

FASD:

The impact of foetal exposure to alcohol



A short introduction



[BBC Cambridgeshire video clip](#)

FASD in the context of our society



Our children with FASD ...

... are probably among the most vulnerable in the UK

- They have an acquired lifelong disability significantly influenced by the relationship our society has with alcohol
- For many this disability is not visible and often is not recognised at all
- In the UK we do not know how many children and families are affected by FASD
- FASD is “The most prevalent of all birth defects in the USA, outnumbering all other pupils with SEN, but rarely recognised and hiding in plain sight in many disguises”

Behavioural descriptions of children with FASD

- “Too lively, ceaselessly agitated, turbulent and quarrelsome”
Lemoine et al., 1968
- “Tremulous, hyperactive and irritable” Jones and Smith, 1976
- “Fidgety, distractible, always on the go, and never sitting still”
Streissguth et al., 1978

There are strengths ...

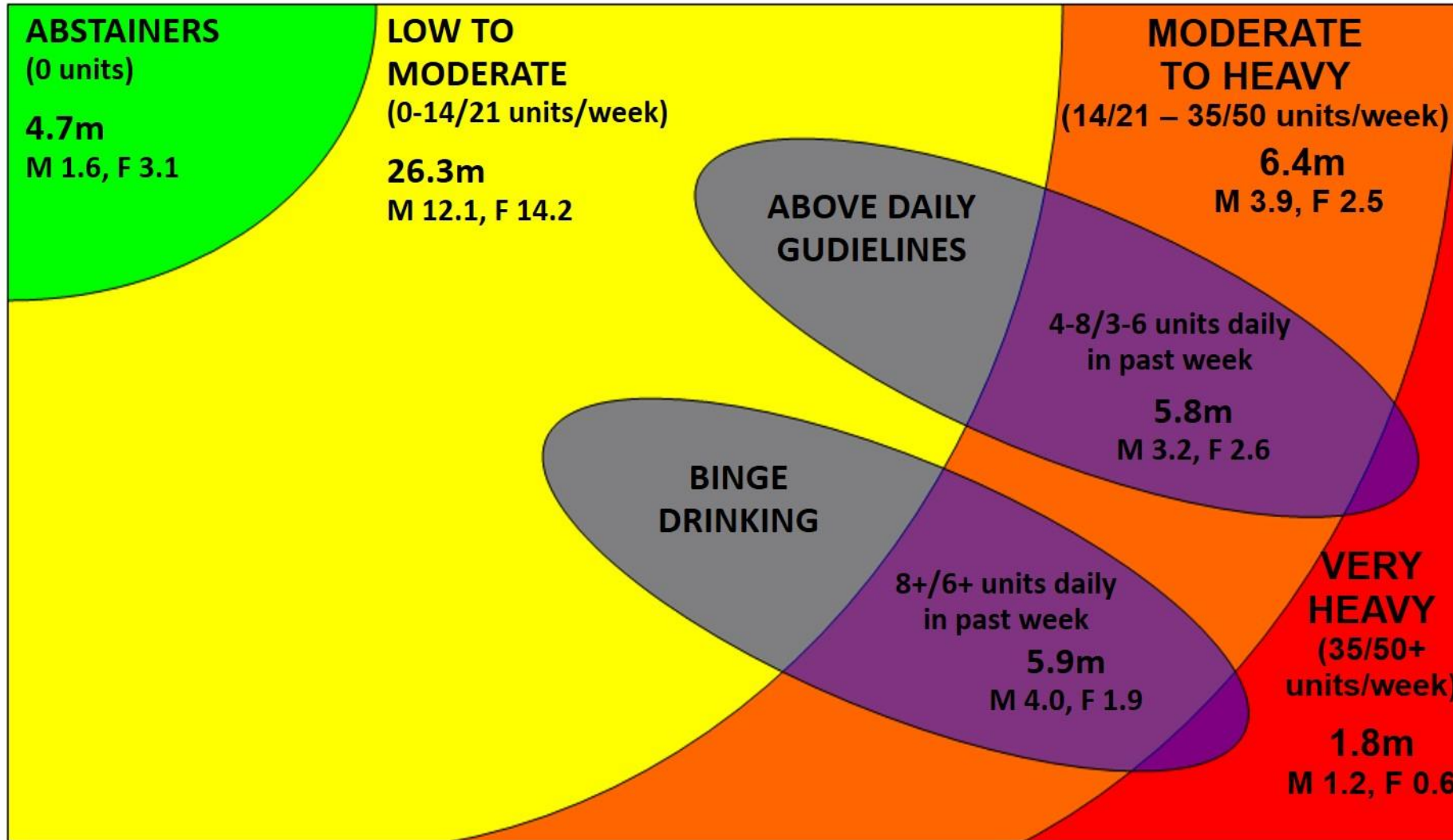
within their definition of the world



Foetal Alcohol Spectrum Disorders

- Foetal Alcohol Syndrome **FAS**
 - Abnormalities of growth, cognition and facial features
 - *With or without confirmed alcohol exposure*
- Alcohol Related Birth Defects **ARBD**
- Alcohol Related neurological Disorders **ARND**
- Foetal Alcohol Effects (partial FAS) **FAE (pFAS)**
 - Multi-disciplinary approach essential
 - Accurate screening for alcohol use in pregnancy also needed

How the population drinks



The doctor said “Only one glass of alcohol a day”. I can live with that.



How many children are affected by parental alcohol misuse?

- In England and Wales (Hidden Harm, 2003)
 - 200,000 – 300,000 children where one or both parents has a serious drug problem – most drug users also misuse alcohol
 - 2-3% of all children under 16
- In Scotland
 - 41,000 – 59,000 children affected by parental drug misuse
 - 4-6% of all children under 16

NB Hidden Harm did not mention alcohol

- Estimates of children affected by parental alcohol misuse vary
- Could be up to 2.5 million in the UK (Velleman, 2003)

Characteristics of problem drug and alcohol misuse in the UK (2007)

- Use of multiple drugs

- **BINGE DRINKING**

- Deprivation and chronic poverty

- Poor diets increase impact on brain of substance misuse

- Chaotic lifestyles

- Inconsistent parenting

Alcohol is more damaging than other drugs

- Alcohol misuse affects many more children than drug misuse
- There is a stronger association with
 - Domestic violence = trauma to the child
