

FASD

A Hidden Developmental Disorder

FASD WORKSHOP

Children in Scotland Workshop

November 2018

- What is FASD?
- Is this a problem for children in Scotland?
- Are there 'at risk' groups?
- How is the diagnosis made?
- What could I do to assist the identification and support to these children and young people?

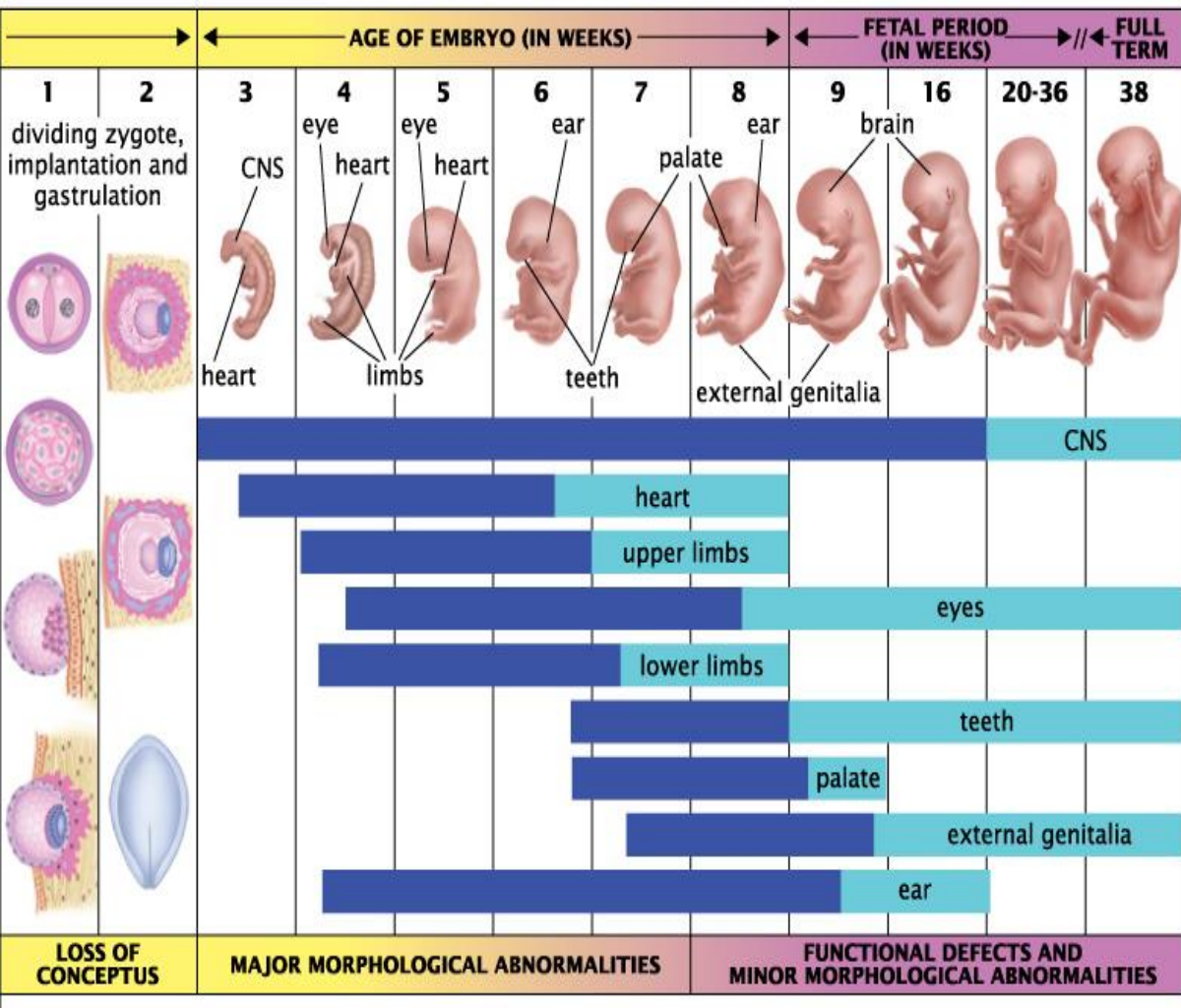
What do we need to know about FASD?

- Alcohol is a teratogen
- Exposure to Alcohol prenatally has varied, but lifelong, detrimental effects on neuro development.
- Individuals affected deserve ,and benefit from early identification and support
- Prevention of secondary mental health disorders
- Early diagnosis may help prevent a subsequent affected pregnancy
- Since 1973 there has been a clear recognition of a syndrome (Fetal Alcohol Syndrome , FAS) directly caused by ingestion of alcohol in pregnancy.
- Now it is recognised that many individuals are subtly affected by PAE, without physical signs, and the term Fetal Alcohol Spectrum Disorder (FASD) is used.

“Babies and Alcohol don’ t Mix!!”



