

People Select Committee

Scrutiny Review of Foetal Alcohol Spectrum Disorder

Final Report

April 2016

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People Select Committee
Stockton-on-Tees Borough Council
Municipal Buildings
Church Road
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Select Committee membership

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Acknowledgements

The Committee would like to thank the following people for contributing to its work:

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Foreword

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Original Brief

Which of our strategic corporate objectives does this topic address?

The Joint Health and Wellbeing Strategy 2012-18 includes the following policy objectives:

- Give every child the best start in life
- Strengthen the role and impact of ill-health prevention (specific action - tackle the drinking culture and reduce the harmful impact of alcohol on communities, families, and individuals)

The Annual Report of Director of Public Health 2012-13 prioritised FASD as an issue that needed greater focus, and this was further reflected in the 2013-14 Report.

What are the main issues and overall aim of this review?

'FASD is the most common, non-genetic case of learning disability in the UK; it is a lifelong disability that has no cure but is preventable. FASD is a term given for a range of disabilities that can be caused when a baby is exposed to alcohol during pregnancy, including behavioural, emotional, physical and neurological issues.' (Director of Public Health Annual Report for The Borough of Stockton-on-Tees 2013 -2014)

The review will determine the levels of awareness, preventative actions that are currently taken, what support is in place, and whether improvements can be made.

Executive Summary

- 1.1 Foetal Alcohol Spectrum Disorder (FASD) is a term given for a range of permanent disabilities that can be caused when a developing baby in the womb is exposed to alcohol; this can include physical disabilities, learning difficulties and behavioural problems. FASD is caused solely by drinking alcohol during pregnancy and is therefore completely preventable. The review has focussed on what preventative measures have been taken and what more could be done.
- 1.2 The Committee found that the established Public Health message in Stockton is that there should be no alcohol during pregnancy. During the period of the review, the UK Chief Medical Officers issued revised National Alcohol Guidelines which included the following advice: 'If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.' The Committee welcomes the new guidance. When developing Public Health messages for public consumption, it is important to focus on this key message.
- 1.3 There has been considerable preventative work undertaken by Stockton's Public Health Team in conjunction with locally based charity FASD Network, although public awareness of FASD remains relatively low compared to other alcohol-related issues.
- 1.4 Overall, Members felt that a national campaign on the scale of No Smoking or Drink Driving was needed to ensure widespread awareness, and even then it will take some time for the messages to be as widely accepted and acted upon.
- 1.5 There was a need for sensitive conversations regarding levels of drinking; it was perceived that many knew that it was not advisable to drink in pregnancy but not necessarily why this was the case. Prevention messages also needed to be aimed at males, recognising their supporting role.
- 1.6 Around half of pregnancies were unplanned so it was likely that many women would drink to some extent without knowing they were pregnant. Preventative messages needed to be sensitive to this, and revised to reflect this.
- 1.7 Reducing levels of drinking overall by targeting the whole population would reduce risks at most levels, and it is important to include FASD in wider campaigns and strategies to reduce alcohol harm overall.