 - Long term neglect = unmet attachment needs and trauma
- Where children are removed from home
 - Interventions are often late
 - There may be multiple placements and attempts at rehabilitation
- FASD is often not recognised
 - The youngest child in a sibling group is likely to be the most damaged by alcohol exposure before birth

The effect of prenatal drug exposure

Adapted from Journal of the American Academy of Pediatrics (February 2013)

	Nicotine	Alcohol	Marijuana	Opiates	Cocaine	Meths
Short term effects / birth outcomes						
Fetal Growth	Effect	Strong Effect	No Effect	Effect	Effect	Effect
Abnormalities	No Agreement	Strong Effect	No Effect	No Effect	No Effect	No Effect
Withdrawal	No effect	No Effect	No Effect	Strong Effect	No Effect	*
Behaviour	Effect	Strong Effect	Effect	Effect	Effect	Effect
Long term effects						
Growth	No Agreement	Strong Effect	No Effect	No Effect	No Agreement	*
Behaviour	Effect	Strong Effect	Effect	Effect	Effect	*
Cognition	Effect	Strong Effect	Effect	No Agreement	Effect	*
Language	Effect	Effect	No Effect	*	Effect	*
Achievement	Effect	Strong Effect	Effect	*	No Agreement	*

* Limited or no data available

Alcohol and other drugs at birth

Effect	Alcohol	Marijuana	Cocaine	Heroin	Tobacco
Low birth wt.	X		X	X	X
Growth issues	X				
Face features	X				
Small head	X				
Dev. delay	X	X			
Hyperactivity	X		X	X	X
Sleep problems	X	X	X	X	X
Poor feeding	X		X		
Excess crying	X	X	X	X	
Risk of SIDS	X			X	X
Organ damage	X				
Resp. problems	X			X	X

Missing the effects

- Alcohol is a drug that has wide social acceptability
 - Drug misuse is noticed, alcohol misuse may be ignored or underestimated
- Work with parents may focus on problem drug use
 - Alcohol misuse may continue unnoticed despite intervention
- Children most severely affected by FASD are unlikely to live with their birth parents
 - Parents may then have other children
 - In mothers who have one child with FAS, the likelihood of FAS in subsequent births is 771 per1000

Children in the care system

- Should always be regarded as traumatised
 - Acquired brain injuries as a result of unregulated stress
 - *Regulatory disorders, processing disorders, social function disorders*
- Are likely to have unmet attachment needs
 - Unable to self-regulate stress
 - Vulnerable to trauma
 - Complex social and emotional difficulties
- Children in the care system have even more complex emotional, behavioural and learning needs ... we are only just understanding the figures
 - Could this be the unrecognised impact of foetal exposure to alcohol?

