The State of Child Health: Fetal Alcohol Spectrum Disorder

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Recommendation

The Board is asked to acknowledge:

- Literature suggests a likely high prevalence of FASD in Ayrshire and Arran;
- the economic and social impact of FASD is substantial;
- FASD is estimated to cost UK £2 billion per annum;
- NHS Ayrshire & Arran have received Scottish Government funding of £930,000 which has allowed staff to develop skills in FASD prevention, diagnosis and support;
- the expertise of NHS Ayrshire & Arran staff locally and the current reputation of NHS Ayrshire & Arran as a centre of excellence for FASD in the UK; and
- alcohol statistics across Scotland and poorer outcomes are strongly linked with those staying in areas with higher levels of deprivation.

The Board is asked to adopt and endorse:

- ‘No Alcohol, No Risk’ message for all staff at every appropriate contact with a woman of child bearing age.
- Fetal Alcohol Advisory and Support Team’s expertise and advice to other boards.
- Implementation of FASD SIGN guideline in Ayrshire and Arran.
- A virtual Pan-Ayrshire knowledge network for FASD to support interested multi-disciplinary staff to connect and to co-ordinate activity and support.
- The FASD strategy for NHS Ayrshire & Arran.

Summary

FASD is caused by alcohol use during pregnancy and is entirely preventable. Research shows that is likely that more than 12,000 individuals in Ayrshire and Arran are affected by FASD. Alcohol consumption across Ayrshire and Arran is higher than the national average, with alcohol-related hospital admissions eight times more common in areas of high deprivation. Early identification of those with FASD is essential to provide adequate supports to help them reach their maximum potential.
Scottish Government funded a pilot project in Ayrshire and Arran for three years to aid the development of a national pathway for the diagnosis of FASD and explore the outcomes of families who accessed the service. A further three years funding has been secured to embed the lessons learned during the pilot project in future service delivery both locally and nationally.

Further local work needs to be carried out within Ayrshire and Arran to continue to raise awareness of FASD, to support those affected and their families, and to ensure adoption of the ‘No alcohol, no risk’ message across all partners.

Key Messages:

1. FASD is preventable. The importance of raising awareness with all staff of the ‘No Alcohol, No Risk’ in pregnancy message, with staff adopting this message at every appropriate contact with a woman of child bearing age.

2. Potential cost savings: diagnosis of FASD and appropriate supports can improve outcomes for the individual and make use of services more effectively.

3. There are clear links with vulnerable groups. 34% of children referred to a community clinic for looked after health assessments and 75% children referred for adoption medicals had a history of antenatal alcohol exposure.

4. Statistics show poorer outcomes for alcohol consumption are strongly related to those staying in areas of higher deprivation.

5. Further work is required across Ayrshire and Arran to continue to increase knowledge and awareness of FASD and to ensure partnership working to facilitate the best outcomes for individuals affected.

Glossary of Terms

<table>
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<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tr>
<td>ABI</td>
<td>Alcohol Brief Intervention</td>
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<td>ADP</td>
<td>Alcohol and Drug Partnership</td>
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<td>CAMHS</td>
<td>Child and Mental Health Service</td>
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<td>CPD</td>
<td>Continuing professional development</td>
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<td>FAAST</td>
<td>Fetal Alcohol Advisory and Support Team</td>
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<td>FAS</td>
<td>Fetal Alcohol Syndrome</td>
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<td>FASD</td>
<td>Fetal Alcohol Spectrum Disorder</td>
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<td>LAAC</td>
<td>Looked After and Accommodated Children</td>
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<td>NHS A&amp;A</td>
<td>NHS Ayrshire &amp; Arran</td>
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<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
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<td>SIMD</td>
<td>Scottish Index of Multiple Deprivation</td>
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1. Background

Key points:

- FASD is caused by alcohol use in pregnancy
  - Small amounts of alcohol can cause harm
  - Most common cause of neurodisability in the western world
- FASD is entirely preventable
- FASD results in vulnerability
  - Mental health issues
  - Addiction
  - Unemployment
  - Homeless
- Most cases remain undiagnosed

1.1 What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) and fetal alcohol syndrome (FAS) are diagnostic terms covering a range of permanent and irreversible lifelong conditions caused by antenatal alcohol exposure. Both conditions are entirely preventable. Prenatal alcohol exposure is therefore a major public health concern.

FASD includes Fetal Alcohol Syndrome – a diagnostic term used in the USA\(^1\), in which an affected individual displays characteristic facial features and growth restriction in addition to atypical neurodevelopment. FAS cases account for 10% of overall FASD cases, meaning that the vast majority of individuals affected by FASD are affected by neurodevelopmental or physical disability in the absence of identifying facial or growth features\(^2\).

Alcohol is the most widely studied antenatal drug of misuse and is regarded as the most teratogenic substance in common use\(^3\). It affects how the brain is ‘wired’ and it is associated with a range of difficulties:

1.2 What is the impact of FASD?

Figure 1 shows an example profile of an 18 year-old with FASD. FASD is often referred to as a ‘hidden disability’ as the vulnerabilities in understanding, social skills and decision making can be masked by an age-appropriate physical demeanour, reading level and expressive language skills.
Each person diagnosed with FASD is affected in an entirely unique way, with no two profiles identical. For example, one person may have poor processing and retentive skills, but have good expressive language that masks their other difficulties.

However in reality, individuals with FASD who remain undiagnosed and unsupported struggle to meet the expectations of society.

Research has demonstrated poor outcomes:

- 94% had mental health problems
- 83% need supported living
- 79% had employment issues
- 35% had been in prison
- 46% of adults had drug and alcohol problems

The scale of FASD and its impact on the population of the UK is grossly under recognised. This unrecognised and unmet need in our children and young people is having a devastating impact and contributing to the difficulties faced by individuals, families and society as a whole. It is estimated to cost approximately £1.3 million to support an affected individual across their life span (excluding criminal justice costs). Estimated cost for UK as whole is £2 billion per annum.

1.3 Do women still drink in pregnancy?

Key points:

- 41.3% of UK women consume alcohol in pregnancy
It is crucial to note that a large percentage of pregnancies in the United Kingdom are unplanned – it estimated that 16.2% of pregnancies are unplanned, 29.0% ambivalent, and 54.8% planned. A fetus may therefore be alcohol-exposed before the mother is aware she is pregnant.

A gold-standard meta-analysis in 2017 estimated that 41.3% of pregnant women in the UK consumed alcohol during their pregnancy. This estimate is 4th highest in the world, behind Ireland (61%), Belarus (47%), and Denmark (46%), and followed by Russia (36%).

