Dr Ges Gregory

Consultant Community Paediatrician
Integrated Neurodevelopment Team
Lead Doctor for Children In Care and Safeguarding
Medical Advisor for Adoption and Fostering

Fetal Alcohol Spectrum Disorders
SENCO Training July 2019
Fetal Alcohol Spectrum Disorders

*Terminologies*

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>PNAE</td>
<td>Pre-natal alcohol exposure</td>
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<tr>
<td>FAS</td>
<td>Fetal Alcohol Syndrome</td>
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<tr>
<td>pFAS</td>
<td>partial Fetal Alcohol Syndrome</td>
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<tr>
<td>FAE</td>
<td>Fetal Alcohol Effects</td>
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<tr>
<td>ARND</td>
<td>Alcohol Related Neurodevelopmental Disorders</td>
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<tr>
<td>ARBD</td>
<td>Alcohol Related Birth Defects</td>
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FASD – Umbrella term

Scotland use FASD as a descriptor rather than a diagnosis. If a child has had exposure but does meet diagnosis yet they suggest that we can identify child to be “be at risk for Neuro-developmental disorders” but not “at risk of FASD”
Fetal Alcohol Syndrome

First described and published as a diagnostic syndrome in The Lancet in 1973


The scale of the problem is escalating
Baby with Fetal Alcohol Syndrome

FAS Facial Characteristics:
- small eye openings
- smooth philtrum
- thin upper lip
Maternal drug misuse

- Poverty
- Physical health problems
- Mental health difficulties /disorders
- Poor antenatal and post natal care
- Inadequate diet
- Exposure to violence
- ALCOHOL
- Smoking
- Sex working / trafficking
- Infections e.g. Hepatitis B, Hepatitis C, HIV
Compared 2 groups – PNAE and PNAE with neglect

Post natal neglect did not make the outcome any worse

Retrospective study for Specialist clinic
Total alcohol per capita (15+ years) consumption, in litres of pure alcohol, 2010

Per capita consumption (litres)
- <2.5
- 2.5–4.9
- 5.0–7.4
- 7.5–9.9
- 10.0–12.4
- ≥12.50

Data Source: World Health Organization
Map Production: Health Statistics and Information Systems (HSI)
World Health Organization
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Incidence and prevalence in the UK?

FAS 1 : 1,000
FASD 1 : 100

Estimates for prevalence in other countries varies depending on culture of drinking.
Higher prevalence in Looked after Children

Risk of FASD in Looked After Children of 27%
Risk of FASD in children placed for adoption 75%

Identifying children who are at risk of FASD in Peterborough: working in a community clinic without access to gold standard diagnosis. Geraldine Gregory, Venkat Reddy, Claire Young. Adoption & Fostering 2015, Vol. 39(3) 225-234

A meta-analysis of published and unpublished studies calculated the pooled prevalence estimates of diagnoses of FAS and FASD for children and young people was reported on in 2013. This gave an overall estimate for FAS at 6% and for FASD at 17% for children in a number of different care settings. (Not UK)

Prevalence of Fetal Alcohol Spectrum Disorders in Child Care Settings: A Meta-analysis. Shannon Lange, Kevin Shield, Jürgen Rehm and Svetlana Popova. PEDIATRICS Vol 132, Number 4, October 2013
Why do we need to consider FASD?

- Neglect associated with mothers continued drinking / drug taking
- Preventable – further children may be protected
- Assessment of child presenting with development delay
- Assessment of child / Young person presenting with learning or behavioural difficulties
- Early identification – better outcome?
- Understanding the future needs for the child
- Assessment and management of secondary or comorbid conditions
- Advice for carers / potential adopters
- Prevention of placement breakdown
- Identify FASD in the mother?
- Management and care for young people and adults – mental health, youth offending and criminal justice services
Assessment of FAS / FASD
Canadian Guidelines 2015

- **Prenatal exposure to alcohol (PAE).**
  - Must be confirmed for FASD – FAS can be diagnosed if considered but denied

- **Facial features / growth defects**
  - Face only in FAS – exposure in early pregnancy
  - Birth and subsequent < 10th centile

- **Exclude other conditions that explain clinical picture**
  - Genetic testing
  - Consider referral to clinical genetics

- **Evidence of significant neurodevelopmental difficulties**
  - Cognitive impairment
  - Executive functioning difficulties
  - Coordination difficulties
Fetal Valproate Syndrome - Facial Features