To sum up: the social context of FASD

- Alcohol causes permanent changes in both the structure and function of the foetal brain
 - Most children affected do not show outward and visible signs
 - They should be regarded as invisibly disabled because of organic brain damage
- In the UK no-one knows how many children are currently affected by FASD
 - Changing patterns of female alcohol misuse, and especially the rise of binge drinking, make it likely that the number is still rising
- The damage to the brain caused by alcohol is irreversible and untreatable
 - We need to know how to help these children

Take Home Message

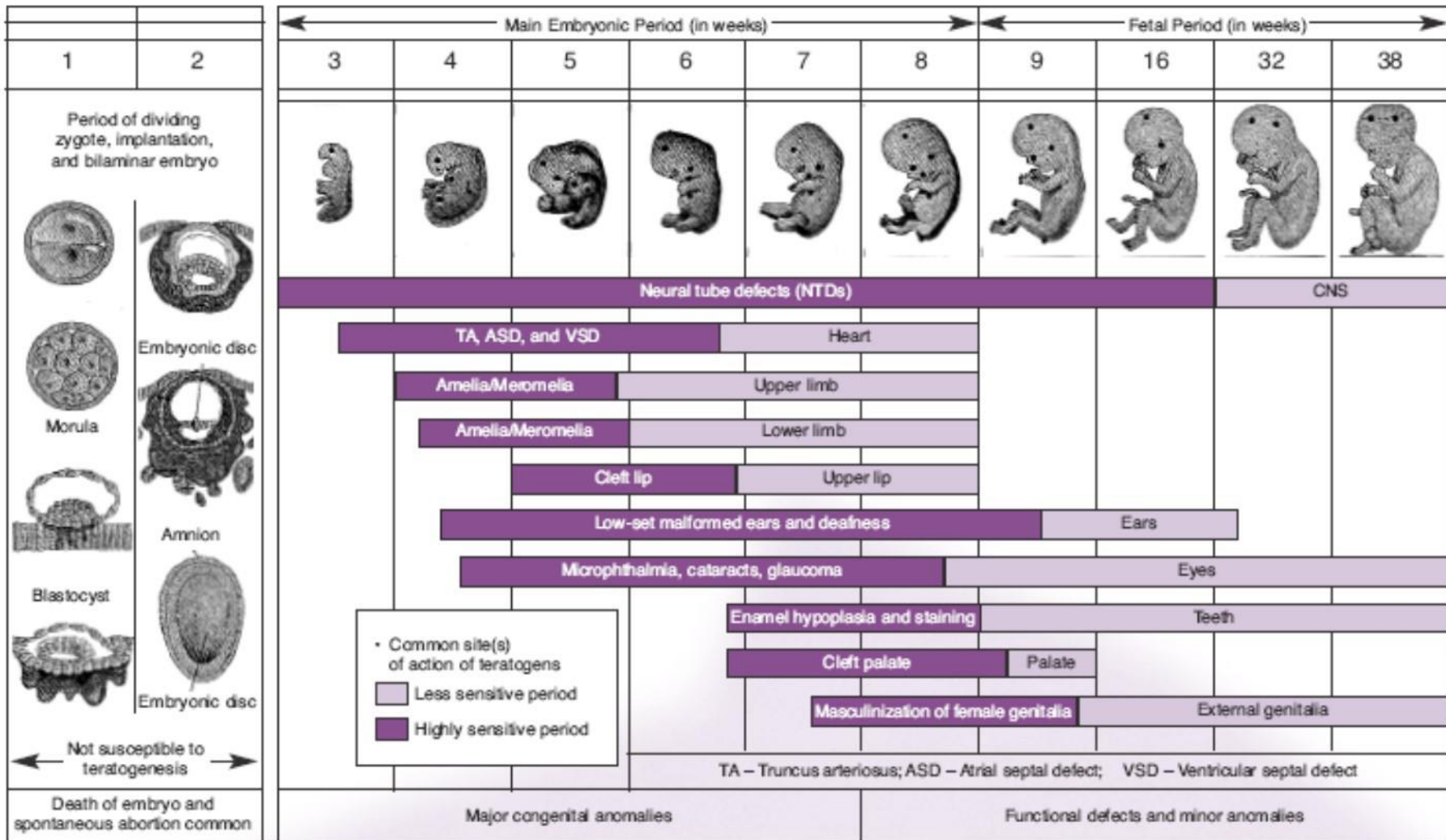
FASD knows no social, national or other boundaries