We also know that within 2016/17, 37.4% of women in Ayrshire and Arran discussed drinking alcohol in the three months prior to becoming pregnant at antenatal booking.

Recently in Glasgow, a team studied metabolite biomarkers of alcohol exposure in the meconium of full-term newborn infants. These metabolites identify third trimester maternal alcohol consumption. They found that 42% of samples showed significant levels of metabolites associated with alcohol consumption with 15% of pregnancies exposed to very high levels of alcohol.

1.4 How prevalent is FASD?

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<tr>
<td>- Affects 3.2% of live births (likely underestimate)</td>
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<tr>
<td>- 4 x as common as autism</td>
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It is estimated that approximately 3.2% of live births are affected by FASD, which is 3 to 4 times the rate of autism. The full extent of FASD remains unknown however, based on community studies using physical examinations, experts estimate that in the United States and Western European countries that 4-5% of school children may be affected. 3.2% is very likely to be an underestimate.

Prevalence is also thought to be higher in vulnerable groups. Children in the UK Child Care system (including those moved on to adoption), for example, are at significantly increased risk. Studies suggest 34% of children referred to a community clinic for looked after health assessments and 75% children referred for adoption medicals had a history of antenatal alcohol exposure.

1.5 What does this mean for FASD in Ayrshire and Arran?

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<tr>
<td>- High prevalence in NHS Ayrshire &amp; Arran</td>
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<td>- High cultural consumption of alcohol</td>
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<td>- Estimated at least 12,000 affected individuals living in Ayrshire and Arran (3.2%)</td>
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<td>- 2,000 under age of 16 years</td>
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<td>- 130 infants born every year affected by pre-natal alcohol exposure</td>
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<td>- Likely underestimate</td>
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<td>- Majority undiagnosed</td>
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<td>- Prevention message is crucial</td>
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It is difficult to estimate UK prevalence in the absence of UK studies. However, in Ayrshire there is a generally high cultural consumption of alcohol. Statistics show that during pregnancy; there are high maternal smoking rates, obesity, poor breastfeeding rates and high reported alcohol/substance misuse. These factors coupled with high deprivation levels, poorer educational attainment, unemployment – also present in Ayrshire and Arran - would suggest a likely high prevalence of FASD⁵.

The Scottish Index of Multiple Deprivation (SIMD) provides a broad overview of the health and wellbeing of the residents of Ayrshire and Arran. Within Ayrshire and Arran there are 151 data zones (each containing approximately 760 residents) that are considered to be amongst the most deprived in Scotland¹⁴. One of the key measures for SIMD is the standardised rate for alcohol related hospital admissions. Alcohol admission rates have remained higher in Ayrshire in comparison to Scotland as a whole. Across Scotland in 2016/17, alcohol-related stays in general hospitals were nearly eight times more frequent for individuals living in the most deprived areas compared to the least deprived areas¹⁵. These statistics help provide a broad overview of the general population within Ayrshire and Arran.

With an estimated prevalence of 3.2% the number of people living in Ayrshire who have been affected by antenatal alcohol exposure is likely to be at least 12,000. Ayrshire Maternity Unit sees approximately 3,500 births per year. The estimated prevalence would result in at least 113 babies born each year that have been affected by antenatal alcohol exposure. Prevalence may be higher.

Prevention of prenatal alcohol exposure is key and the rationale behind this message also needs publicised and understood both locally and nationally for cultural and meaningful change to occur.

Awareness of FASD in health care workers in NHS Ayrshire & Arran has vastly increased in the last few years. FASD is now being routinely considered and assessed for in Child and Adolescent Mental Health Services and Community Paediatrics. Intensive training has been provided to paediatricians, health visitors, midwives, mental health nursing, clinical psychologists, and social care workers in order to improve recording of alcohol exposure and identification, assessment access and capacity, and recording of those affected by FASD. In a context of increasing recognition and diagnosis rates, there is an urgency to ensure that there is a strong understanding of FASD within partnership agencies. We must make certain that appropriate supports can be accessed by individuals and families.

There is recognition within Ayrshire and Arran that although there is current provision to diagnose children with FASD, there is not current provision to diagnose adults. Discussions are currently taking place to seek ways to address this issue.

1.6 Does diagnosis matter?

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<th>Key points:</th>
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<tr>
<td>• Early identification and support</td>
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<td>• is protective</td>
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<tr>
<td>• improves attainment</td>
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<tr>
<td>• reduces behavioural problems, social exclusion and mental illnesses</td>
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<td>• reduces cost</td>
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FASD remains undiagnosed in the majority of cases and children and young people affected often move between different aspects of NHS provision. The assessment of FASD can be largely dependent upon professional groups being aware of the condition and confident in the process by which individuals can be formally identified, assessed and supported. FASD also carries a high likelihood of co-morbid physical and psychological difficulties. Early identification of FASD is a protective factor that is associated with a reduction in associated adverse outcomes such as mental health issues, poor educational attainment, homelessness and involvement with the criminal justice system. The pivotal factor is that children can be accurately understood in terms of their social and neurological profile. This is with the dual benefit of reducing assumptions of what may be driving learning or behavioural difficulties, and to impart knowledge of the child’s learning profile so that others’ (particularly colleagues in education) can harness the child’s strengths and target areas to maximise attainment and enjoyment of school.

Individuals with FASD are more likely to access services such as health care, mental health services, substance use treatment programmes, criminal justice and require additional support through school and further education which collectively contribute to the overall cost of FASD across the lifespan.

2. Scottish Government Funding

The Board’s previous commitment to the Alcohol and Pregnancy agenda laid the foundations for the successful bid for Scottish Government funding. At total of £930,000 of funding has been secured (August 2015 – March 2021).

2.1 Pilot project – Diagnosis and Support Pathway

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<th>Key points:</th>
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<tr>
<td>- Scottish Government funding of £430,000 (August 2015 - September 2018)</td>
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<td>- Diagnosis, assessment and support focus</td>
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<td>- Knowledge and expertise developed</td>
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<td>- Service evaluation near completion (launch Sept 2018)</td>
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<td>- Enhanced local services</td>
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<td>- NHS A&amp;A now has reputation of a centre of excellence for FASD</td>
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<td>- Staff hold a number of key roles nationally</td>
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NHS A&A previously piloted three specialist midwife posts jointly funded by the Alcohol and Drug Partnerships team and by the Fresh Air-Shire service, looking specifically at delivery of alcohol brief interventions and training of staff, and smoking cessation for pregnant women. The post holders developed an innovative alcohol screening tool for use with antenatal women.