**Chris Steer ; Neil McIntosh ; Debbie Miller.
SCOTTISH PAEDIATRIC SURVEILLANCE UNIT
FETAL ALCOHOL SYNDROME Survey Review
May 29th 2013**



ALCOHOL HARM IN PREGNANCY

Depends on the:-

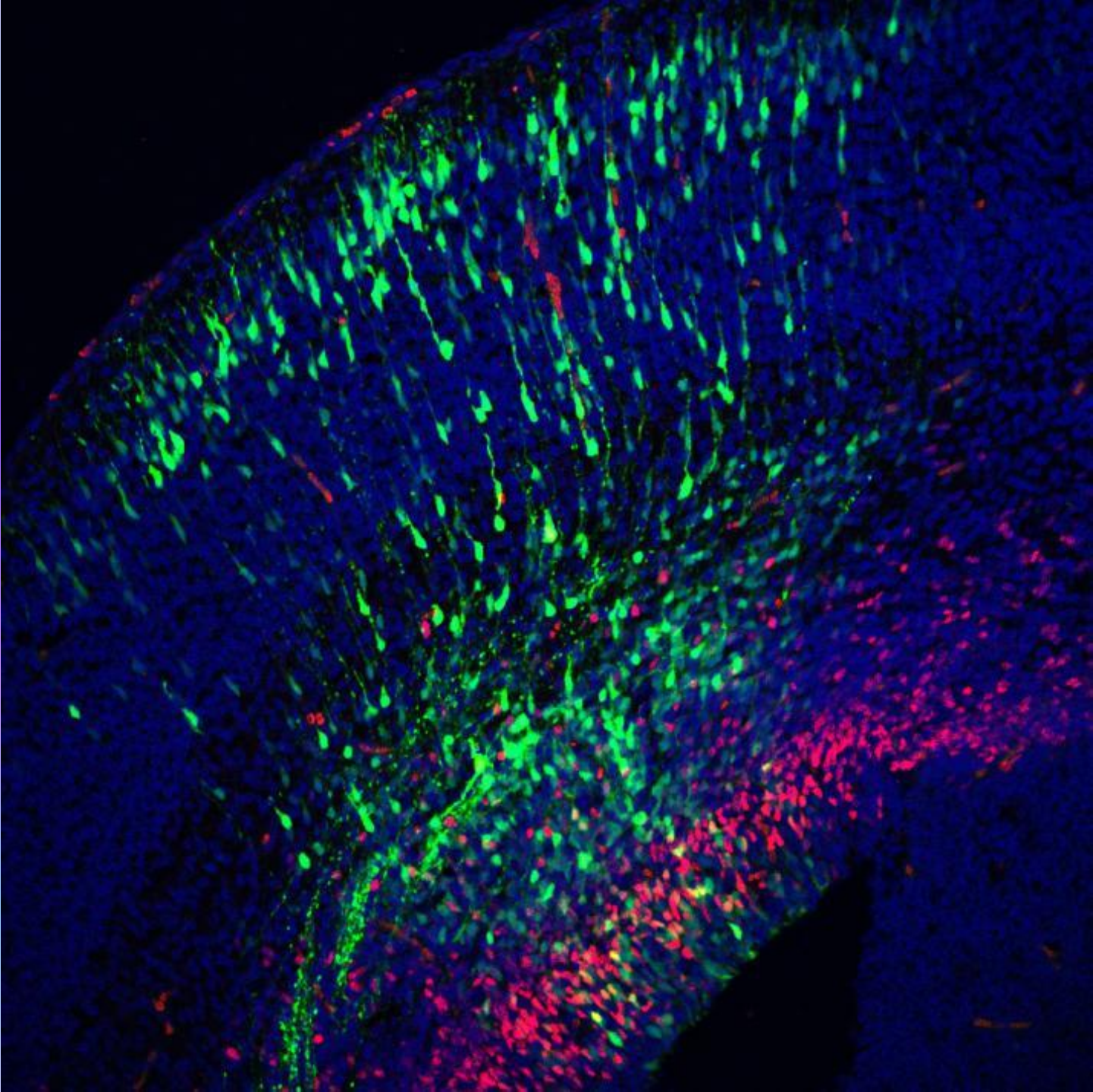
“QUANTITY, FREQUENCY, AND TIMING OF Alcohol EXPOSURE”

“Maternal Risk Factors for Fetal Alcohol Spectrum Disorders. Not As Simple As It Might Seem”