- It is found wherever pregnant women consume alcohol
- It has major economic and social implications for society

The impact of FASD ...
on children ...
on carers ...
on schools



Foetal alcohol spectrum disorders



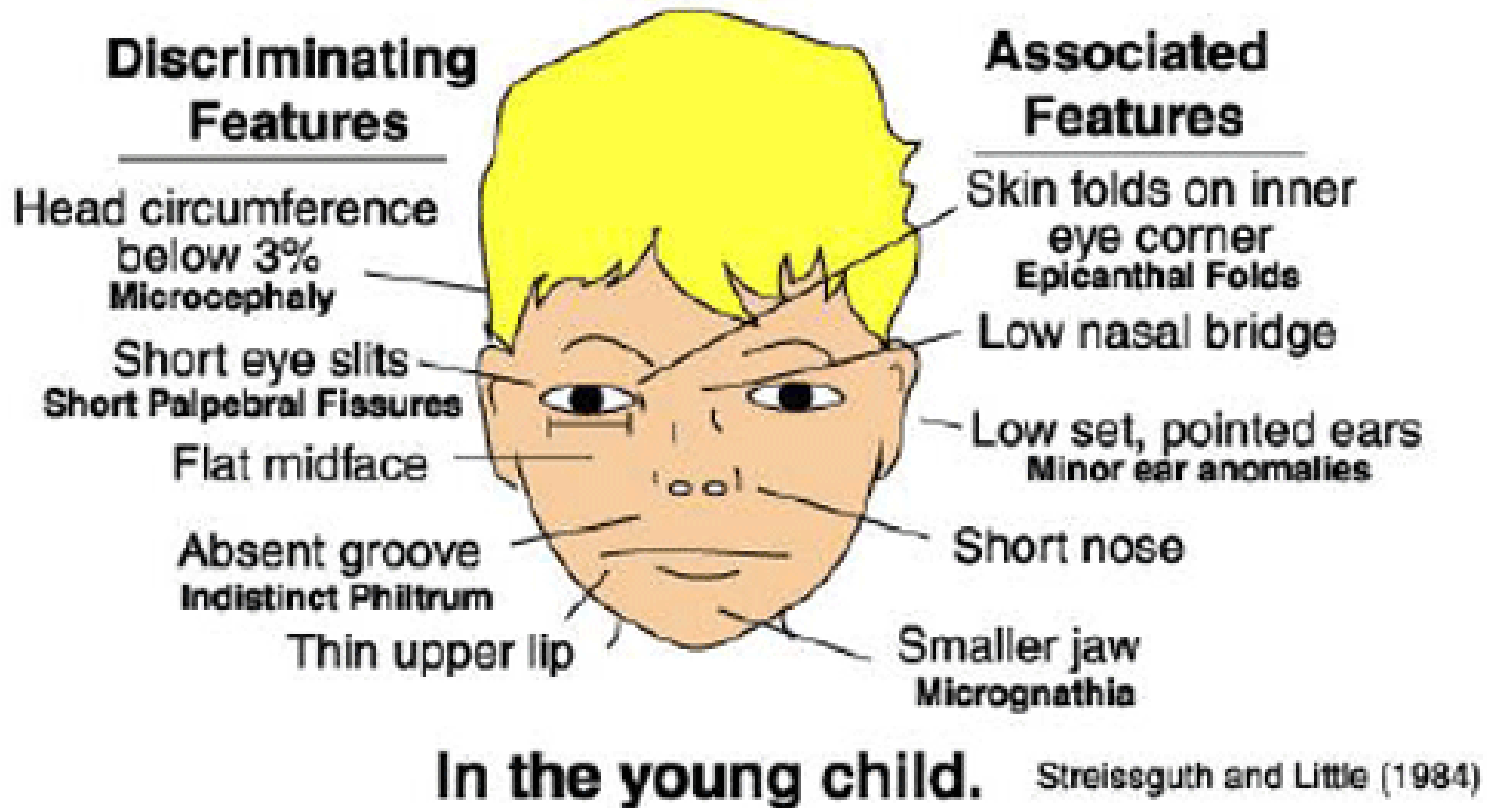
Schematic illustration of critical periods in human prenatal development. During the first 2 weeks of development, the embryo is usually not susceptible to teratogens; a teratogen either damages all or most of the cells, resulting in death of the embryo, or damages only a few cells, allowing the conceptus to recover and the embryo to develop without birth defects. Dark purple denotes highly sensitive periods when major defects may be produced (e.g., amelia, absence of limbs). Light purple indicates stages that are less sensitive to teratogens when minor defects may be induced (e.g., hypoplastic thumbs).