With this previous commitment to the alcohol and pregnancy agenda, the Scottish Government commissioned NHS A&A to pilot the pathway for assessment, diagnosis and support for children affected by antenatal alcohol exposure as developed by the Scottish Government’s FASD Care Pathway Group, for all children pre-birth to 11 years of age.
In 2014, NHS Ayrshire & Arran were successful in securing funding to set up a novel multidisciplinary clinic for the assessment and support of children with suspected Fetal Alcohol Spectrum Disorder. This was as part of the Scottish Governments strategy to support Children Affected by Parental Substance Misuse and the development of a National Pathway for the Diagnosis of FASD.

The primary objective of the pilot was to explore the outcomes for children and families who accessed assessment, diagnosis, and support of FASD in Ayrshire.

Secondary objectives were:

- Examine the two processes by which children and families access assessment, diagnosis, and support with FASD in Ayrshire
- Explore service user satisfaction
- Explore changes in knowledge and attitudes to FASD amongst professional groups in Ayrshire.

36 children were assessed via the pilot pathway, and since 2015 the team are aware of more than 200 cases within CAMHS and Community Child Health Services where support has been provided.

The service evaluation looks at four key areas: Processes, Outcomes, Satisfaction and Knowledge. The results of the evaluation will be available in September 2018. The evaluation data is the property of NHS Ayrshire & Arran.

In addition, the FAAST members have been involved in a number of key roles nationally –

- FASD SIGN Guideline Group members (launch November 2018)
- Support FASD Clinicians’ Forum (Scottish Government funded)
- Link with Clinicians from the National UK FASD clinic
- Awareness raising at national, cross sector, conferences and events
- Promoting curriculum change within relevant professional groups

2.2 Extended Funding: Growth of Knowledge and Support

Key points

- 3 years of additional funding now secured (£500,000)
  - Funding established ‘Fetal Alcohol Advisory and Support Team’
- Local remit
  - Establish local multi-agency knowledge network/virtual hub
  - Continue to support cross-sector service developments for FASD
- National remit
  - Training and awareness raising
  - Case consultancy and support

Following the success of the pilot, additional funding was sought to establish the formation of a Scottish Government Fetal Alcohol Advisory & Support Team. The driver was to maintain the momentum of current learning, and ensure that the experience gained thus far is embedded in future service delivery both at local and national level.
The overarching aim is to “Work together to improve knowledge, attitudes and confidence to better support individuals affected by FASD” with the ultimate aim of improving outcomes for all individuals affected by FASD.

Anticipated work streams include Prevention, Awareness and Identification, Training, Consultancy and Research. Ultimately the aim of the project will be to improve outcomes for individuals affected by prenatal alcohol exposure; with a clear focus on education and prevention.

The additional funding allows expansion from a local focus to extending consultation, training and support nationally. Our Prevention and Communication strategy will have a national focus as well as continuing momentum in Ayrshire. The project involves health and community partner agencies, and takes a longitudinal view of how supports can be implemented and sustained by all of our available community resources (such as the third sector and education services more broadly). We will seek to strengthen links with Educational Psychology and other professions who are identified as critical partners in supporting positive outcomes for individuals with FASD. In addition to this the team will develop knowledge of current thinking in ‘Implementation Science’ in an attempt to better support and sustain the development of FASD services across Scotland.

We will intensively support the creation of any FASD special interest or knowledge group that arises in any agency and as part of this, an early aim is to identify ‘FASD Champions’ within NHS Ayrshire & Arran partner agencies. These will be interested and dedicated parties who believe that they can have an impact on the implementation of new services for those affected.

2.3 National Remit of NHS Ayrshire & Arran Staff

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<th>Key points:</th>
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<tr>
<td>NHS Ayrshire &amp; Arran staff are involved in:</td>
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<tr>
<td>- National case consultation</td>
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<tr>
<td>- FASD SIGN guideline (launch due Autumn 2018)</td>
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<tr>
<td>- Peer engagement</td>
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<tr>
<td>- Clinical pathways development</td>
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<tr>
<td>- Training and awareness raising</td>
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<tr>
<td>- Sharing of learning</td>
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<td>- Independent research</td>
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The team will provide clinical consultancy and resources to those across Scotland. This already occurs on an ad-hoc basis, but would be openly available and advertised as a service by September 2018. Members of the FAAS Team are on the FASD SIGN Guideline group and will encourage the implementation of these guidelines through our activities with other clinicians. We will link with partner agencies to facilitate the writing and implementation of these national guidelines.

In order to facilitate services to work with individuals affected by FASD after the involvement of Fetal Alcohol Advisory and Support Team, we will encourage the development of peer supervision and clinical forums. This allows our colleagues to learn from, and be supported by, one another, not just by our team. We will contribute to the
FASD Clinicians Forum, and encourage and contribute to professional CPD and training around FASD.

We aim to be involved with the pathway group for the development of neurodevelopmental assessment and treatment in NHS A&A and would be keen to contribute to discussion on similar topics nationally. We can consult about clinical pathway design and implementation, and how to create services that work for individuals affected by FASD. Through strategic input via the Children’s Change Programme, we are keen to stress the prevalence of FASD in LAAC populations and promote proactive screening in these populations.

The FAAS Team continues to offer a local training calendar for individuals across the Health and Social Care Partnerships. This training has been designed and dates have been allocated. This is general FASD awareness training aimed at raising the profile of FASD as a consideration for professionals across health and social care.

The team aims to design a FASD Learn-pro module for NHS staff within the first year (by April 2019). This would be completed in collaboration with the Learn-pro team in NHS A&A.

Our awareness trainers will design Training for Trainers on FASD awareness, in order to alleviate the pressures of training on the FAAS team exclusively. This will allow the message to be taken forward by others and be fully implemented in health and social care, rather than requiring the FAAS team to sustain the momentum. This is proposed to occur in collaboration with our colleagues in NES and initial steps will be to discuss whether this could be appropriately integrated within their existing frameworks.

The team will promote awareness training in specific populations such as Adult Mental Health, Learning Disability, and the Criminal Justice system. These services have been identified as those for whom awareness around FASD is low but is needed in order to best serve the needs of those affected by prenatal alcohol exposure.

The team will evaluate the need for bespoke FASD awareness training for those in populations who may have specific needs which make generic training unsuitable. Some examples of these populations include forensic or criminal justice services, adoptive services, and carer groups.

The team will offer local and national diagnostic training. This training has been designed for specific disciplines (Clinical Psychology/CAMHS, Paediatrics) and is available for use locally in a role-specific manner by appropriate FAAST clinicians. This will be further developed in collaboration with colleagues from the Manitoba FASD Centre and the Scottish Government. The training will then be offered nation-wide.