1.8 The Committee recommends that:

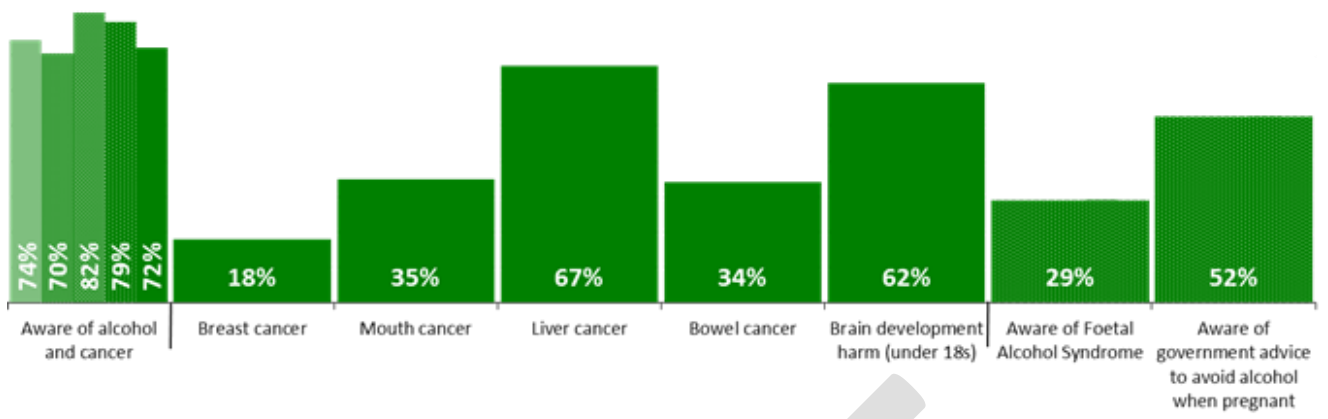
1. **Stockton Council should welcome and support the new UK Chief Medical Officers' guidelines on drinking on pregnancy;**
2. **The Council should build on previous work and undertake to raise awareness of FASD in Stockton utilising all relevant methods, including:**
 - a) **a dedicated public information campaign, using all effective media including Stockton News;**
 - b) **further engagement with licensed premises;**
 - c) **continuing to offer multi-agency training (including promotion to schools)**
 - d) **promoting and monitoring use of the FASD Animation**
3. **Promotional material should be reviewed to ensure the most effective and appropriate key messages are used;**
4. **The Council should circulate the Committee's report to local MPs, Department of Health, and the regional Public Health Network, to increase national and regional awareness of FASD and promote the use of public information campaigns;**
5. **Committee supports participation in the Regional FASD Research Project, and Public Health should consider the results in due course;**
6. **Ensure FASD is reflected in the development of the revised Alcohol Strategy for Stockton-on-Tees;**
7. **The work of FASD Network UK be commended.**

Introduction

- 2.1 This report outlines the findings and recommendations following the People Select Committee's review of Foetal Alcohol Spectrum Disorder (FASD).
- 2.2 FASD is a term given for a range of permanent disabilities that can be caused when a developing baby in the womb is exposed to alcohol; this can include physical disabilities, learning difficulties and behavioural problems. At the extreme end, this can cause Foetal Alcohol Syndrome (FAS) and children with this Syndrome have more distinctive physical characteristics.
- 2.3 FASD is caused solely by drinking alcohol during pregnancy and is therefore completely preventable. The review has focussed on what preventative measures have been taken and what more could be done.

Background

- 3.1 Alcohol is recognised as a causing significant harm to the population's health and wellbeing.
- 3.2 10.8million adults in England are drinking at levels that pose some risk to their health, and 1.6million adults may have some form of alcohol dependence. There is an estimated cost to society of £21billion (including crime, lost productivity, and health costs) and alcohol is associated with a wide range of health and social harms (Public Health England).
- 3.3 Research on FASD has been carried out primarily in the USA and Canada; limited work in the UK means that currently the incidence of FASD in the UK is not accurately known. There is currently no reliable evidence on the incidence of FASD across the UK. However, international studies estimate that at least 1% (with some prevalence studies estimating up to 5%) of the population are affected by FASD. When applying the 1% rate to Stockton-on-Tees this means that at least 476 children could be affected by FASD, and 25 babies would be born each year with FASD.
- 3.4 A key issue is around difficulties with diagnosis and problems in making a causal link between disabilities which may be caused by a number of factors, and drinking during pregnancy. FASD is often thought to present similar symptoms to Autism Spectrum Disorder.
- 3.5 International evidence and prevalence data means that FASD can be considered the leading cause of preventable non-genetic learning disability in the UK. FASD is completely preventable through not drinking alcohol during pregnancy (British Medical Association, 2007)
- 3.6 Each year Balance (the North East Alcohol Office) carry out a survey of public perceptions towards alcohol. The alcohol dashboard for Stockton includes public survey information and this indicates that public awareness of FASD remains relatively low for Stockton, as follows:



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Findings and Recommendations

Public Health and Awareness Raising

4.1 The Committee found that the established Public Health message in Stockton is that there should be no alcohol during pregnancy. In publicity materials, the Public Health Team highlights that 'the best and safest choice for you and your baby is to avoid alcohol, both during your pregnancy and when thinking about starting a family'.