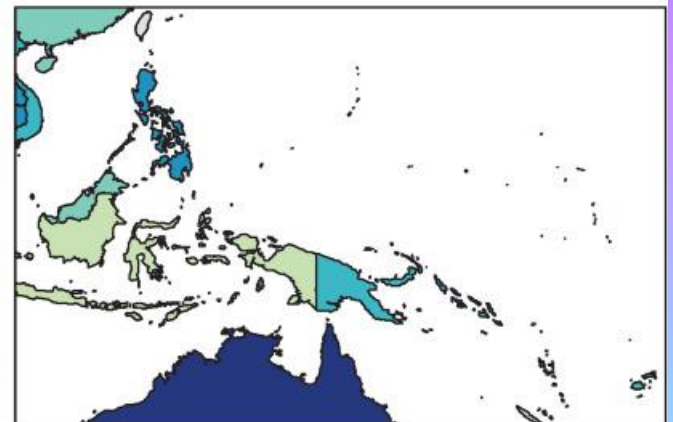
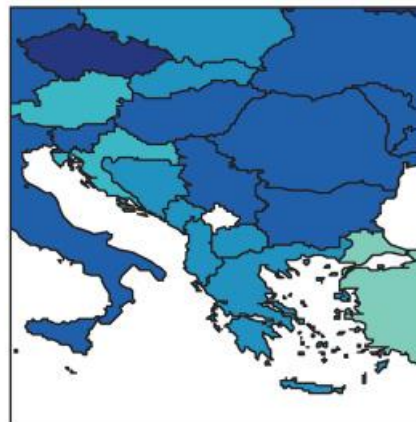
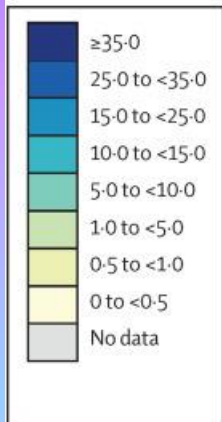
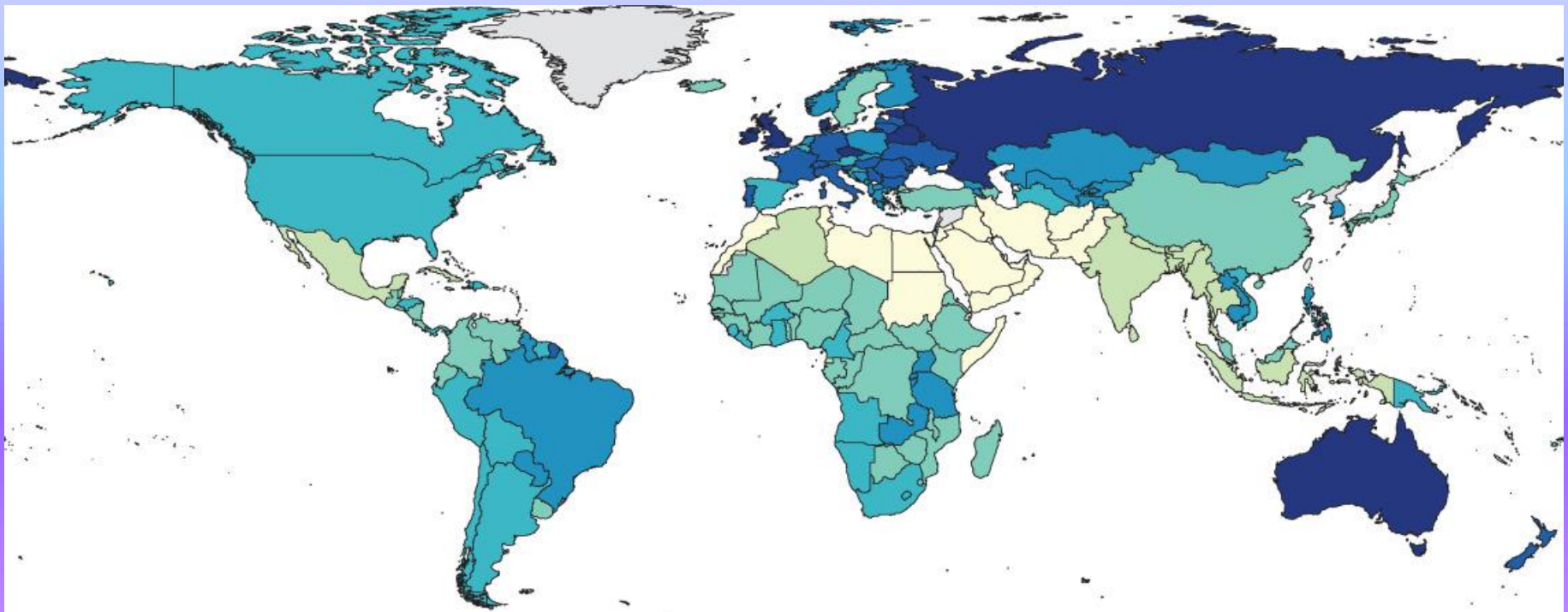
Philip A. May, Ph.D., and J. Phillip Gossage, Ph.D.
 ALCOHOL RESEARCH AND HEALTH. 34(1)
 2011

Alcohol exposure during weeks 6 to 9 results in the typical mid facial and ocular anomalies of full blown FAS ; CNS development is affected by alcohol at all stages, including during late pregnancy.