The team will make links with college and university-level professional education courses where early knowledge of FASD embedded within the curriculum would improve future clinician awareness of FASD. These include the Doctorate in Clinical Psychology at Glasgow University as an initial target for inclusion of FASD onto the curriculum, in respect to neurodevelopmental conditions. In some cases it will be possible only to create optional lectures around this topic, which will be offered by the team.

In addition to the extensive clinical experience the FAAS team has gained over the past 2½ years, the findings from the project service evaluation provide important learning points. With the agreement of the Scottish Government, these will be circulated locally and nationally by September 2018. The FAAS team are committed to ensuring a wide
audience is reached and the service evaluation findings will be available and delivered in a variety of formats (e.g. full document, executive summary, service user summary, presentations at meetings and conferences).

The team has had an Assistant Psychologist and a Clinical Psychologist with the ability to conduct separate research projects. These projects would contribute both to the evidence base surrounding FASD in Scotland and also to the expertise of the team. Ethics proposals are under submission with Research and Development for two separate additional research projects – one qualitative and one quantitative. These will continue to pass through ethics and would start as soon as approval is received.

In summary, the project will span a number of areas and work on a multilevel basis to meet our aims and deliver desired outcomes for those affected by FASD.

See Appendix A - ‘Driver Diagram - Fetal Alcohol Advisory and Support Team’

3. **Ongoing FASD work across Ayrshire and Arran**

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<thead>
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<tr>
<td>- FASD Strategy for Ayrshire and Arran 2018-2021 agreed by all partners</td>
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<td>- The first permanently funded post in Scotland with hours dedicated to FASD.</td>
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<td>- Extensive Multi-agency training and awareness provided</td>
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<td>- &gt;2,000 staff in 2 year period</td>
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<td>- Only NHS-established FASD support group UK</td>
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<td>- Parent resource – now in use throughout Scotland</td>
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<td>- Education resource in progress</td>
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<td>- Establishing links with Third Sector Organisations</td>
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There has been ongoing work on FASD across Ayrshire and Arran for a number of years. Since 2012, the three local Alcohol and Drug Partnerships have funded a post responsible for delivering FASD training and education across all three partnerships. The post also had responsibility for the training of midwives on recording and delivery of alcohol brief interventions (ABI), collating ABI figures, delivering tiered and bespoke training, developing resources, highlighting gaps in service, and supporting services users and staff. Bespoke training was also available for carers and educational establishments who were dealing with a child diagnosed with FASD.

The post was originally a Specialist Midwife (Alcohol) but changed to a Substance Misuse Specialist due to availability of staff. Due to changing funding allocations to ADPs from Scottish Government, funding for this post continues to be short-term, and the post is reconsidered on a yearly basis. Allocations for ADPs from Scottish Government are often not confirmed until July, which means that there are contractual difficulties around supporting a member of staff in this post. At this time, this post in Ayrshire and Arran is currently vacant.

Due to the continued work on FASD in Ayrshire and Arran, and the ongoing commitment to FASD, public health resourced and funded the only permanent FASD post in Scotland. This post is equivalent to half-time hours, with the rest of the post dedicated to improving maternal health.
Both of these posts have complimented the work of the FASD Clinical Co-ordinator within the pilot project, with just fewer than 2,000 staff trained across a wide range of disciplines from Sept 2016 to June 2018.

An FASD strategy (Appendix B) has been developed for Ayrshire and Arran and agreed by all partners. The ‘Making Sense of Fetal Alcohol Spectrum Disorder: Ayrshire and Arran Strategy, 2018-2021’ looks at four key areas: Prevention; Training & Awareness; Diagnosis; Interventions and Support. Each of the four key areas has actions and measures agreed. Partnership working is a key component of this strategy to reduce the social, financial and educational impact of FASD and ensure that every individual reaches their full potential.

The central message surrounding this work is ‘No Alcohol, No Risk’. FASD is entirely preventable. Prevention of FASD is key to reducing the prevalence of FASD across Ayrshire and Arran.

The ‘No Alcohol, No Risk’ message needs to be recognised by the population at large and most significantly delivered by all key partners throughout Ayrshire and Arran. The rationale behind this message must also be promoted and understood. It is the goal of the strategy that all key professionals will have the confidence to promote the ‘No Alcohol, No Risk’ message at every suitable contact with women of child-bearing age.

Training will continue to be offered on a regular basis throughout Ayrshire for all multiagency staff. A library of resources will be completed and made available for staff throughout Ayrshire.

Children within Ayrshire shall continue to be assessed and diagnosed with FASD where appropriate within mainstream services.

A professional support hub shall be created within Ayrshire to provide expertise and ensure partnership working to help improve outcomes for children diagnosed with FASD. Working in collaboration with key partners will reduce the likelihood of additional adverse effects and ensure the best possible outcomes for each individual.

A local FASD conference: Breaking Down Barriers was held in March 2017 and attended by more than 200 delegates. Within the scope of the new project funded by Scottish Government it is likely that we will hold a future conference in Ayrshire and Arran.

A support group for parents and carers was established in January 2016. This is the only NHS-backed support group in the UK. The group meets once a month and provides much needed support for families living with FASD. The group is currently supported by both the public health funded post, and the FASD Clinical Co-ordinator. But as the pilot draws to a conclusion there may be issues with continuing support for the group.

A parent/carer resource has been developed with input from families attending the support group. The resource is widely used both locally and across Scotland, with further work developing a resource pack for professionals and education underway.

Locally and nationally, we aim to link with third sector organisations such as Barnardos, Includem, NoFAS, FASD Trust, FASD Scotland, and WhoCares? This would help support the development of future services to improve the outcomes for those affected by FASD and their families. In addition, collaboration will reduce the strain on health services to whom the affected individuals are approaching for support.
4. Conclusion

The innovative work carried out within Ayrshire and Arran on FASD, alongside the local research, has been a driving force in mapping the way for future service development across Scotland. It is critical that training and education across all agencies continues to allow identification of individuals with FASD to help them achieve their maximum potential.