4.2 During the period of the review, the UK Chief Medical Officers issued revised National Alcohol Guidelines. This included the following guideline on pregnancy:

- If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.
- Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk.

Most women either do not drink alcohol (19%) or stop drinking during pregnancy (40%).

The risk of harm to the baby is likely to be low if a woman has drunk only small amounts of alcohol before she knew she was pregnant or during pregnancy.

Women who find out they are pregnant after already having drunk during early pregnancy, should avoid further drinking, but should be aware that it is unlikely in most cases that their baby has been affected. If you are worried about how much you have been drinking when pregnant, talk to your doctor or midwife.'

4.3 The Committee welcomes the new guidance and this is in line with the established local message. It should be noted that the Guidelines cover several issues and must be read together, otherwise there is a potential for mixed messages in relation to the level of risk; for example, some may feel that 'some' alcohol is acceptable due to a perceived low risk. When developing Public Health messages for public consumption, it is important to focus on the key message that 'the safest approach is to not drink alcohol at all'.

4.4 The Committee heard from health professionals who welcomed the new guidelines as these replaced the previous more ambiguous advice.

4.5 The guideline was being consulted on with a closing date of 1 April 2016. Balance has responded in support of the guidelines as a whole, as follows:

- ' - The weekly guideline is extremely clear in communicating you are safest not to drink more than 14 units, to keep health risks from drinking alcohol to a low level.
- The new guidelines communicate clearly the risk of a number of cancers increases from any level of regular drinking- there is no level of drinking that can be considered as completely safe.
- The recommendation for women who are pregnant or planning a pregnancy to not drink any alcohol at all is clear.
- The advice on single occasion drinking is clear- it is advisable to spread this drinking over three days or more and have 'alcohol free days'. It is communicated clearly if you have one or two heavy drinking sessions, you increase your risks of death from long term illnesses and accidents and injuries.

- The guidelines are clear in stating people have a right to accurate information and advice about alcohol and its health risks, and there is a responsibility on Government to ensure the information is provided for people, so they can make informed choices.'

- 4.6 The Stockton Director of Public Health report for 2013 identified 'no alcohol in pregnancy' as a key public health challenge that has a significant impact on the health and wellbeing of the population. This challenge has been carried through subsequent reports and remains a focus for the Public Health team.
- 4.7 FASD Network UK is a locally based national support charity, working to raise awareness and support on a voluntary basis. Public Health has been proactive on this issue and worked with the charity, together with North Tees Trust and Lifeline Alcohol Support to increase awareness, reduce pregnancies where alcohol is a risk factor, and promote support strategies for local practitioners.
- 4.8 The Stockton multiagency alcohol action plan in 2013 identified there was a lack of both public and professional awareness of FASD and the risks associated with it.
- 4.9 To increase local awareness a range of actions taken to date include:
- a) A **multiagency FASD briefing and training programme** is available (full day, half day and bitesize training offered) and professionals from key groups that have participated in the training include:
 - Youth Offending and Youth Direction
 - Primary Schools
 - Secondary Schools
 - Voluntary Sector Organisations
 - Children's Centres
 - Family Support Team
 - Social Work
 - Health Centres
 - b) Approximately 200 practitioners have taken part in FASD training, with FASD training now being offered through the Local Safeguarding Children Board (LSCB) multiagency training programme for practitioners across Stockton Borough.
 - c) An **infographic poster** sharing key statistics about alcohol in pregnancy and information about FASD has been distributed to local licenced premises through the PubWatch scheme for local pubs to display in female toilets, to businesses involved in the Better Health at Work Scheme and organisations who also received the information leaflet. The poster and a version produced by Balance are included at **Appendix 1**. (Nb. in future, publicity materials will be based around the messages in the Balance poster in order to be sensitive to the issue that 50% of pregnancies were unplanned.)
 - d) A **public information leaflet (below) and A5 postcard** has been produced to cascade key messages about FASD including:
 - Stockton-on-Tees Public Health Team recommend no alcohol during pregnancy or when thinking about starting a family
 - If a mother has consumed small amounts of alcohol before she knew she was pregnant the risk the baby is low
 - It is never too late to stop drinking alcohol during pregnancy

- Signposting information to midwife, GP and alcohol support services

NHS

Alcohol and pregnancy don't mix - know the risks

Alcohol is a poisonous substance to your baby. If you drink alcohol it passes through your bloodstream via the placenta and to your baby. There is no way to know for sure how much alcohol you can consume before it impacts on your unborn baby.