EFFECTS ARE VARIABLE AND DIFFICULT TO PREDICT IN INDIVIDUAL PREGNANCIES



- In countries with similar populations to Scotland where reporting systems are more established, alcohol is noted to affect 1 in 100 live births
- Despite this, case reporting in Scotland has remained low.
- Prevalence of FASD in the UK is estimated to be 3%(at least)
- **This makes neurodevelopmental disorder related to PAE one of the commonest preventable causes of impairment**



Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population in 2012

Popova S et al. Lancet. Global Health 2017. 5 (3) . e 290-99

One unit is:



Half a pint of regular beer, lager or cider



A small glass of wine



A single measure of spirits



A small glass of sherry



A single measure of aperitifs

Each of these is more than one unit:



A pint of 3.5% beer, lager or cider



A pint of 5% beer, lager or cider



A 330ml bottle or can of 4.5% alcopop or lager



A 500ml can of 4% lager or strong beer



A 500ml can of 8% lager



A medium (175ml) glass of 11% wine



A bottle of 12% wine

UK Chief Medical Officers recommend max. 2016 – 14 Units per week!



**We used to think children
would be identified by their
facial features**

Jones K.L and Smith D.W. Lancet 1973. 2.999-1001

*- Introduction of the clinical term,
"Fetal Alcohol
Syndrome"*

**Now we know 90%
of affected children
will NOT have
characteristic facial
features**

This a more relevant image



DEVELOPMENTAL PROBLEMS:-

	YES	NO	NOT KNOWN
Seizures	2		
Gross Motor Delay	19	15	7
Fine Motor Delay	16	14	11
Incoordination	7	13	21
Impaired Hearing	0	35	6
Visual Impairment	7	26	8
Intellectual Impairment *	7	5	29
“Behaviour” problems **	7	11	23
“Emotional” problems ***	5	13	23

[* - comments included “too early to assess, will be evaluated later, awaiting assessment, delayed social smile, limited attention”]

[** - comments included “ too young to assess, short concentration span, concentration difficulties, quite hyperactive, irritable at times (previous NAS), ADHD diagnosed and treated, short concentration span, behavioural problems”]

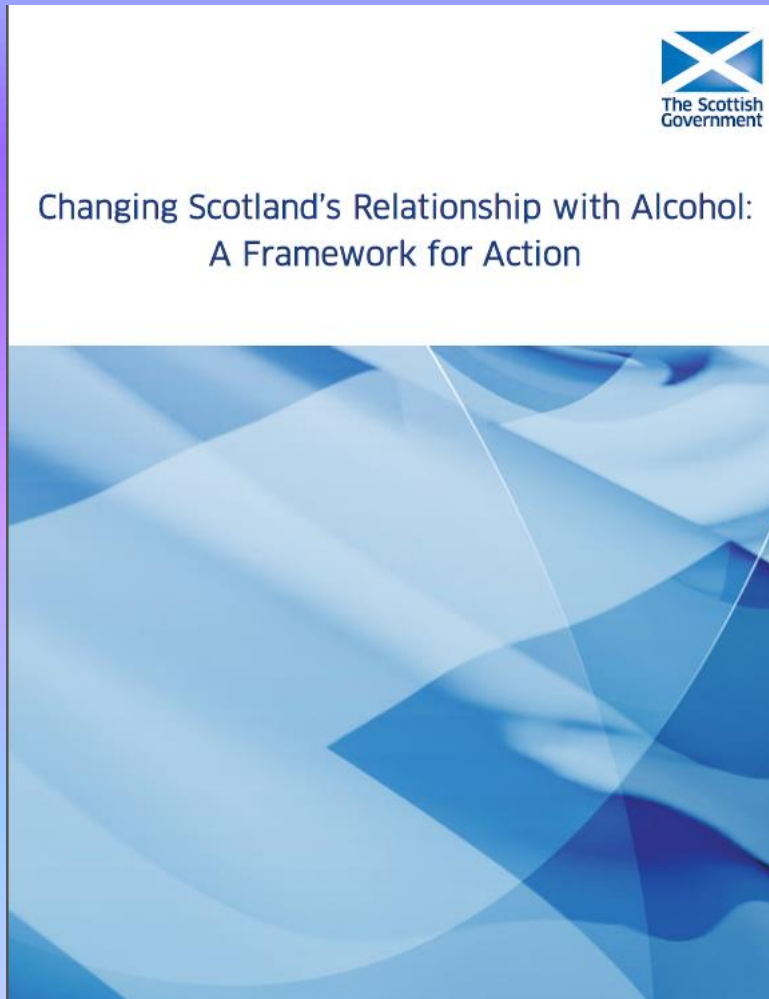
[*** - comments included “too young to assess, temper tantrums, attachment – overfamiliar with strangers but physical neglect, fearful of sudden noises, severe emotional and behavioural difficulties”]

So Consider:

- Do we drink in Scotland?
- Do we have unplanned pregnancies?
- Do we have children with undetermined/undiagnosed causes for their neurodevelopmental and behavioural problems?
- Is FASD a concern?
- **THE ANSWER TO ALL IS YES**

Scotland and FASD ?