The ‘No Alcohol, No Risk’ message is an essential component for all staff working with women of child bearing age. Further work is required across Ayrshire and Arran to continue to increase knowledge and awareness of FASD and to ensure partnership working to facilitate the best outcomes for individuals affected.
References


### Monitoring Form

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<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Policy/Strategy Implications</strong></td>
<td>The ‘Making Sense of Fetal Alcohol Spectrum Disorder’ strategy supports ongoing work across Ayrshire and Arran.</td>
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<td></td>
<td>The FASD SIGN guideline is due for launch in Autumn 2018. It is anticipated that the recommendations can be imbedded within current services.</td>
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<tr>
<td><strong>Workforce Implications</strong></td>
<td>No current workforce implications.</td>
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<tr>
<td><strong>Financial Implications</strong></td>
<td>No current financial implications.</td>
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<tr>
<td></td>
<td>Potential long-term cost savings by using existing resources more effectively and decreasing need.</td>
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<tr>
<td><strong>Consultation (including Professional Committees)</strong></td>
<td>Consultation and engagement on the development of the FASD strategy has taken place with partners.</td>
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<tr>
<td><strong>Risk Assessment</strong></td>
<td>Not undertaken</td>
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<tr>
<td><strong>Best Value</strong></td>
<td>The work around FASD could impact a number of Best Value themes including: Effective Partnerships, Vision and Leadership, and Use of resources.</td>
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<tr>
<td>- Vision and leadership</td>
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<td>- Effective partnerships</td>
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<tr>
<td>- Governance and accountability</td>
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<td>- Use of resources</td>
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<tr>
<td>- Performance management</td>
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</tr>
<tr>
<td><strong>Compliance with Corporate Objectives</strong></td>
<td>This paper addresses a number of corporate objectives including: improving health and wellbeing of the population and reducing inequalities, creating compassionate partnerships and delivering best value.</td>
</tr>
<tr>
<td><strong>Single Outcome Agreement (SOA)</strong></td>
<td>Partnership working is key to the delivery of this work.</td>
</tr>
<tr>
<td><strong>Impact Assessment</strong></td>
<td>Equality Impact Assessment (EQIA) has yet to be carried out but will be if required in the future.</td>
</tr>
</tbody>
</table>
Appendix A
“Driver Diagram - Fetal Alcohol Advisory and Support Team”

**Aim:**
To improve outcomes for individuals affected by FASD

**Objectives:**
1. To develop FASD local / national knowledge hubs within generic services to aid work on FASD prevention, identification and support in Scotland.
2. To deliver training locally and nationally to improve knowledge, attitudes and confidence in professionals working with individuals with FASD.
3. To further knowledge of FASD via the systematic expansion of the evidence base and to further develop practice based research and audit.

**Primary Drivers**

- **Prevention**
  - Support midwives to deliver ABIs.
  - Support midwives / neonatal staff to improve alcohol documentation in neonatal / maternity records.
  - Make midwives aware of role in FASD prevention.
  - Co-creation of overarching public health strategy.
  - FASD Awareness Day.

- **Consultancy**
  - Offer local and national case consultation.
  - Offer local and national resources.
  - Facilitate peer supervision and clinical forums on FASD.
  - Link with partner agencies to facilitate writing / implementation of national guidelines.
  - Offer consultation around clinical pathway development.

- **Training**
  - Offer FASD Awareness training calendars across HSCP’s.
  - Learn-pro module design and launch.
  - Design & launch of national T4T.
  - Evaluate need for, and offer bespoke Awareness training (adult, forensic).
  - Development of Diagnostic Training (specific).
  - Strengthen links with existing NES frameworks.
  - Professional Training to include FASD awareness.

- **Support**
  - Support FASD specialist hub development in HSCPs locally and nationally.
  - Continue to develop links with Education.
  - Establish links with Adult/Forensic Services.
  - Establish links with Vol Orgs.
  - Continue to develop FASD support group.

- **Communication**
  - Develop Communication Strategy.
  - Gain online presence (e.g. social media, website).
  - Develop Local FASD Strategy.
  - Bank of resources.
  - Work to gain representation on HSCP/ADP meetings & identify champions.

- **Research**
  - Disseminate service evaluation results.
  - Carry out independent quantitative and qualitative research projects.
  - Present findings at local, national and international events.
Appendix B

Making Sense of Fetal Alcohol Spectrum Disorder: Ayrshire & Arran Strategy 2018-2021
What is FASD?
The term Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a range of irreversible physical, psychological, neurological and developmental conditions that may affect a person when they were exposed to alcohol during pregnancy. Studies have shown that exposure to alcohol during pregnancy can lead to long-term effects on growth, behaviour, cognition, language, and achievement, with alcohol being the most common identifiable teratogen (substance causing birth defects) associated with intellectual disability. Prenatal alcohol exposure is therefore a major Public Health concern.

How common is FASD?
It is estimated that approximately 2% of live births are affected by FASD which is twice the rate of autism. The full extent of FASD remains unknown however, based on community studies using physical examinations, experts estimate that in the United States and Western European countries that 4-5% of school children may be affected. It is difficult to estimate UK prevalence in the absence of UK studies. However, in Ayrshire there is a generally high cultural consumption of alcohol along with other poor lifestyle choices. These are particularly apparent during pregnancy, high maternal smoking rates, obesity, poor breastfeeding rates and high reported alcohol/substance misuse. These factors coupled with high deprivation levels, poorer educational attainment, unemployment and low aspirations would suggest a likely high prevalence of FASD. With an estimated prevalence of between 2 and 5% the number of people living in Ayrshire who have been affected by antenatal alcohol exposure is likely to be between 7,336(2%) and 18,340(5%). Ayrshire Maternity Unit sees approximately 3,500 births per year. The estimated prevalence would result in 70(2%) - 175(5%) babies born each year that have been affected by antenatal alcohol exposure.

Prevalence is also thought to be higher in vulnerable groups. Children in the UK Child Care system (including those moved on to adoption), for example, are at significantly increased risk. Studies suggest 34% of children referred to a community clinic for looked after health assessments and 75% children referred for adoption medicals had a history of antenatal alcohol exposure.

What are the cost implications of FASD?
Whilst there are very few studies in the UK with regards to the cost of FASD, there are various studies from America and Canada estimating the cost across the lifespan. The estimated lifetime cost of care, including social and health care services, for each child born with FASD in Canada is thought to up to $2.44 million. The estimated cost to the Canadian Criminal Justice system is estimated to be $234 million CND. The calculated expense of raising a child with FASD is 30 times the cost of preventing the FASD. The estimated cost to care for a child with FASD was 9 times
that of a child without FASD. In the UK this is thought to estimated as high as £3 billion.\textsuperscript{17} Individuals with FASD are more likely to access services such as health care, mental health services, substance use treatment programmes, criminal justice and require additional support through school and further education which collectively contribute to the overall cost of FASD across the lifespan.

