

Fetal Alcohol Spectrum Disorders – Hiding in Plain Sight

Thursday, 7th November & Friday, 8th November 2014

Summary of speaker presentations

1. Fetal Alcohol Harm – What is the scope of the problem Margaret Stafford, Specialist Health visitor/Substance Misuse



Margaret Stafford -
What is the scope of

- What causes Fetal Alcohol Harm
- What is Fetal Alcohol Spectrum (FAS), Fetal Alcohol Spectrum Disorder (FASD) and other alcohol related harms relating to maternal drinking?
- FASD is the leading cause of preventable disability worldwide – statistics provided.
- Primary characteristics of FAS/FASD and subtypes, e.g. physical and social and secondary disability and how this affects the growing child/young person.
- Common traits and abilities.
- Working with individuals with FAS/FASD.
- FAS/FASD presents a lifetime of challenges, with no cure and requires permanent and ongoing support.
- This is not solely a female issue.

2. European Birth Network Support Network – FASD Pip Williams



Pip Williams - How
fetal alcohol harm cha

- Personal story from a birth mother detailing history of drinking, domestic violence and trauma throughout pregnancies and early years.
- Confusion between nature/nurture influences and resulting behaviours seen in children.
- Comparison between pre and post diagnosis, ultimate diagnosis and feelings of sadness, anger, confusion and relief this brought.
- Final diagnosis and detailed explanations of how both sons affected by Alcohol Related Neurodevelopment disorder.
- Earlier diagnosis resulted in better outcomes.
- Activities enjoyed by sons and services that have helped and supported them.
- How can we identify woman at risk
- What is wrong with these women should be turned around – What has happened to these women.
- Many problems causing women to self medicate, treat the cause not just the symptoms.

- No real support for women at anti-natal appointments.
- What mums noticed – barriers to diagnosis. What would have helped?
- Paper trails – drink/drug use needs to be recorded.
- Common disorders identified with FASD
- Women with FASD. Birth experiences and relapse.
- Think FASD first – especially if the child has been adopted, fostered, has been in care or mother has been in care.
- Your role is to be brave.

3. Supporting families where FASD features
Jayne Livingstone, Social Worker, Aberdeenshire Council



Jayne Livingstone -
 Role of the Social Wo

- The importance of guidance and direction for parents, carers and professionals.
- Suspicion of FASD – should I push – internal debate, is the outcome going to be of benefit to the family?
- Scenario of own practice experience – What are the presenting issues for a client with a possible FASD diagnosis.
- Dilemma – will a diagnosis trigger a relapse? How to support through diagnosis, acceptance and ongoing recovery.
- What professionals need to work in this field – knowledge, skills and information?
- What can be applied to pre and post diagnosis
- Vision of the Care Pathway for the future.

4. Margo Irvine, Service Manager, Family Outreach Centre, Aberlour Childcare Trust.
Working with families with FASD



Margo Irvine -
 working with families

- Examples of good practice at Aberlour, Family outreach, Family Support and Community Services.
- Incidence of families referred to services with alcohol related use.
- Aberlour model of working with families/children and young people.
- Triggers that could indicate FASD
- Assessment paperwork – asking questions about alcohol intake prior to and during pregnancy.
- Strategies for working with families affected by FASD at varying life stages.

**5. Ann Sutherland, GIRFEC Project Manager - Grampian, & Angela McKinnon , Aberdeenshire CHP Child Health Lead
FASD & GIRFEC**

- What is GIRFEC
- Where did it come from – origins and core components
- How does the GIRFEC approach translate into practice
- Who is the names person and what are their responsibilities
- The Child's Assessment and Plan.
- The GIRFEC Framework, 5 Key Questions and the National Practice Model.
- How the GIRFEC approach will improve the outcomes for children with FASD



Ann Sutherland -
FASD & GIRFEC

**6. Eileen Calder, Director, FASD Scotland
Where are they? Adults with FASD**

- Where are our adults with FASD?
- Estimated prevalence.
- Problems and concerns for age 18+ that could indicate FASD.
- Emergence of secondary disability.
- IQ Scores and Adaptive functioning.
- Implications for Criminal Justice and Substance Misuse services.
- Consequences for not recognising FASD in individual and in adult prisoners.
- Dealing with stress
- Case studies of individuals who have conquered their FASD difficulties and gone on to succeed in life and achieve their potential.
- Change in view necessary – change programmes to fit individuals.
- Interventions cannot be prescriptive.
- Strengths and abilities of individuals with FASD
- Traits for successful interventions.



Eileen Calder- Where
are they? Adults with

ADDITIONAL RESOURCES

Foetal Alcohol Syndrome is the biggest cause of non-genetic mental handicap in the western world and the only one that is 100% preventable.