Initiatives promoting Change



“Changing Scotland ’s Relationship with Alcohol: A framework for action ”, - (a “whole population approach ”)

- 1.reduced consumption.***
- 2.supporting families and communities.***
- 3.positive public attitudes and choices.***
- 4.improved treatment and support.***

-“No Alcohol No Risk” CMO messaging 2016

***-Minimum Unit Price for Alcohol
2018***

(Continued) Scottish Government (SG) Support for:-

• ***Alcohol Brief Interventions in Primary care, A/E. Maternity Services, - ongoing, combined with Specialist Midwifery support***

• ***NES Learn-Pro FAS e-learning Modules 2012***

(www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/fasd.aspx)

• ***Fetal Alcohol Spectrum Disorder Awareness Toolkit 2013***

(www.gov.scot.Publications/2013/10/3881)

Fetal Alcohol Spectrum Disorder Awareness Toolkit

Scottish Government Child and Maternal Health Division

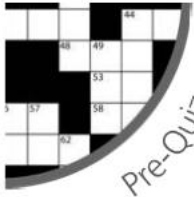


•***Scottish Government Fetal Alcohol Spectrum Disorder Awareness Toolkit 2013***

[www.gov.scot.Publications/2013/10/3881](http://www.gov.scot/Publications/2013/10/3881))

September 2013





Pre-Quiz



Access full navigation ➔

(www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/fasd.aspx)

**NES Learn-Pro FAS e-learning Modules 2012*

CURRENTLY UNDER REVISION

Continued:-

•Maternity and Childrens FASD Advisory Group within Children and Families Directorate of SG

-Liaison with important stakeholders e.g. Educational Psychology, Preconceptual (Nutrition) Care Group, Legal Services, Education, Social services, Voluntary Groups and support for research and educational initiatives to raise FASD awareness and improve clinical skills and confidence

•SG support for Scottish Health Action on Alcohol Problems (SHAAP), - intercollegiate evidence based advocacy and lobbying group Drs Peter Rice and Eric Carlin (e.g. for minimum unit price machinations!)

•SG support for Alcohol Biomarker (Meconium Alcohol Ester) Study (Published 2016 – Abernethy C et al Arch Dis Child.

- <http://dx.doi.org/10.1136/archdischild-2016-311686>)

Continued

- ***SG support for the Ayrshire and Arran Multidisciplinary FASD Diagnostic Study (2016 et seq. Drs Sarah Brown, Jennifer Shields, Lorna Fulton and team)***
- ***SG support for the University of Manitoba outreach educational initiative, commenced 2013 and annual review visits since***
 - ***Professor Anna Hanlon Dearman and FASD multidisciplinary group. (FASD seminars and interactive education sessions)***
- ***SG support for the Scottish National FASD Clinicians Forum,***
 - ***2015 et seq. – twice Yearly meetings, - lectures, presentations, case reports and peer interaction.***
- ***SG support to establish Scottish National FASD Care Pathway***
(<http://www.knowledge.scot.nhs.uk/scormplayer.aspx?ppkgurl=/ecomscormplayer/fasdpathway/>)

FASD Care Pathway Development

- Wide experience reference group involving Health, Education, Social Care ,Third Sector colleagues and parents and carers exchanged information and views over an 18 month period.
- Smaller core group met to develop the Pathway of Care
- The Pathway utilises GIRFEC (Getting It Right For Every Child) methodology to ensure comprehensive review and support of the children affected

The Fetal Alcohol Spectrum Disorder Diagnostic Pathway Scotland 2017



A range of problems known as

Fetal Alcohol Spectrum Disorder (FASD)

can affect the baby if the mother drinks alcohol during pregnancy even before she knows she is pregnant.

Identifying and supporting mothers and their children at the earliest opportunity is important. **The FASD Pathway** has been launched to help clinicians make a diagnosis as early as possible to provide support, and advise parents and carers how to seek help for their child.

[FASD Care Pathway](#)

<http://www.knowledge.scot.nhs.uk/scormplayer.aspx?pkgurl=/ecomscormplayer/fasd/pathway/>

[Webinar Introduction and Launch](#)

<https://meetings.webex.com/collabs/url/iX007N9-NB17n-HhUp0ox9gT5bNMONShQ5rV9JBDy3C00000>

Why wasn't this happening already?