**What can we do to improve outcomes?**

FASD remains undiagnosed in the majority of cases and children and young people affected often move between different aspects of service provision. The assessment of FASD can be largely dependent upon professional groups being aware of the condition and confident in the process by which individuals can be formally identified, assessed and supported. FASD also carries a high likelihood of co-morbid physical and psychological difficulties.\textsuperscript{11} Early identification of FASD is a protective factor that is associated with a reduction in associated adverse outcomes such as mental health issues, poor educational attainment, homelessness and involvement with the criminal justice system.\textsuperscript{12} It can add to the collaborative understanding of the affected child or young person. The pivotal factor is that children can be accurately understood in terms of their strengths and difficulties. This will help to reduce assumptions of what may be driving learning or behavioural difficulties, and to share knowledge of the child’s neuropsychological profile so that others’ (particularly colleagues in education) can harness the child’s strengths and target areas to maximise attainment and enjoyment of school.\textsuperscript{13} Appendix 1 demonstrates some of the outcomes later in life for those affected with FASD.

**What have we done so far?**

In 2010 NHS A&A, in response to SG HEAT Target, piloted an Antenatal Alcohol Brief Intervention (ABI) service. This was funded in collaboration with the three local Alcohol & Drug Partnerships. The post holders developed an innovative screening tool for use with antenatal women. This work has been presented at international conferences. The funding was subsequently reduced with one member of staff supporting the ABI work and delivering FASD multidisciplinary training. This post continues to be funded by the ADPs and is hosted within NHS A&A Public Health Department and is reviewed on a year to year basis. Funding for a half-time post within Public Health has been secured on a permanent basis to consider the FASD agenda.

With this previous commitment to the Alcohol & Pregnancy agenda, the Scottish Government (SG) commissioned NHS A&A to pilot a pathway for assessment, diagnosis and support for children and families affected by antenatal alcohol exposure for all children pre-birth to 12 years. The research component of the pilot will facilitate learning that can be shared locally, nationally and internationally. The Fetal Alcohol Assessment & Support Team (FAAST) had capacity to assess and support 36 children over 2 years. In addition to the pilot caseload, the team have highlighted the high number of children within current local services who meet the criteria for FASD assessment. Learning outcomes from the pilot enable the team to support other clinicians and professionals to assess, diagnose and support families affected by FASD.
A local FASD conference: Breaking Down Barriers was held in March 2017 with 200 attendees. Feedback from the conference was positive although the evaluation highlighted that there is currently no provision for FASD diagnosis for adults in NHS A&A. This is an area for further exploration.

Training for FASD awareness has been available across Ayrshire and Arran for multidisciplinary staff and partner agencies for more than five years. Bespoke training is also available for carers and educational establishments who are dealing with a child diagnosed with FASD.

**What do we want this strategy to achieve?**

First, we want to continue to raise awareness of FASD and the primary message that it is preventable. The adoption of the No Alcohol, No Risk message by all partners would be our first objective.

FASD is not just a health issue, it’s everyone’s business. We must all take ownership and work together to reduce the social, financial and educational impact of FASD and ensure that every individual reaches their full potential.

Although the primary diagnosis of FASD is usually made within health services, FASD is not just a health issue. Individuals who live with FASD will come into contact with numerous services across their lifespan. It is vital that we work in partnership to improve the outcomes for all individuals affected by FASD.

It was decided that the simplest way to lay out this strategy was to consider four key areas. **Prevention; Training & Awareness; Diagnosis; and Interventions & Support.**

**Prevention**

Evidence suggests that women who drink to hazardous levels (more than 14 units/week) are more likely to drink throughout their pregnancy. Alcohol has become normalised within our culture and with an estimated 50% of pregnancies being unplanned, the risk of alcohol exposure to the developing fetus increases. FASD is 100% preventable. It is essential that everyone working across Ayrshire and Arran Health Board, the three Integrated Health and Social Care Partnerships (IH&SCP) and three local Councils are mindful of the No Alcohol, No Risk message.

**Activities:**

The No Alcohol, No Risk message for pregnant women and those trying to conceive ensures continuity of advice offered by Midwives and key professionals across the IH&SC Partnerships.

In Ayrshire & Arran, the No Alcohol, No Risk message and the inception of Antenatal Alcohol Brief Interventions (ABIs) was introduced in response to the Scottish Government HEAT target (2008-2011). Where there is evidence that a pregnant woman has consumed alcohol following conception, the Midwife will offer a Brief
Intervention. An ABI is a short, structured conversation that seeks to motivate the woman to abstain from alcohol for the duration of her pregnancy. This in turn will reduce further alcohol exposure and prevent alcohol related harm, including FASD.

A locally produced Alcohol & Pregnancy resource further supports the No Alcohol, No Risk message. The Scottish Government is currently supporting the resource with a condensed version being included in the Health Scotland document Ready, Steady, Baby Book.

Collaborative working across the 3 Alcohol & Drug Partnerships (ADPs) and three local councils is instrumental in supporting the prevention work to reduce alcohol related harm during pregnancy. The 3 ADPs, in conjunction with NHS A&A Public Health, fund a Substance Use Specialist (Pregnancy) post to support midwives with alcohol screening and delivery of ABIs. Working together across the IH&SCP, schools and higher educational establishments will provide a greater awareness of the potential risks caused by alcohol during pregnancy and ensure the No Alcohol, No Risk message is clear.

**Proposed Actions:**

1. To work in partnership with other agencies to ensure that by 2019 every client contact promotes the No Alcohol, No Risk message.
2. To identify champions by 2018 across Integrated Health and Social Care partnerships and local councils to help spread the message among staff.
3. To support midwives to screen for alcohol use and deliver Antenatal Alcohol Brief interventions.
4. To reduce the number of pregnancies exposed to alcohol by monitoring ABI’s.

**Measures:**

1. All attendees at FASD training will be invited to participate in post-training evaluation regarding promoting the No Alcohol, No Risk message.
2. Identify 6 champions, 1 in each IHSCP, and 1 from education in each local council area, All champions will have attended training.
3. Numbers of midwives who have undertaken refresher training.
4. No of ABI’s delivered in Ayrshire and Arran.

**Training & Awareness**

There are no known safe levels of alcohol during pregnancy. High levels of alcohol consumption is known to increase the risk of Fetal Alcohol Spectrum Disorder (FASD) however, the risks from low level drinking are less clear. That said, it cannot be predicted what fetus is most vulnerable and which one will be affected by low level alcohol exposure. Even low levels of alcohol exposure have been known to cause FASD which can lead to developmental, behavioural and learning concerns. It is essential that there is a clear message of No Alcohol being the safest option during pregnancy. Training and awareness is the key component in keeping this message consistent.
Activities:

A multidisciplinary FASD training programme has been devised in response to evidence that services required accessible information and education to support their understanding and recognition of FASD. In partnership with the three ADPs, a full training and awareness calendar is delivered across Ayrshire (Appendix 2).

