-341.

Roberts, S.C.M., Thomas, S. and Treffers, R. et al. (2017) 'Forty Years of State Alcohol and Pregnancy Policies in the USA: Best Practices for Public Health or Efforts to Restrict Women's Reproductive Rights?' Alcohol and Alcoholism, 52(6), pp715-721.

Roozen, S., Stutterheim, S.E. and Bos, A.E.R. et al. (2020) 'Understanding the Social Stigma of Fetal Alcohol Spectrum Disorder: From Theory to Intervention' Foundations of Science https://doi.org/10.1007/s10699-020-09676-y

Rossen, L., Hutchison, D. and Wilson, J. et al. (2016) 'Predictors of postnatal mother-infant bonding: the role of antenatal bonding, maternal substance use and mental health' Archives of Women's Mental Health, 19: pp609-622.

Russell, M. (1984) 'New assessment tools for risk drinking during pregnancy'Alcohol Health & Research World, 18: pp55-61.

Russell, M., Martier, S. and Sokol, R.J. et al. (1996). 'Detecting risk drinking during pregnancy: a comparison of four screening questionnaires'. American Journal of Public Health.; 86(10), pp1435-1439.

Rutman, D. and Van Bibber, M. (2010). 'Parenting with fetal alcohol spectrum disorder'. International Journal of Mental Health and Addiction, 8: pp350-361.

Sagalyn, D. (2011) 'Army General Calls for Changing Name of PTSD' Nation PBS Newshour

Salmon, A. (2007) 'Beyond shame and blame: Aboriginal mothers and barriers to care'. In N. Poole and L. Greave (Eds.), Highs and lows: Canadian perspectives on women and substance use. Centre for Addiction and Mental Health Canada

Santos, A., Chambel, M.J. and Castanheira, F. (2016). 'Relational job characteristics and nurses' affective organizational commitment: The mediating role of work engagement'. Journal of Advanced Nursing, 72(2), pp294–305. https://doi.org/10.1111/JAN.12834/FORMAT/PDF

Saunders, J.B., Aasland, O.G. and Babor, T.F. et al. (1993). 'Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption—II' . Addiction, 88(6), pp791-804.

Savage, C., Wray, J. and Ritchey, P.N. et al. (2003). 'Current screening instruments related to alcohol consumption in pregnancy and a proposed alternative method'. Journal of Obstetric, Gynecologic, and Neonatal Nursing, 32(4), pp437-446.

Schuetze, P., Eiden, R.D. and Chan A.W.K. (2002) 'The Effects of Alcohol in Breast Milk on Infant Behavioral State and Mother-Infant Feeding Interactions' Infancy, 3(3), pp349 – 363.

Scobie, G. and Woodman, K. (2017) 'Interventions to reduce alcohol use during pregnancy. Edinburgh: NHS Health Scotland'

Schölin, L. (2016) 'Prevention of harm caused by alcohol exposure in pregnancy: Rapid review and case studies from Member States' World Health Organisation Regional Office for Europe. Copenhagen Denmark

Schölin, L., Schölin, L. and Smith, L. (2019). Data from Midwives' Assessment of expecting Mothers' Alcohol use (MAMA). Edinburgh DataVault. Doi:10.7488/daa2a13f-4748-4d16-9e15-9a7f304618a2

Schölin, L., Hughes, L. and Bellis, M.A. et al. (2019) 'I think we should all be singing from the same hymn sheet' – English and Swedish midwives' views of advising pregnant women about alcohol'. Drugs: Education, Prevention and Policy, 26(5), pp394-400. DOI:10.1080/09687637.2018.1478949

Schölin, L. and Fitzgerald, N. (2019) 'The conversation matters: a qualitative study exploring the implementation of alcohol screening and brief interventions in antenatal care in Scotland.' BMC Pregnancy Childbirth, 19: p316

Schölin L., Watson, J., Dyson J. et al.. (2019). Alcohol guidelines for pregnant women: Barriers and enablers for midwives to deliver advice. The Institute of Alcohol Studies https://www.ias.org.uk/wp-content/uploads/2020/06/rp37092019.pdf

Scottish Intercollegiate Guidance Network (2019). SIGN 156: Children and young people exposed prenatally to alcohol (Clinical Guidance)

Seib, C.A., Daglish, M. and Heath, R. et al. (2012) 'Screening for alcohol and drug use in pregnancy'. Midwifery, 28: pp760–764.