- Poor recording of alcohol histories
- Unreliable and varied approaches to history taking
- Wariness to ask routinely about alcohol intake
- Reluctance on part of paediatricians to consider FASD as a diagnosis
- Lack of confidence in ability to make the diagnosis
- Concern that patient/ parent relationship would be compromised
- Lack of belief that it made any difference for the child

Possible Symptoms in the Pre-school years

- **Infancy 'difficultness':**
- Hard to settle
- Poor sleep pattern
- Feeding problems
- Premature/small birth weights
- Born <36 weeks
- Baby under 10th centile for head circumference and weight
- Congenital heart disease
- Irritable; failure to habituate
- Failure to thrive
- **0-2 years:**
- Excessive arousal, short attention
- Atypical sensory responsitivity
- Sleep problems
- ADD with or without hyperactivity
- Language delay
- Developmental delay - fine motor skill impairment
- Impulsivity
- Distractible
- Poor memory
- Incorrigible
- Challenging behaviours

Preschool 3-5 years:

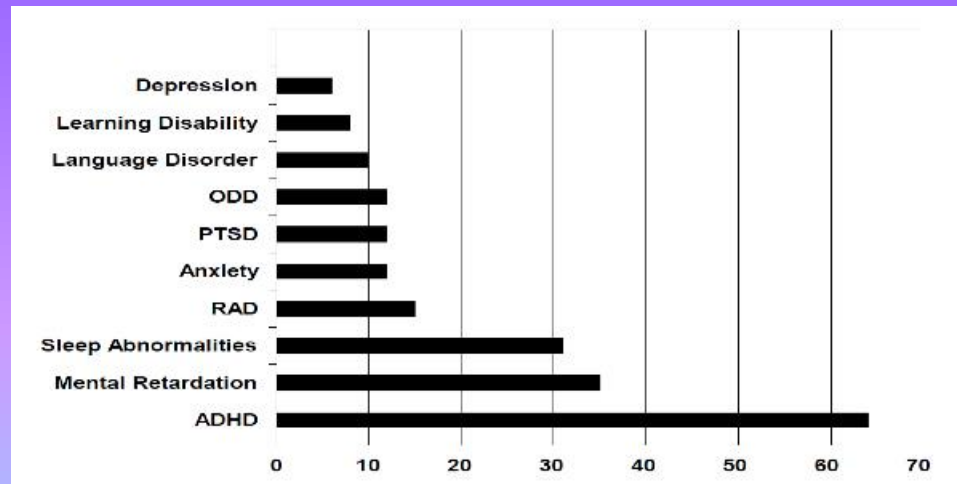
All of above plus:

- Language delay
- Delayed auditory processing
- Unable to sit still or pay attention
- Multiple sensory overload
- Difficulties in forming friendships
- Doesn't learn from mistakes
- Can't do complex problem solving (maths)
- Information processing deficits
- Can't sort - numbers, sequencing
- Verbal learning poor

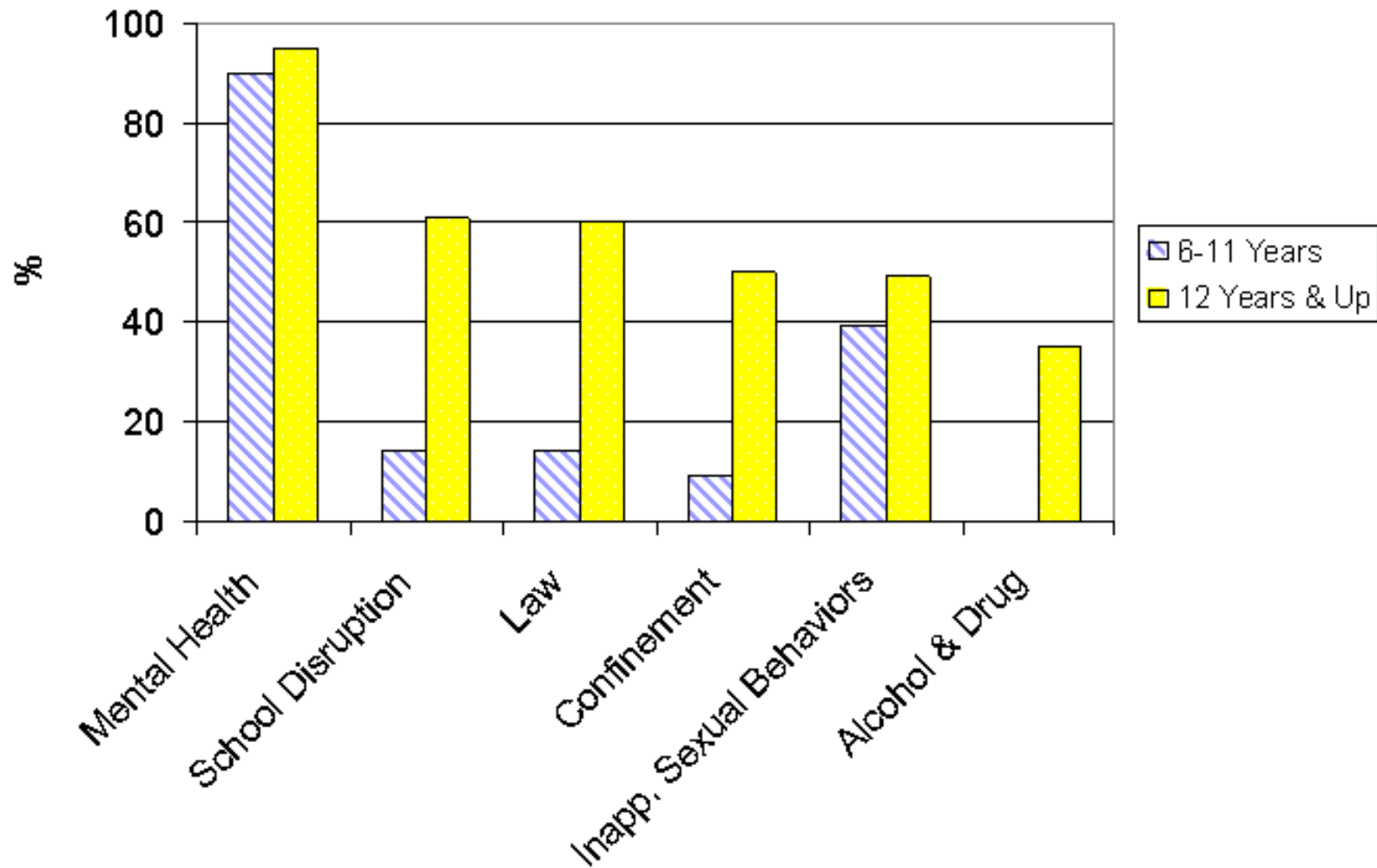
School age:

- Identified as requiring additional support
- Lack of progress across Literacy Numeracy and health and wellbeing
- Attention deficit, impulsivity, hyperactivity
- Memory problems
- Poor social/peer group interactions
- Aggressiveness
- Unable to sit still or pay attention
- Multiple sensory overload
- Doesn't have friends
- Doesn't learn from mistakes
- Can't do complex problem solving (maths)
- Information processing deficits
- Can't sort - numbers, sequencing
- Verbal learning poor
- Sensory processing difficulties
- May have recorded learning disability
- Can't read social cues
- Repeats instructions but doesn't follow them
- At risk from offending behaviour, known to the police
- School failure
- Exclusion from school on multiple occasions
- Sexually inappropriate

Co- morbidities with FASD



Secondary Disability Issues faced by people with FAS/FAE Problems in:



How might this involve colleagues working in the Care Sector ?

- Addiction services for women of child bearing age
- Women with children in abusive situations
- Women with mental health problems using alcohol as a support
- Irritable poorly setting infants
- Seeking assessment for children with neurobehavioural problems particularly attention difficulties, oppositional and aggressive impulsive behaviours, autistic features.
- Secondary presentations of mental health problems in affected young people associated with school failure, sleep fragmentation, depression, suicide, addiction
- Encouraging vulnerable young women to use contraception if they can't be persuaded not to drink excessively.
- Consider possibility of this in children and young people displaying anti social behaviour and involved with the judicial system
- Remembering that LAC children are a high risk group for FASD

Diagnostic assessment for FASD

(Now supported by SIGN Guidance document)

- Alcohol history reported and shared in an appropriate way.
- Assessment of facial features
- Assessment of areas of brain function of the individual. This assessment should also contribute to the support plan.
- This should be a multi agency assessment using the GIRFEC model to share and enhance the outcome for the child and family.

Facial Characteristics:-

■ Measure

– Palpebral Fissure

■ Size

– Upper lip

■ Thinness

– Philtrum

■ Smoothness

*(can also utilise photographic
Facial Recognition Software)*

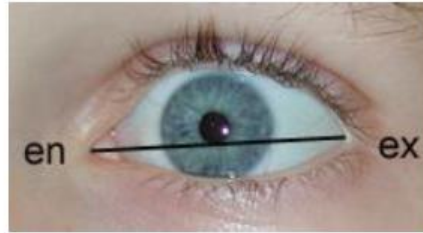


Figure 2A. Palpebral Fissure Length (PFL). Distance from endocanthion to exocanthion.



Figure 2B. PFL measured with a small ruler while patient looks up to fully expose exocanthion.



Figure 4. It is important that the patient have a relaxed facial expression (no smile). A smile can alter lip thinness and philtrum smoothness. This is the same person with and without a smile. Note that without the smile, the lip and philtrum would both receive a correct Likert rank of # 1 on the Caucasian Lip-Philtrum Guide 1. With a smile, the lip and philtrum would both receive an *incorrect* Likert rank of # 4.