Education staff are in an ideal place to identify early signs of FASD. A training schedule has been devised to increase teaching staff awareness and understanding of FASD. Additionally, specialist training is offered to early years centres, schools and colleges following diagnosis of a child with FASD.

Since 2012, the requests for, and the attendance at training and awareness sessions has increased. Whilst training sessions were initially attended mainly be health staff, over the last five years the FASD training sessions are now attended by a wide variety of multi-disciplinary staff.

In the last year – September 2016-September 2017 – 60 training sessions have been delivered to a total of 955 participants. Team members have also spoken at 6 conferences, attended by 453 delegates.

This can also be demonstrated by the wide range of partners who attended our most recent FASD awareness raising conference (Figure 1 & with further breakdown in Figure 2).

![Figure 1: Attendance at Conference](image)

- Social Work: 34%
- Education: 29%
- Other: 26%
- CAMHS: 5%
- Community Paediatrics: 4%
- 3rd party organisation: 2%
Whilst our figures demonstrate some of the training and awareness raising going on, it is important that we continue to support this momentum across Ayrshire and Arran and all partners.

**Actions:**

1. To increase public awareness of FASD.
2. To provide resources and support that will benefit professionals when formulating care/neuropsychological plans for children and young people with FASD by 2019.
3. To ensure agencies/services work together to raise the awareness of FASD.
4. To provide health and other key professionals including education, with the confidence to promote the No Alcohol during pregnancy message at every suitable contact with women of child bearing age by 2019.

**Measures**

1. One learning event a year available to both public and professionals alongside FASD awareness day.
2. A library of resources will be made available in collaboration with FAAST and education services.
3. Identify 6 champions, 1 in each IHSCP, and 1 from education in each local council area. All champions will have attended training.
4. 10 full day training sessions will be available throughout the year for all multiagency staff across Ayrshire.

**Diagnosis**

The assessment of FASD can be largely dependent upon professional groups being aware of the condition and confident in the process by which individuals can be formally identified, assessed and supported.

Dr John McClure, MBE was instrumental in the very early stages of diagnosing children with FASD in Ayrshire. He first diagnosed FASD in 1973. Many children,
now adults, owe the understanding of their condition to his innovative vision and commitment

The Fetal Alcohol Assessment & Support Team (FAAST) currently provides on-going commitments to increase clinician knowledge and confidence when assessing and diagnosing FASD.

Activities

The FAAS Team committed to the assessment of 36 children within the life of the pilot (December 2015-March 2018). Findings from the pilot will be made available 2018. With support from colleagues in Manitoba, Canada the team developed an assessment, diagnostic and support service in NHS Ayrshire & Arran. This was in response to the National FASD Pathway\textsuperscript{13} to provide children and young people a formal assessment to explain the challenges that they experience in their daily lives due to antenatal alcohol exposure. The assessment process involves a Speech & Language Therapist, an Occupational Therapist, a Paediatrician and a Clinical Psychologist. A support network has been established to support clinicians and AHPs, out with the pilot team, to effectively assess children and young people who have been prenatally exposed to alcohol.

With the support of a research assistant, the team are able to gather data that will be used for research purposes. The outcome from the research and data collection is being used to share learning and areas of good practice with others at a local, national and international level.

Members of the FAAS Team are currently involved with the FASD SIGN Guideline group. This is likely to be ready for review late 2018.

Actions:

1. To continue to support clinicians to record antenatal alcohol use as part of routine assessments.
2. To promote clinicians and Allied Health Professionals confidence to effectively assess and diagnose FASD in children and adult services.
3. To identify champions within IHSCPs and educational establishments by 2018 to help co-ordinate care for those diagnosed with FASD.

Measures

1. FAAS team will devise a training package to support clinicians, number of attendees will be recorded.
2. Number of clinicians supported with diagnosis for children and adults.
3. Identify 6 champions, 1 in each IHSCP, and 1 from education in each local council area. All champions will have attended training.
Interventions & Support

Every individual diagnosis of FASD is unique. The way in which a developing fetus is affected is dependent on timing, frequency and amount of alcohol exposure. Appendix 3 shows the affect of alcohol on the developing fetus and Appendix 4 demonstrates the nine brain domains impacted by prenatal exposure to alcohol. It is a pivotal factor that individuals are accurately understood in terms of their strengths and difficulties. Appendix 5 demonstrates how the effect on the brain domains can manifest in an individual. A neurological profile is a key component in reducing assumptions of what may be driving learning or behavioural difficulties, and it is essential to share knowledge of the child’s neuropsychological profile so that others’ (particularly colleagues in education) can harness the child’s strengths and target areas to maximise attainment and enjoyment of school.

Additionally, support and understanding for families is essential. An understanding of the individual profile will help parents/carers to advocate for their child in order to achieve the best outcome for them at home, at school and in the community.

Activities

Following the assessment process, interventions are offered for the child/young person by the Clinical Psychologist. This includes feedback to help with their understanding of their challenges/difficulties. Signposting to other services are made if necessary. Supports for parents to help them build confidence in implementing strategies are offered. This may be face-to-face or by providing literature and online resources.

Team Around The Child meetings are arranged following diagnosis to offer the opportunity for families to meet with all the professionals involved in the care of the young person. The meetings allow professionals to offer individual support to the family. Education staff will work collaboratively with the assessment team to determine how best to support the child within the school environment to maximise attainment.

A Parent Support Group (Making Sense of FASD) runs once a month to offer support for families either during the process or following assessment/diagnosis. Parents find support from others in a similar situation beneficial and good networks have been built offering each other support and advice.

A Parent/Carer Resource has been developed to provide some practical advice and strategies to help with common challenges experienced by families living with FASD. There is currently no provision to provide a diagnostic pathway for adults with FASD. However, plans are in place to develop resources to support adults living with difficulties that may be associated with antenatal alcohol exposure and local meetings are being arranged with fellow professionals around development of a diagnosis pathway for adults with FASD.

Actions:

1. To continue partnership working to improve outcomes of those affected by FASD.
2. To provide a support group for families affected by FASD.
3. To provide a support hub for professionals looking after individuals affected by FASD.
4. To provide support and resources for adults who may be affected by antenatal alcohol exposure by 2019.