(Permission granted from publisher Moore, Persaud; *The Developing Human*, W.B. Saunders Co, 1998, p.548) to reproduce Figure 3 and include in this report.

Birth defects

- Cleft palate
- Small teeth
- Hearing problems
- Heart defects
- Kidney problems
- Genital changes
- Sacral dimple
- Unusual chest shape
- Small head
- Curved fingers
- Shorter fingers and toes
- Small nails
- Low muscle tone
- Eye problems
- Fits
- Failure to thrive/growth deficiencies

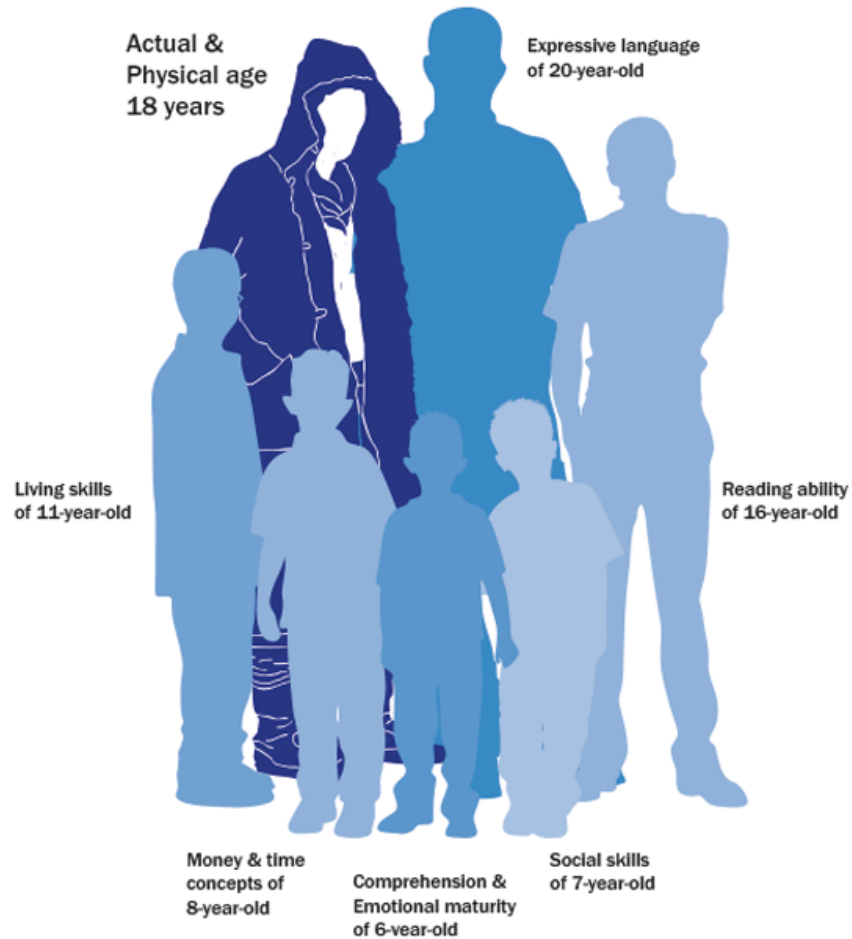
Facial features of FAS



Behavioural problems

- Working memory
- Short term memory
- Planning and organisation
- Receptive language
- Obsessions
- Hyperactivity, fidgeting
- Inattention
- Lack of social understanding
- Impulsivity
- Lack of judgment
- No understanding of consequences
- Central nervous system damage – pain, hunger, temperature, toileting
- Concepts – time, money, maths, ownership
- Relationships – over-friendly, appearing to have attachment issues