Sessa, F., Salerno, M. and Esposito, M. et al. (2022) 'Understanding the Relationship between Fetal Alcohol Spectrum Disorder (FASD) and Justice: A Systematic Review'. Healthcare, 10: p84 https://www.mdpi.com/2227-9032/10/1/84

Shaker, I., Scott, J.A. and Reid, M. (2004) 'Infant feeding attitudes of expectant parents: breastfeeding and formula feeding' Journal of Advanced Nursing, 45(3), pp260-268.

Sher, J., Frank J.W. and Doi, L. et al. (2019) 'Failures in reproductive health policy: overcoming the consequences and causes of inaction' Journal of Public Health, 41(2), pp209-215.

Sher, J. (2020a) 'Sex, alcohol and the Covid-19 pandemic' Holyrood, April 2020. Available at: https://www.holyrood.com/comment/view,sex-alcohol-and-the-covid19-pandemic_15379.htm

Sher, J. (2020b) 'Fetal Alcohol Spectrum Disorders: preventing collateral damage from COVID-19' The Lancet Public Health, 5(8), p424.

Sher, J. (2022) 'Preconception health education and care: Making and celebrating progress' International Journal of Birth and Parent Education. 9(2), pp3-8.

Simpson, R.F., Hermon C. and Liu, B. et al. (2019) 'Alcohol drinking patterns and liver cirrhosis risk: analysis of the prospective UK Million Women Study' Lancet Public Health, 4: pp41–48.

Smith, L., Savory, J. and Couves, J.et al. (2014). 'Alcohol consumption during pregnancy: Cross-sectional survey. Midwifery, 30(12), pp1173-1178.

Skagerström, J., Chang, G. and Nilsen, P. (2011) Predictors of Drinking During Pregnancy: A Systematic Review. Journal of Women's Health; 20(6), pp901– 913.

Söderström, K. and Skolbekken, J-A. (2012) 'Pregnancy and substance use: z 10-3 solution. 1 Ethical and clinical reflections related to incarceration of pregnant women to protect the foetus from harmful substances' Nordic Studies on Alcohol and Drugs, 29(2), pp155-171.

Sokol, R., Martier, S.S. and Ager, J.W. (1989) The T-ACE questions: Practical prenatal detection of risk-drinking. American Journal of Obstetrics and Gynecology, 160(4), pp863-870.

Stade, B.C., Bailey C. and Dzendoletas, D. et al. (2009) 'Psychological and/or educational interventions for reducing alcohol consumption in pregnant women and women planning pregnancy' Cochrane Database of Systematic Reviews, CD005228.

Stahre, M., Naimi, T. and Brewer, R. et al. (2006). 'Measuring average alcohol consumption: the impact of including binge drinks in quantity-frequency calculations'. Addiction, 101(12), pp1711–1718.

Stone, R. (2015) 'Pregnant women and substance use: Fear, stigma, and barriers to care'. Health Justice. 3(1), pp1-15. http://doi.org/10.1186/s40352-015-0015-5.

Strandberg-Larsen, K., Andersen, A-M. N. and Olsen, J. et al. (2006). Do women give the same information on binge drinking during pregnancy when asked repeatedly? European Journal of Clinical Nutrition, 60(11), pp1294–8.

Strandberg-Larsen, K., Rod Nielsen, N. and Nybo Andersen, A.M. et al. (2008) 'Characteristics of women who binge drink before and after they become aware of their pregnancy. Eur J Epidemiol, 23(8): pp565-72. doi: 10.1007/s10654-008-9265-z. PMID: 18553140.

Stranger Hunter, M. (2021) 'Asking women what they want and nurses/nidwives what they know'Queens Nursing Institute Scotland. Edinburgh. Available at: Asking Women What They Want and Nurses/Midwives What They Know (qnis.org.uk)

Suttie, M., Foroud, T. and Wetherill, L. et al. (2013) 'Facial dysmorphism across the fetal alcohol spectrum'. Pediatrics.131(3), pp779-788. https://doi.org/10.1542/peds.2012-1371.

Sword, W., Green, C. and Akhrar-Danesh, N. et al. (2020) 'Screening and Intervention Practices for Alcohol Use by Pregnant Women and Women of Childbearing Age: Results of a Canadian Survey' Women's Health Santé Des Femme, 42(9), pp1121-1128.

Symon, A., Rankin, J. and Butcher, G. et al. (2016) 'Evaluation of a retrospective diary for peri-conceptual and mid-pregnancy drinking in Scotland: a cross-sectional study' Acta Obstetricia et Gynecologica Scandinavica, 96: pp53–60.

