

# Fetal Alcohol Spectrum Disorder (FASD)

- why FASD is everybody's business

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*(Scottish Government Funded)* Fetal Alcohol Advisory & Support Team

# Hopes for today



- Have knowledge of culture and context of alcohol use in the UK and also in pregnancy.
- Have awareness of the key features of FASD & its potential prevalence generally & in specific populations.
- Have knowledge of the brain differences experienced by affected individuals.
- Understand the risks associated with not offering early identification & support, across the lifespan.
- Gain a brief summary of key learning from our team's journey in FASD & further CPD opportunities in FASD.

# Fetal Alcohol Assessment & Support Team (FAAST)



- Expertise and knowledge gained from a locality pilot project giving input to >200 assessments for children with prenatal alcohol exposure.
- We have been providing FASD awareness training, developed in partnership with Public Health to colleagues across NHS Scotland, Social Care, Justice & 3<sup>rd</sup> sector. **6000+ professionals trained in FASD awareness to date.**
- We have also co-facilitated diagnostic training for ~300 clinicians, hosted by the Scottish Government and & team from Manitoba, Canada.
- We have published our initial pilot service learning in an evaluation (spanning clinical service delivery, training outcomes & service user perspectives.) Results available online at:

<https://www.nhsaaa.net/services-a-to-z/fetal-alcohol-spectrum-disorder-fasd/>



# Alcohol, Culture & pregnancy

Consumption,  
Prevalence & Guidelines



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# Setting the scene – alcohol use in UK



*Alcohol is embedded in our culture, and consumption continues to grow...*

- The Lancet recently reported a 10% rise in alcohol consumption in 189 countries between 1990 and 2017 and are forecasting a further 17% increase over the coming decade (Manthey et al, 2019).
- 27% of drinkers in the UK binge drink on their heaviest drinking days (Office for National Statistics, 2017).
- Figures show that 10.2L and 12.6L alcohol per week is sold for every adult in Scotland, equivalent to 20 – 24 units (Scottish Government, 2018).
- In 2017, 14% more alcohol was sold per adult in Scotland than in England & Wales (Giles & Robinson, 2018).

# Alcohol Use in Pregnancy

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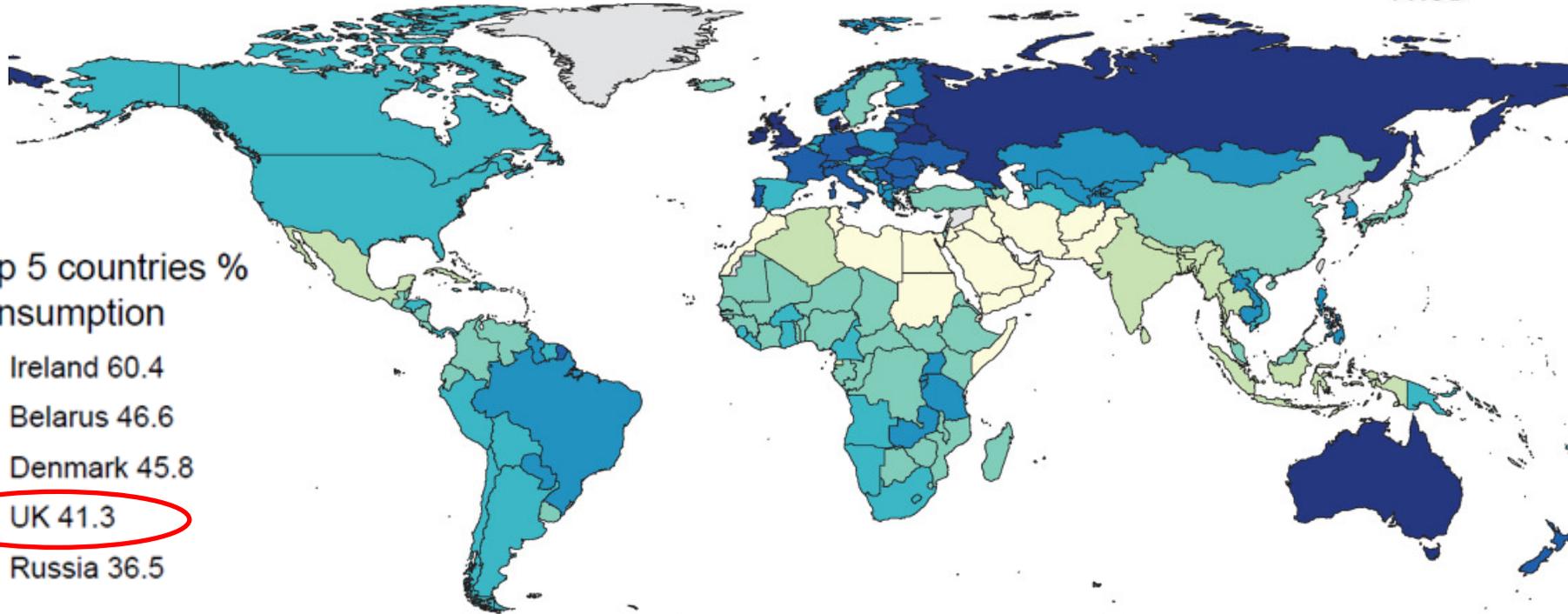
**New guidelines bring the rest of the UK in line with Scotland. The Chief Medical Officers' guideline (Department of Health, 2016) now states that:**