An 18-year-old with FASD



Diagnosis can be very difficult

- Children affected by FASD may look normal
 - They may have no diagnostic facial features
- They may be very verbal
 - Receptive language may be more impaired than expressive
- They may be intelligent
 - Although cognitive ability generally impaired – average IQ 79
- They may be socially appealing and likeable
 - Professionals tend to see the problems as lying with the carers
- No agreed diagnostic protocol in the UK
 - Multiple diagnoses are common

Assessment strategies

- Digital facial photography
- Speech and language assessment
- Occupational therapy assessment
- Cognitive assessment
- ADHD and ASD screening
- Behaviour checklist
- Story stems

Assessment in looked after children

The Health Assessment

7.4.6 The assessment should take special consideration of conditions that may be more prevalent in looked after children and which may be otherwise misdiagnosed. **In particular, the possibility that a child may be experiencing symptoms related to foetal alcohol syndrome should be considered when there is a history of maternal alcohol misuse. Symptoms are not always physically obvious and foetal alcohol syndrome may manifest itself in ways that could present as conduct or behavioural**

The FASD Maze

- Parents and carers may become lost in a diagnostic maze
- They may be passed from professional to professional
 - Diagnosis often depends on the interest of the person running the clinic
- They are often given multiple diagnoses
 - This brings a wide range of conflicting explanations and advice
 - “... you should be less protective”
 - “... you need to let your child go”
 - “... your child needs to develop independence”
 - The consequences can be disastrous, as children with FASD often need the protection of an external brain for life
 - *Such advice can lead to injury, death or involvement in crime*

Multiple diagnoses are common

- The characteristics of children and young people with FASD overlap with the characteristics of children and young people with other disorders and conditions, such as:
 - ADHD / ADD
 - Autistic spectrum disorders
 - Sensory integration disorders
 - Mental health disorders such as bipolar disorder, depression ...
 - Conduct disorders
 - Reactive attachment disorder

Children with FASD in the care system

- Placements, including adoptive placements, may disrupt
 - Children may be labelled as 'hard-to-place'
- Normal parenting techniques do not work
 - Children with FASD are among the most vulnerable to being abused while they are in care
- At 18 – 25 they are on their own, without the protection of the external brain of their carers
 - They often end up homeless, in prison or dead

Outcomes for children with FASD (outcomes for children in care)

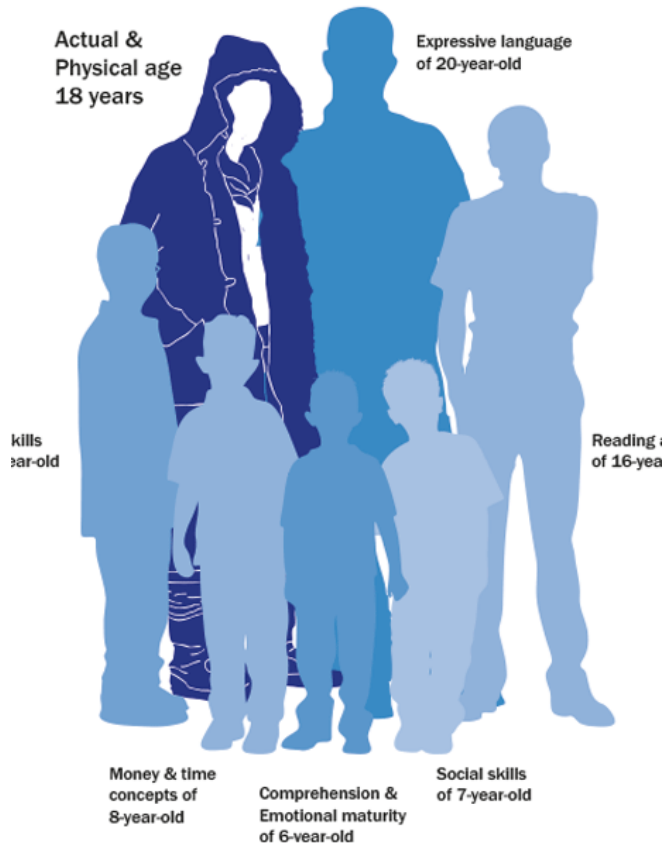
- Children and young people with FASD are more likely to:
 - Have low self-esteem
 - Have poor or no educational qualifications
 - Have mental health problems
 - Use alcohol to extreme
 - Be unemployed
 - Engage in inappropriate sexual behaviour
 - Have unwanted early pregnancies
 - Have problems with the law
 - End up in prison
 - Be homeless
- Studies of children in care show similar poor outcomes