- Tall forehead
- Medial eyebrow deficiency
- Flat nasal bridge
- Broad nasal root
- Shallow philtrum
- Long upper lip
- Thin vermillion border
Multidisciplinary Approach to Assessment
Any age of child or adult

➢ Paediatrician / Clinician
➢ Psychologist- clinical or educational
➢ Neurodevelopment service
➢ Occupational Therapist
➢ Speech and Language Therapist
➢ Clinical Geneticist
➢ Other
Alcohol is a Teratogen

*Teratogens are drugs, chemicals, or even infections that can cause abnormal fetal development*

- Crosses placenta to foetus and crosses blood brain barrier
- Direct effect on foetal brain development by disrupting neuronal proliferation and migration, or by causing cell death
- Indirect effect on umbilical blood flow resulting in hypoxia in the foetus
- Decreases protein synthesis and alters hormone levels resulting in growth retardation
- Effects of maternal poor health, other substance misuse, neglect in child after birth
NEW ADVICE - January 2016
Men and women no more than 14 units per week

Pregnant women.
Safest approach is not to drink at all
Drinking in pregnancy can lead to long term harm
The more you drink the bigger the risk
Surveillance of Fetal Alcohol Syndrome (FAS) commenced in October 2010. The study aims to determine the incidence of FAS in the UK and Ireland, investigate which services are accessed by babies and children affected by the condition; and raise awareness about FAS among clinical practitioners.

This study is not investigating Fetal Alcohol Spectrum Disorder.
Neuro-development Assessment to include

- Cognitive assessment
  - Memory – working memory
  - Verbal comprehension
- Executive functioning
- Adaptive behaviours
- Coordination difficulties
- Sensory Processing
- Secondary disabilities ADHD and Autism
Executive Functioning

Executive functions are the brain's ability to maintain an appropriate problem solving set for attainment of future goals.

*BRIEF:* Behaviour Rating Inventory of Executive Function

- Inhibition - ability not to act on impulse
- Flexible problem solving
- Emotional control - ability to modulate emotional responses
- Initiation of tasks, ideas,
- Working memory – hold information to complete a task
- Planning and organising – future orientated tasks
- Organise materials – keeping track of belongings
- Monitoring – assess own performance, achieve goal
BRIEF could be a predictive screening tool
Pitfalls of not picking up “hot” executive functioning deficits
Risk Factors for Adverse Life Outcomes in FAS and FAE

Secondary Disabilities in FASD © 2000 2002

415 young people and adults

The primary disability refers to the brain damage from prenatal exposure that has a direct effect on development and cognition.

Secondary Disabilities are those not present at birth but occur as a result of the primary disabilities.

- ADHD: 60%
- Disrupted School Experience: 43%
- Trouble with the Law: 42%
- Confinement (mental health, alcohol/drugs, crime): 60%
- Inappropriate Sexual Behavior including promiscuity: 45%
- Alcohol and or drug Problems: 30%
Neuropsychological profile assessment more accurate than IQ alone
Fig. 1. Overlapping and specific neurocognitive impairments between FASD and ADHD. See text for details. Note: Identified neurobehavioral deficits for children with fetal alcohol spectrum disorders (FASD) and attention-deficit/hyperactivity disorder (ADHD). Impairments listed reflect findings from comparisons between the 2 clinical groups and not in comparison with typically developing controls. Deficits indicated represent areas where each clinical group displays greater impairments compared to the other, not absolute impairment. For details and related references, see text and Table 2. [Color figure can be viewed at wileyonlinelibrary.com]
Cognitive Functioning in Children Prenatally Exposed to Alcohol and Psychotropic Drugs

Dalen et al Neuropediatrics 2009; 40:162-167

Cognitive functioning compared in 29 children with FAS, 35 children with FAE, and 66 children exposed to psychotropic drugs in utero. Tests used were Wechsler and the NEPSY

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<tr>
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<th>FSIQ</th>
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<tbody>
<tr>
<td>FAS</td>
<td>70</td>
</tr>
<tr>
<td>FAE</td>
<td>78</td>
</tr>
<tr>
<td>Drugs</td>
<td>103</td>
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In addition to the low IQ there are also problems in processing and attention which have a significant affect on the child’s functioning.
Development of Executive Functioning skills in FASD

- FASD
- Normal
FASD
What it is like

Expressive language age 20

Actual age 18

Reading Age 15

Living skills age 11

Money and time concepts age 8

Comprehension and emotional maturity age 7

Social skills age 7