Stockton-on-Tees Borough Council Public Health Team recommends the best and safest choice for you and your baby is to avoid alcohol, both during your pregnancy and when thinking about starting a family.

Foetal alcohol spectrum disorder (FASD) is a term given for a range of disabilities that can be caused when a baby is exposed to alcohol during pregnancy. Drinking in pregnancy may cause your baby to have serious conditions including:

- Learning Difficulties
- Hyperactivity
- Attention Issues
- Behavioural Issues
- Poor social skills and problem solving skills
- Physical and growth defects

Does alcohol affect breastfeeding?

Breastfeeding has many health benefits for both you and your baby. Anything you eat or drink while pregnant or breastfeeding can have an effect on your baby, including alcohol. Alcohol can pass through your breast milk in small amounts to your baby so express milk in advance or avoid breastfeeding for 2-3 hours after having an alcoholic drink.

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- e) The information leaflet has been cascaded to services including GP surgeries, pharmacies, community centres, children's centres, voluntary sector services, community midwife clinics and libraries.
- f) In 2015 Stockton Public Health Team, the Stockton based FASD network UK and Teesside University, supported by Chapel Road Youth Club developed a **two minute animation** aimed at 13-19 year olds. The animation shares key messages about FASD and alcohol in pregnancy, promoting the Stockton Public Health and international message of no alcohol during pregnancy. By watching the animation and learning about the dangers of drinking alcohol during pregnancy young people will be able to make informed choices later in life to help ensure every baby in Stockton is helped to have the best start in life.
- g) A session plan has been developed to be used alongside the animation and is free for all services working across Stockton Borough to use. The animation is currently being delivered through youth direction activities, youth offending teams, Harbour service, school nursing, young people's substance misuse services. A FASD lesson plan is currently being developed by Education Improvement Services which will be used with the animation as part of the Risk Taking Behaviour PSHE toolkit for secondary schools.
- h) **FASD Awareness Day** takes place on September 9th and activities for FASD Awareness Day 2015 included:

- FASD awareness raising materials distributed through Stockton Borough midwife clinics
 - FASD Awareness Stands during week of 9th supported by lifeline service and midwifery services at North Tees Hospital, Stockton Central Library and Thornaby ASDA.
 - FASD banner on internet during week of 7-11 September (1,440 banner clicks)
 - FASD article on KYIT (2,995 views of article)
 - Distribution of FASD infographic through Stockton Pub Watch for licensed premises to display on toilet doors
 - FASD infographic sent to businesses taking part in the Better Health at Work Scheme to display in public staff areas
- 4.10 Work is planned to continue to offer FASD training to multiagency partners across the borough, raise awareness, and to monitor use/impact of the FASD animation loop across services working with children and young people.
- 4.11 The Committee was pleased to consider the work of the locally based FASD Network UK. The Charity started providing help to local families in the North East and North Yorkshire but is now linked in to people across the UK via social media. There are around 200 local families involved across region, with 800 connected with it online. The Charity does not receive core funding or provide commissioned services and its activities are therefore of a largely voluntary nature.
- 4.12 The Network has had success in raising awareness, and practitioners have signposted families to them for further help. The charity has held support groups, family activities, and training of both caregivers and professionals. They have worked with Sunderland University to provide an introductory online module, and contributed to regional paediatric training sessions in 2016.
- 4.13 The Network stated that there were some ongoing challenges. There was a perceived barrier to services (eg. through CAMHS) due to delays to/lack of a diagnosis. In terms of support services, the Committee agreed that the key issue was around using existing resources more effectively, and ensuring the gateways into services/carer support did not exclude those with FASD.
- 4.14 The Committee was impressed with the work of the charity, and the efforts and enthusiasm of the founder, Maria Catterick.