Remember there are also strengths ...

within their definition of the world



Remember that 18-year-old with FASD?



- How can carers, schools and society get to grips with such a varied range of capabilities in one single individual?
- How can we recognise and build on strengths?
- How can we help others to understand the impact of foetal exposure to alcohol?

Working with children with FASD: Practical issues and strategies



Research 2013 – Dr Raja Mukherjee et al

The experience of carers was marked by:

- Lack of information
- Lack of knowledge among professionals
- Having to fight for things
- Feeling misunderstood and blamed
- Family stress, and the difficulty of providing the benefits of one-to-one attention
- Isolation
- Concerns about the future

Adopters, foster carers and other connected carers ...

... are often misjudged as over-protective, anxious or even poor parents

- Yet as birth mother's untreated alcoholism gets worse they are frequently asked to take another sibling
- The next child is more damaged and difficult, and problems get worse as the children grow older
- It is not unusual to find overburdened families caring for three or four siblings – all with FASD

Traditional parenting methods fail

- People parenting children with FASD are often advised by well-meaning professionals to try strategies which do not work
 - Strategies which fail increase parental stress
 - Strategies which fail convince children that they are failures
- For traditional parenting to work, the child must:
 - Understand the concept of 'future earning'
 - Have the impulse control to change behaviour in future
 - Understand cause and effect
 - Have some understanding of the impact on others
- Children with FASD cannot do these things

Symptoms at under 5 include:

- Sleep disturbance, poor wake/sleep cycle
- Poor sucking responses/feeding problems
- Failure to thrive
- Hyper/hypo sensitivity to light / cold / pain
- Delays in walking and talking
- Delayed toilet training
- Difficulty in following directions
- Temper tantrums and disobedience
- Distractibility

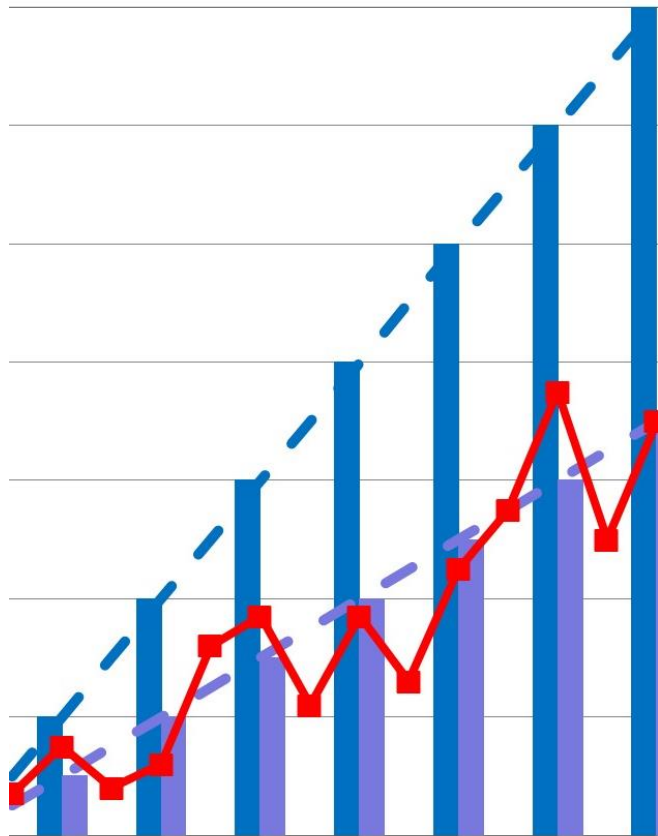
Further problems begin in school ...