- If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all, to keep risks to your baby to a minimum.*
- Drinking in pregnancy can lead to long-term harm to the baby, with the more you drink the greater the risk.*

**However, approximately 46% of pregnancies in the UK are unplanned/ambivalent (Wellings et al, 2013). In 2017, 11.3% of pregnant women who took part in an ONS survey said that they had drunk in the last week (Office for National Statistics, 2018).**

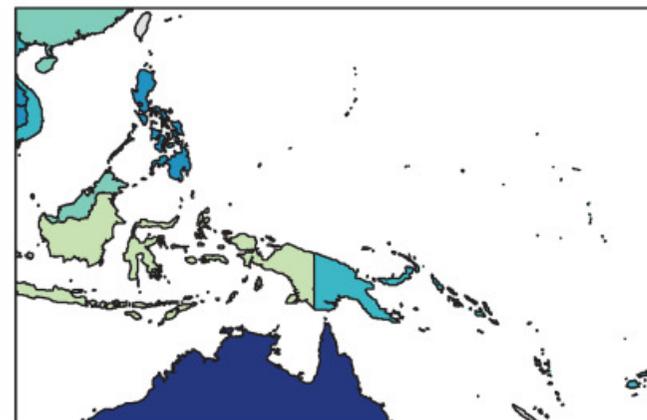
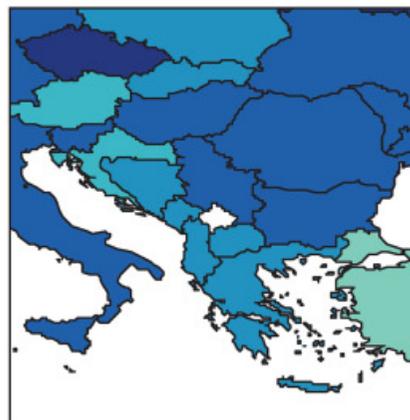
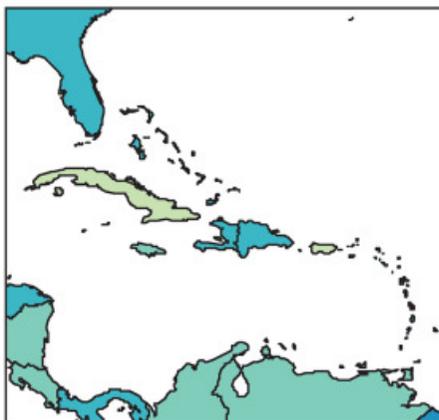
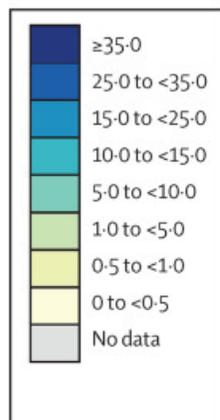