Healthcare

- 4.15 Local GP Paul Williams submitted information to the review. He believed that most patients were aware that alcohol should be avoided in pregnancy. Although most antenatal care is provided by midwives, he was not aware of any guidance issued to GP about FASD diagnosis, or systematic approach to prevention in general practice. There was agreement that more professional and public awareness would be helpful.
- 4.16 Maria Catterick reported that there are relatively few paediatricians who feel confident in making confirmed diagnoses of FASD. A private clinic was available in Surrey, and the nearest specific NHS service was in Liverpool. Although FASD was not easily diagnosed, genetic screening could rule out genetic conditions, helping to narrow down diagnostic challenges.

- 4.17 There were currently three paediatricians training in FASD in the Royal Victoria Infirmary and one in North Tees University Hospital that were agreeing to specialise in this area. Diagnosis did not normally occur in post natal wards as the process took longer, and North Tees and Hartlepool Trust did not record incidence as there was no national code for it.
- 4.18 The Committee found that the North East Maternity Network had taken a lead in raising awareness of FASD. Any alcohol exposure is recorded in a new born child's Red Book, which would assist in tracking back to determine possible causes of disabilities. However, maternity services were only involved in patient care from 8 weeks onwards, and so could not effectively influence behaviour in the early stages of pregnancy.
- 4.19 In relation to smoking, very direct advice is provided to expectant mothers; specific advice on alcohol needed to be provided in a supportive manner.
- 4.20 Safeguarding interventions may be made if there is evidence of significant levels of drinking during pregnancy.
- 4.21 A regional study had been initiated that would test 'book-in' bloods taken by midwives to more accurately assess the levels of drinking in pregnancy. Stockton had previously committed to take part, and the project would start with sampling in the Northumberland area. This would be important to assist in building the evidence base for FASD prevalence in the area.

Education and Children's Services

- 4.22 The Committee found that it was important to start promoting messages on alcohol safety and harm reduction to children of school age.
- 4.23 A local toolkit covering Risk Taking Behaviours for schools had been developed by the Education Improvement Service and this included guidance and support for lesson plans. In 2016-17 this will include information on FASD in secondaries, and a primary version was being developed. These were not compulsory for schools to use in lessons but a good take up was anticipated, as the majority of schools had taken part in the training session linked to the toolkit.
- 4.24 In addition, five secondary schools and eight primaries had attended the school specific FASD training organised by Public Health and outlined above. Ultimately schools needed to take ownership of the preventative work they would undertake.
- 4.25 Schools had noted that very few children born with FASD had received a formal diagnosis, and that the condition overlapped with a range of developmental type disorders. However, Education and Health Care Plans were increasingly referencing FASD as a factor. The Parent and Child should be at the heart of this process using person-centred planning.
- 4.26 The Committee found that local Children's Centres recognised that they were an ideal venue for prevention measures covering a range of issues, and would look to see what more they could do. Ante-natal support was targeted at the more vulnerable expectant mothers, and midwife clinics were based in local centres. Big Life (a provider of a commissioned children centre) recognised an opportunity to integrate FASD prevention into its volunteer and buddy programmes linked to the Fairer Start project in Stockton Town Centre.

- 4.27 Lifeline Alcohol Support was co-located with the Youth Direction team. Youth services included universal, targeted, and preventative work, and this provided the opportunity to undertake informal education work. The Risk Taking Behaviour Roadshow was provided in partnership with schools. The animation highlighted at 4.9f) was developed in conjunction with Chapel Road Youth Club, and a session plan had been created to enable support to be provided to any young people that recognised the symptoms in themselves having watched the video.