- Children with FASD lack core skills and attributes needed to manage school life and to learn
 - Sitting still
 - Listening
 - Concentrating
 - Understanding cause and effect
 - Following complex verbal instructions
 - Planning
 - Organising their time
 - General delay in physical and cognitive skills

... and social problems affect school life

- Difficulty predicting consequences
- Appearance of capability without actual ability
- Poor understanding of social rules
- Difficulty separating fact from fiction
- Easily influenced by others
- Behaviour difficulties
 - Temper tantrums
 - Lying
 - Stealing
 - Disobedience, defiance of authority

“He can do it if he tries harder”



- Performance always fluctuates from day to day
- These peaks and valleys are not predictive
- Parents and teachers are on an emotional; roller coaster
- These children are trying even when they fail, and are often exhausted by trying

Reframing



Acting like a child		Is a child
Won't		Can't
Lazy and does not try		Exhausted with trying
Does not care		Does not understand feelings
Refuses to sit still		Over stimulated /needs contact
Forgets everything		Can't remember
Fussy, demanding		Hypersensitive
Steals		Does not understand ownership
Does not get the obvious		Does not learn from experience
Calculating and sly		Does not understand

The delayed after-effect!



School

- Child accumulates stress chemicals throughout the day at school.
- Child holds it together while at school.



- Parents experience the meltdown once child gets home.
- Teacher doesn't see the problem.

Sustainable classrooms

- A calm, uncluttered, structured learning environment
- Opportunity for small group work / small class sizes
- Small step approach to tasks, instructions and activities
- Repetition, repetition, repetition
- Tasks to reflect the child's developmental and learning profile
- Visual and kinaesthetic learning
- Frequent breaks from concentration and opportunities for physical exercise
- Support with peer relationships, interactions, life skills

All Party Parliamentary Group for looked after children and care leavers

- Education Matters in Care
 - Key recommendation 6

... Teachers should receive greater training to improve their understanding of and ability to manage issues such as trauma, attachment and foetal alcohol spectrum disorders

Take Home Message

Carers are still too often the 'experts' on FASD

- There are strategies that we know work
- There are strategies that we know to avoid
 - More research and evidence-based interventions need to be developed, understood and used

Strategies that don't work

- Physical punishment
- Threats
- Taking away treats
- Stickers
- Star charts
- Time out
- Abstract instructions
- Contracts
- 'Talking therapies'
- Child protection case conferences
- Removing the child from an otherwise loving and supportive home

What is needed in order to develop effective strategies?

- Early diagnosis, preferably before starting school
- The child being aware of their own condition
- Carers who understand FASD and how this affects their child
- A supportive wider network in which people understand FASD and how it affects the child and the family
- Stability of placement, particularly between age 8 and age 12

Strategies that do work ...

- ... must start from the recognition that this child or young person needs a working external brain
- Appropriate strategies include:
 - Cues – sensory signs to make sense of instructions
 - Role models – other children who do understand instructions
 - Environment – appropriate stimulation and soothing
 - Attitude – maintaining appreciation of the child
 - Discipline and praise – different impact on children with FASD
 - Supervision – remembering that need for an external brain!
 - Structure – keeping the world predictable and manageable

Supporting the child with FASD

- What will you take away from today in relation to meeting the needs of children and young people with FASD?
- What kind of additional support do they need at home?
- What educational support do they need?
- What kind of placement best meets their needs?
 - At home with family? Adoption or fostering? Residential? Mainstream education? Special education?
- What one change would you make in your daily life/work to improve support for children with FASD?

What do children with FASD think?



- They fear growing up
 - They are confused and frustrated
 - They understand the challenges that they face
 - They worry about the future
 - They know they can't cope and aren't in control
- Research by Bedford Borough Council Youth Service

Recovery is a right for every child

Article 39 of the UN Convention on the Rights of the Child

- *The UK is a party to this convention, with a commitment to implement*

- States Parties shall take all appropriate measures to promote the physical and psychological recovery and social reintegration of a child victim of:
 - Any form of neglect, exploitation or abuse ...
- Such recovery and reintegration shall take place in an environment which fosters the health, self-respect and dignity of the child

And finally ...

- What do you think are the key messages for professionals?
- Jot down some ideas
- Think about how you could get these messages to the people who need them
- Share your ideas with other people
- What developments in the setting in which you work do you think would improve life for children and young people with FASD?
- What will you do next?
- Share your thoughts on your next steps with other people