Nine brain domains potentially affected in FASD



→ 'Patchy' cognitive profile with a disorganised brain

→ 3 or more affected domains indicates CNS impairment and support Diagnosis (more than Minus 2 SD's using Standard tests)

→ Highly variable from individual to individual

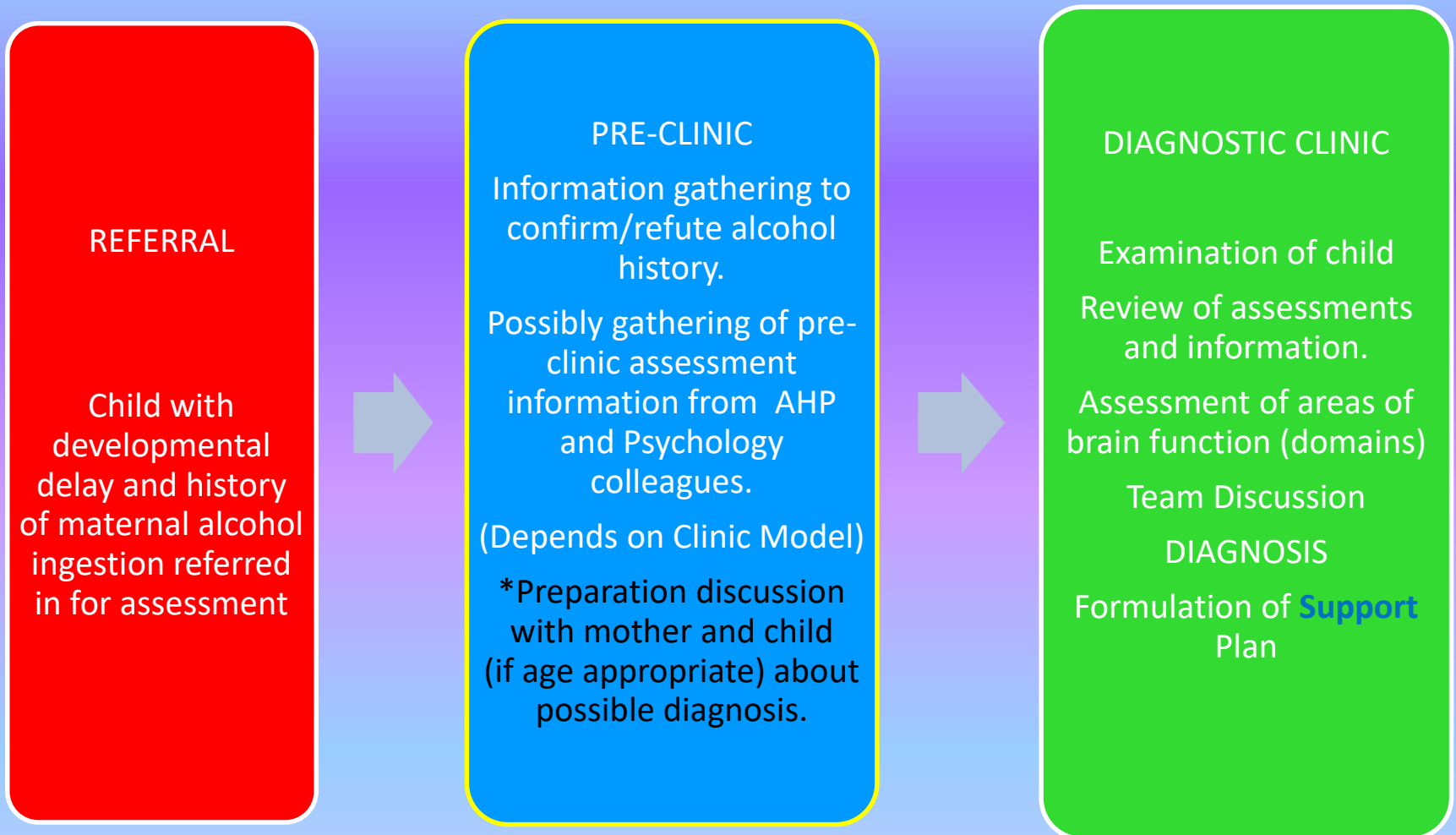


Terminology

- FAS (Fetal Alcohol Syndrome)
- FASD (Fetal Alcohol Spectrum Disorder)
- **FASD with or without sentinel facial features
(Canadian terminology)**
- Neuro-Developmental Disorder due to Pre-Natal Exposure to Alcohol (NDPAE)

The How to Do It Guide

Available through the FASD Pathway website





Some examples of life stories to help illustrate the diverse nature of the condition, and how lives are affected.

Eileen Calder

FREE DOWNLOADABLE RESOURCES

- **Resources for Teachers**

[Primary School Framework](#)

[Secondary School Framework](#)

[SSAT Resources for Schools](#)

[Executive Functioning 101](#)

[Educational Success](#)

[What Educators Need to Know](#)

[Teaching Maths to Children with FASD](#)

[Behaviour and Discipline](#)

- **Resource for Caregivers**

[Strategies not Solutions](#)

Resource for Caregivers

- [Strategies not Solutions](#)
[I am a Caregiver](#)
[Let's Talk FASD](#)
[FASD Information Sheets](#)
[Overlapping Characteristics](#)
[Making Sense of the Madness- Jeff Noble](#)
[Choosing a School](#)
[Parent Carer Forums](#)
[EHCP Exemplar Guide](#)
[Sleep Diary](#)

Resources for Children



[All about me](#)

[Survival in School](#)

[Survival at Home](#)