Licensing

- 4.28 Members found that from a licensing perspective there were no legal obligations on expectant mothers /licensed trade, but there was an opportunity for further public health messages to be promoted on premises. Pubwatch had been previously supportive when FASD Network UK had raised the issue with them.
- 4.29 General alcohol harm reduction activities would be undertaken in future including mapping problem areas, but the availability and price of alcohol (including drinking in the home) continued to be key issues. The Committee found that the Council was developing a revised Alcohol Strategy and were conscious that this needed to reflect FASD.

Conclusions

- 5.1 Overall, Members feel that a national campaign on the scale of No Smoking or Drink Driving was needed to ensure widespread awareness, and even then it would take some time for the messages to be as widely accepted and acted upon.
- 5.2 There was a need for sensitive conversations regarding levels of drinking; it was perceived that many knew that it was not advisable to drink in pregnancy but not necessarily why this was the case. Prevention messages also needed to be aimed at males, recognising their supporting role.
- 5.3 The number of unplanned pregnancies was 50% so it was likely that many women would drink to some extent without knowing they were pregnant. Preventative messages needed to be sensitive to this, and revised to reflect this.
- 5.4 Reducing levels of drinking overall by targeting the whole population would reduce risks at most levels, and it is important to include FASD in wider campaigns and strategies to reduce alcohol harm overall.

FASD, Alcohol & Pregnancy



Alcohol and Pregnancy Don't Mix

What is FASD?

Foetal Alcohol Spectrum Disorder (FASD) is a term given for a range of disabilities that can be caused when a baby is exposed to alcohol during pregnancy, this can include:

Physical Disabilities

Learning Disabilities

Behavioural Problems

A baby is fully developed by the end of the first trimester of pregnancy

FALSE

Important growth and development to the central nervous system and body continue throughout the 40 weeks of pregnancy

It is just heavy drinking that is the problem

FALSE

The only way to ensure no risk to your baby is by not drinking alcohol in pregnancy

Only a small amount of alcohol can pass to the baby

FALSE

Alcohol passes freely through the placenta so what mum drinks, baby drinks

Surveys and research suggest the number of women drinking alcohol in pregnancy could be as high as 7 out of 10

FASD is permanent and there is no cure

FASD is **PREVENTABLE** - no alcohol, no risk

two glasses of wine counts as a **binge** (6+ units)

50% of pregnancies are **unplanned** so women who drink socially can harm their baby before they realise they are pregnant

For more information about FASD please visit www.fasdnetwork.org
If you are concerned about your drinking talk to your GP, midwife or contact Lifeline Alcohol Support Services on 01642 625980



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ALCOHOL & PREGNANCY DON'T MIX - NO ALCOHOL NO RISK!

WHAT IS FASD?

Foetal Alcohol Spectrum Disorder (**FASD**) is a term given for a range of disabilities that can be caused when a developing baby in the womb is exposed to alcohol – this can include physical disabilities; learning difficulties and behavioural problems – **FASD** is permanent and there is no cure!

But FASD is preventable – no alcohol no risk! 0-4-9.

MYTHS AND FACTS

Myths:

- A baby is fully developed by the end of the first 3 months – so women only need to avoid alcohol during this period. **FALSE.**
- If a woman drank in pregnancy and the baby was fine - then it's OK to do it again. **FALSE.**
- It's just heavy or binge drinking that is the problem. **FALSE.**

Facts:

- Whilst there may be the additional increased risk of miscarriage from drinking alcohol in the first three months, alcohol can damage important growth and development throughout the entire pregnancy.
- The risk of **FASD** depends upon many factors and there is no way of knowing the impact that alcohol may have on the unborn baby – when trying for a baby, or at any stage of pregnancy, a woman can benefit her baby by completely avoiding alcohol.
- Alcohol is a poison - even small amounts can damage the development of an unborn baby - alcohol passes freely through the placenta – so whatever a woman drinks the baby drinks too.



Approximately 1% of all babies born may have some form of **FASD**, meaning around one baby is born each day in the North East with **FASD**.



Binge drinking for a woman is 6+ units in a single session. That's about 2 large glasses of wine.



FASD is the most common, non genetic cause of learning disability in the UK

Any woman wanting to know more about **FASD** should speak to her midwife.

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BALANCE
Getting the
measure of alcohol