Tan, C., Denny, C. and Cheal, N. et al. (2015) 'Alcohol Use and Binge Drinking Among Women of Childbearing Age - United States, 2011-2013' MMWR. Morbidity and Mortality Weekly Report; Atlanta, 64: pp37.

Thanh, N.X. and Jonsson, E. (2016) 'Life Expectancy of People with Fetal Alcohol Syndrome' J Population Therapeutics Clinical Pharmacology, 23(1), pp53-59.

Thomas, R. and Mukherjee, R. S. (2018) 'Exploring the experiences of birth mothers whose children have been diagnosed with FASD' Advances in Dual Diagnosis, 12(1), pp27-35.

Tough, S., Tofflemire, K. and Clarke, M. et al. (2006) 'Do women change their drinking behaviors while trying to conceive? An opportunity for preconception counselling' Clinical Medicine and Research, 4(2), pp97-105.

Tran, N.T., Najman, J. M. and Hayatbakhsh, R. (2014). 'Predictors of maternal drinking trajectories before and after pregnancy: evidence from a longitudinal study. The Australian & New Zealand Journal of Obstetrics & Gynaecology, 55(2), pp123-130.

Tran, N.T., Williams, G.M. and Alati, R. et al. (2015) 'Trajectories and predictors of alcohol consumption over 21 years of mothers' reproductive life course' SSM Population Health, 1: pp40-47.

Ulleland, C. (1970) 'Offspring of alcoholic mothers' Pediatric Research, 4: p474.

Van Der Wulp, N.Y., Hoving, C. and De Vries, H. (2013) 'A qualitative investigation of alcohol use advice during pregnancy: Experiences of Dutch midwives, pregnant women and their partners'. Midwifery, 29: pp89–98.

Verbiest, S. and McClain, E. K. (2022) 'Improving health and wellbeing before, between and beyond pregnancy' International Journal of Birth and Parent Education, 9(2), pp15-19.

Walker, M., Al-Sahab, B. and Islam, F.et al.. (2011). 'The epidemiology of alcohol utilization during pregnancy: An analysis of the Canadian Maternity Experiences Survey (MES)'. BMC Pregnancy and Childbirth, 11: p52. doi:10.1186/1471-2393-11-52.

Warren, K.R. and Hewitt, B.G. (2009) 'Fetal Alcohol Spectrum Disorder' Developmental Disabilities Research Reviews, 15, pp170-175.

Warren, K.R. (2015) 'A review of the history of attitudes toward drinking in pregnancy. Alcoholism: Clinical and Experimental Research, 39(7), pp1110-1117. https://doi.org/10.1111/acer.12757.

Wilsnack, S.C. (2012) 'The GENACIS Project: A review of findings and some implications for global needs in women-focused substance abuse prevention and intervention'. Substance Abuse and Rehabilitation,3(I), pp5-15. https://med.und.edu/genacis/index.html.

Wilson, J., Tay, R. and McCormack, C. et al. (2017) 'Alcohol consumption by breastfeeding mothers: Frequency, correlates and infant outcomes'. Drug Alcohol Review, 36(5), pp667-676.

Wilton, J. and Williams, A. (2019) 'Engaging with complexity Providing effective trauma-informed care for women' Centre for Mental Health. Mental Health Foundation.

Wozniak, J.R., Riley, E.P. and Charness, M.E. (2019) 'Clinical presentation, diagnosis, and management of fetal alcohol spectrum disorder'. Lancet Neurology, 18(8), pp760-770.

Young, B., Lewis, S. and Katikireddi, V. et al. (2018) 'Effectiveness of Mass Media Campaigns to Reduce Alcohol Consumption and Harm: A Systematic Review' Alcohol and Alcoholism, pp1–15. doi: 10.1093/alcalc/agx094

Yoshida, S., Wilunda, C. and Kinura, T. et al. (2017) 'Prenatal alcohol exposure and suspected hearing impairment among children: A cohort population based retrospective cohort study' Alcohol and Alcoholism, 1:53:3: pp221-227.

Zabotka, J., Bradley C. and Escueta, M. (2017) 'How Could I Have Done This?' Thoughts of Mothers of Children with Fetal Alcohol Syndrome' Journal of Social Work Practice in the Addictions. 17(3), pp258-274. DOI: 10.1080/1533256X.2016.1243123

Zizzo, N. and Racine, E. (2017) Ethical challenges in FASD prevention: scientific uncertainty, stigma, and respect for women's autonomy. Can J Public Health, 108(4), pp414–417. doi: 10.17269/CJPH.108.6048

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