**Measures**

1. Number of times FASD is on partnership agendas, number of presentations given at partnership meetings.
2. Number of families attending support group
3. Creation of professional support hub in each of the three areas.
4. Creation of adult resources, available from FAAS team in 2019

**Conclusion**

Prevention of alcohol exposed pregnancies, early identification of children ‘at risk’ of FASD and support for families affected by FASD is pivotal to the long term health and wellbeing of our population, and in turn, improved outcomes for those affected by FASD.

Partnership working across IH&SCPs and Local councils, to ensure commitment to the No Alcohol, No Risk during pregnancy message, will be valuable in reducing the number of alcohol exposed pregnancies.

**Early identification of FASD is a protective factor that is associated with a reduction in associated adverse outcomes such as mental health issues, poor educational attainment, homelessness and involvement with the criminal justice system.**

On-going support for children, adults, their families and the community is essential for long term physical and mental well-being.

It is essential that professional groups are aware of the condition and gain confidence in the process by which individuals can be formally identified, assessed and supported. Working in collaboration with key partners will reduce the likelihood of additional adverse effects and ensure the best possible outcomes for each individual.

This strategy endeavours to set out the way we can work in partnership to ensure that every child has the best possible start in life. We must all take ownership and work together to reduce the social, financial and educational impact of FASD and ensure that every individual reaches their full potential.
References


14. National pathway REF.


Appendix 1

Problems with FASD

“Fetal alcohol spectrum disorders” (FASD) is an umbrella term describing the range of effects that can occur in an individual who was prenatally exposed to alcohol. These effects may include physical, mental, behavioral, and/or learning disabilities with lifelong implications. FASD is not a diagnostic term used by clinicians. It refers to specific conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

- 94% had mental health problems
- 23% had received inpatient care for mental illness
- 83% of adults experienced dependent living
- 79% of adults had employment problems
- 60% of those age 12 and older had trouble with the law
- 35% of adults and adolescents had been in prison for a crime
- 45% engaged in inappropriate sexual behavior
- 43% had disrupted school experiences (e.g., dropped out)
- 24% of adolescents, 46% of adults, and 35% overall had alcohol and drug problems

Appendix 2

Fetal Alcohol Spectrum Disorder (FASD) Training – 2018

Fetal Alcohol Spectrum Disorder (FASD) is a range of characteristics displayed by children who have been exposed to alcohol in-utero. Children may display physical, cognitive, social or emotional disabilities which last a lifetime. FASD has been recognised as a growing concern and it is estimated that it may affect between 2-5% of live births locally. Caring for children with FASD is challenging but awareness, education, early intervention and support will foster the child’s early learning, self-esteem and readiness for life-long learning.

The training will provide an awareness and understanding of the issues around drinking alcohol during pregnancy. The training looks at Fetal Alcohol Spectrum Disorder and the disabilities caused when a pregnant women drinks alcohol, fetal development and the effects of alcohol on the developing brain. Information on strategies and approaches for supporting individuals who may/may not have a diagnosis of FASD but display some of the characteristics of the disorder will also be provided. This includes discussing the challenges displayed by individuals with FASD and advice, practical tips and guidance for caregivers and professionals.

FASD Full Day Training (9.30am – 4.30pm)

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<tr>
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<td>Training Centre, Ayrshire Central Hospital</td>
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</tr>
<tr>
<td>28th March 2018</td>
<td>Education Centre, University Hospital, Crosshouse</td>
<td>Room 2A</td>
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<tr>
<td>26th April 2018</td>
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<td>15th June 2018</td>
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<td>12th November 2018</td>
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<td>12th December 2018</td>
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To book a place on any of the dates above please e-mail: FASDtraining@aapct.scot.nhs.uk
### Appendix 3

<table>
<thead>
<tr>
<th>Age of Embryo (in weeks)</th>
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<tr>
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<td>4</td>
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<td>5</td>
<td>9-16</td>
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<td>6</td>
<td>20-36</td>
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<td>7</td>
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</table>

**Dividing Zygote, Implantation and Gastrulation**

- **Not susceptible to teratogens**
- **Prenatal death**
  - Major morphological abnormalities
  - Functional defects and minor morphological abnormalities

**Common Site of Action of Teratogen**

- **Heart**
- **Eyes**
- **Teeth**
- **Palate**
- **External Genitalia**
- **Brain**

**Appendix 3**

- CNS
- Upper limbs
- Lower limbs
- Ear

- CNS
- Heart
- Upper limbs
- Eyes
- Lower limbs
- Teeth
- Palate
- External genitalia
- Ear

- Major morphological abnormalities
- Functional defects and minor morphological abnormalities

- 1-2: dividing zygote, implantation and gastrulation
- 3-4: heart
- 5-6: eye
- 7-8: ear
- 9-16: palate
- 20-36: external genitalia
- 38: brain

- Full term
Appendix 4

Nine brain domains affected by FASD
Appendix 5

Executive Functioning
- May have trouble with planning, sequencing, problem solving and organisation.
- May be impulsive.
- Difficulty controlling emotions.
- Challenges with transitions and change.
- Often repeats mistakes and has difficulty understanding consequences.
- Difficulty with abstract ideas/concepts.
- Difficulty managing time.

Sensory and Motor
- Maybe unable to make sense of what is going on around them.
- May under or over react to sensory input, for example, light, noise, touch, smell and/or taste and movement.

Academic Skills
- May have difficulty in school particularly with maths, reading, time and money.
- May have difficulty with comprehension, organisation and abstract concepts.
- May have difficulty with age appropriate tasks.
- May have normal IQ.
- Learn better with visual or ‘hands on’ approach.

Brain Structure
- Brain and head circumference may be small.

Living & Social Skills
- May not understand personal boundaries and have difficulty reading social cues.
- May be socially vulnerable and easily taken advantage of.
- May have difficulty seeing things from another’s point of view.
- Socially and emotionally immature... may behave younger than actual age.

Focus & Attention
- Can be easily distracted, over-stimulated or impulsive.
- May have difficulty paying attention and be over active.
- ‘Can’t sit still’.

Cognition (Reasoning & Thinking)
- Difficulty with attention, learning, memory, planning and organisation.
- Difficulty with understanding complex ideas.
- Wide range of IQ.

Communication
- May speak well but not always understand the full meaning.
- Delayed language milestones for age.
- Difficulty with lengthy conversations.
- Difficulty following instructions.
- May be able to repeat instructions but not able to follow them through.

Memory
- Difficulty with long and short term memory – may seem forgetful.
- Difficulty recalling sequences or complex instructions.
- Relatively better visual memory.
- Easily forget steps in normal daily routine.
- Appear to lie but are really ‘filling in the blanks’.

What Parents and Carers need to know