USEFUL WEBSITES	
Website Address	Summary Information
http://www.fasaware.co.uk/	<p>FAS Aware UK believes that all people should have access to information, advice and guidance to make informed choices about the effects of alcohol during pregnancy and the detrimental impact on the adults and children throughout their lives.</p> <p>Through awareness raising, training, campaigning and facilitating support networks, FAS Aware UK will seek to address these issues in a supportive and practical way.</p>
http://www.nofas-uk.org/	<p>The National Organisation for Foetal* Alcohol Syndrome UK (NOFAS-UK) is dedicated to supporting people affected by foetal alcohol spectrum disorders (FASD), and their families and communities. It promotes education for professionals and public awareness about the risks of alcohol consumption during pregnancy.</p>
http://www.fasdscotland.com/	<p>FASD Scotland offers:</p> <ul style="list-style-type: none">• Information and awareness about the lifelong risks of prenatal exposure to alcohol.• Information, support and advocacy to families caring for a child affected by FASD.• Strategies for managing FASD.• Advice and training to reduce FASD Secondary Disabilities.

	<ul style="list-style-type: none"> • Training for professionals involved with individuals affected by FASD • Partnership with other agencies to prevent FASD and Secondary Disabilities
http://www.eurobmsn.org/	<p>The European Birth Mother Support Network is a network of women who consumed alcohol during pregnancy and may have a child or children with Fetal Alcohol Spectrum Disorders (FASD).</p> <p>The network is a place where mothers can share their experience and support each other.</p> <p>www.facebook.com/groups/FASDUK</p> <p>All you have to do is click join group, look out for a message in your Facebook inbox or 'other' inbox and will be added.</p>
http://www.fasdtrust.co.uk/	<p>The FASD Trust was started in January 2007 in response to the growing number of requests for information on FASD being received by Simon and Julia Brown, adoptive parents of a child with FASD.</p> <p>FASD UK co-ordinate a Facebook group with over 250 family and professional members</p>
TOOLKITS AND E-LEARNING	
Web address	Summary Information
http://www.mencap.org.uk/FASD	The toolkit has been designed primarily for general practitioners, but it also contains advice for pregnant women, families and carers of children and adults affected by FASD.

	<p>The information and videos in this toolkit helps increase understanding of FASD, the effects of alcohol on the foetus, the process of diagnosis for FASD as well as support and strategies for a person caring for a child/adult with FASD.</p>
<p>http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/fasd.aspx</p>	<p>This e-learning resource has been developed to support a range of activity led by the Scottish Government to substantially reduce the harm caused by alcohol consumption in pregnancy across Scotland.</p> <p>The course content was developed by 'Children in Scotland' with input from the child and maternal health team at NES and the Scottish Government Fetal Alcohol harm national working group. (2013)</p>
<p>http://www.scotland.gov.uk/Publications/2013/10/3881</p>	<p>This FASD Awareness Toolkit contains information and tools to help raise awareness of fetal alcohol spectrum disorder. (2013)</p>
<p>http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright/national-practice-model</p>	<p>When assessment, planning and action are needed, practitioners can draw on the <i>Getting it right for every child</i> National Practice Model, which can be used in a single or multi-agency context. Wellbeing wheel, My World Triangle and Resilience Matrix available to download from this site.</p>
<p>FURTHER READING SUGGESTED BY SPEAKERS AT THE CONFERENCE</p>	
<p>http://depts.washington.edu/chdd/ucedd/ctu_5/parentchildprog_5.html</p>	<p>The Parent-Child Assistance Program (PCAP) is a home visitation intervention program that works with women who abuse alcohol or drugs during pregnancy, with the aim of preventing future alcohol- and drug-exposed births among these mothers. PCAP supports mothers in achieving this goal by helping them complete substance</p>

	<p>abuse treatment and stay in recovery and by motivating them to choose effective family planning methods.</p>
<p>http://www.uvic.ca/hsd/socialwork/assets/docs/research/Substance%20Using%20Women%20with%20FASD%20-%20Service%20ProvidersPerspectives%20report-web.pdf</p>	<p>The overall purpose of this project was to consolidate and expand knowledge regarding effective, appropriate substance use treatment approaches and resources for women living with Fetal Alcohol Spectrum Disorder (FASD).</p>
<p>http://alcoholpregnancy.childhealthresearch.org.au/</p>	<p>The Telethon Institute for Child Health Research '<i>Alcohol and Pregnancy and FASD Research Program</i>' commenced in 2001 when it was identified there was little information available from Australia on which to base public health practice. This is the first comprehensive, multi-centre program of research in Australia addressing prenatal alcohol exposure.</p>
<p>http://www.bcapop.ca/index.html</p>	<p>Website of a non-profit society made up of Pregnancy Outreach Programs (POPs) from across British Columbia, Canada. POPs provide free prenatal and early parenting support to women who experience health or lifestyle challenges during pregnancy, birth and the transition to parenting. The BCAPOP supports POPs in their work to enhance maternal and infant health for the long-term benefit of communities.</p>
<p>http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/FAS_FAE/fas_fae_2003_e.pdf</p>	<p>Canadian Fetal Alcohol Spectrum toolkit. (2003)</p>