# Global prevalence (%) of alcohol use (any amount) during pregnancy among the general population



## Top 5 countries % consumption

- Ireland 60.4
- Belarus 46.6
- Denmark 45.8
- UK 41.3
- Russia 36.5



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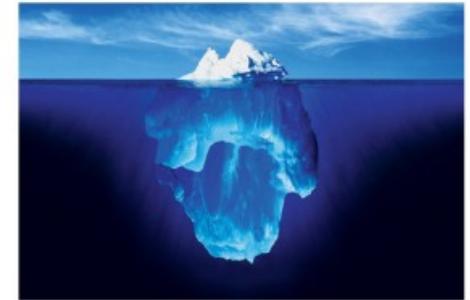


# How prevalent is alcohol use in pregnancy in Scotland?

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Study at Princess Royal Maternity Hospital, Glasgow  
(Abernethy et al, 2018)



- *Methodology:*
  - Sampling of meconium allows detection of ethanol biomarkers (these indicate alcohol use **from 20 weeks gestation**)
- *Results:*
  - ~40% of women in Scotland consume alcohol during pregnancy.
  - **Significant quantities of alcohol biomarkers were found in 15% of babies: 1 in 7 babies exposed to frequent, binge levels**
  - **No association** between biomarkers and age, ethnicity, postcode, smoking status, birth weight or head circumference.



# Alcohol as a Teratogen

Mechanisms of toxic effects

# Many factors can influence the effects of prenatal alcohol exposure

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**Prenatal alcohol exposure does not always = FASD**  
**Dose, Timing & Frequency are key factors.**

**In alcohol exposed pregnancies, FASD is impossible to predict because of the complex interplay between a multitude of factors:**

- Nutrition and maternal metabolism
- Health and concurrent drug use
- Mother's Age
- Placenta Function
- Stage of pregnancy
- Type of Alcohol ingested
- Pattern of Drinking - "*Binge culture*"
- Genetics – maternal & fetus
- Paternal Factors (alcohol use prior to conception)



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# How much is too much?



- To meet criteria for FASD to be considered, you must have evidence of **3 binge exposures during gestation** (a 'binge' is over 6 units in one condensed sitting).
- Affected individuals have a profile of a **brain injury** as neurons are damaged prior to leaving the womb.
- **The causal agent is ethanol.** Ethanol interacts in a harmful way to neuronal and cell development leading to damage to the brain, CNS and other organs of the body.

**“Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus.”**

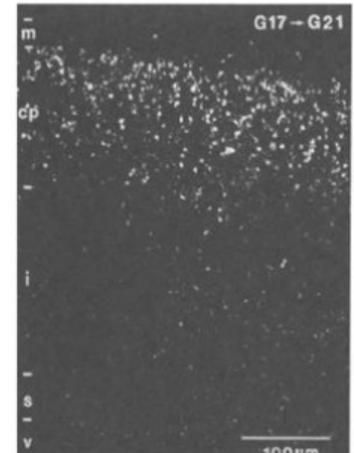
*American Institute of Medicine Report to Congress, 1996 (Stratton, Howe, & Battaglia, 1996)*

*Images from Miller (1996).*

And then migrate to here



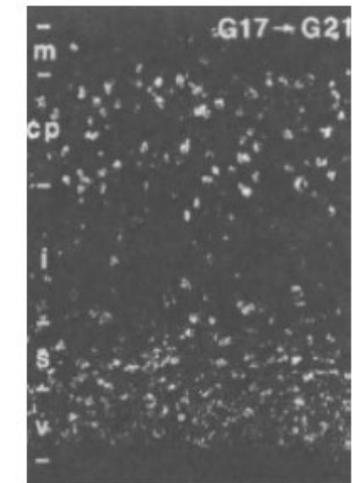
control



Neurons are 'born' here migrate to here



ethanol



Neurons are 'born' here



# What is FASD



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# What is FASD?

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Although it may not be detected at birth, FASD can become apparent later in life.

It carries a wide range of implications, encompassing a *spectrum of lifelong acquired brain injuries*:

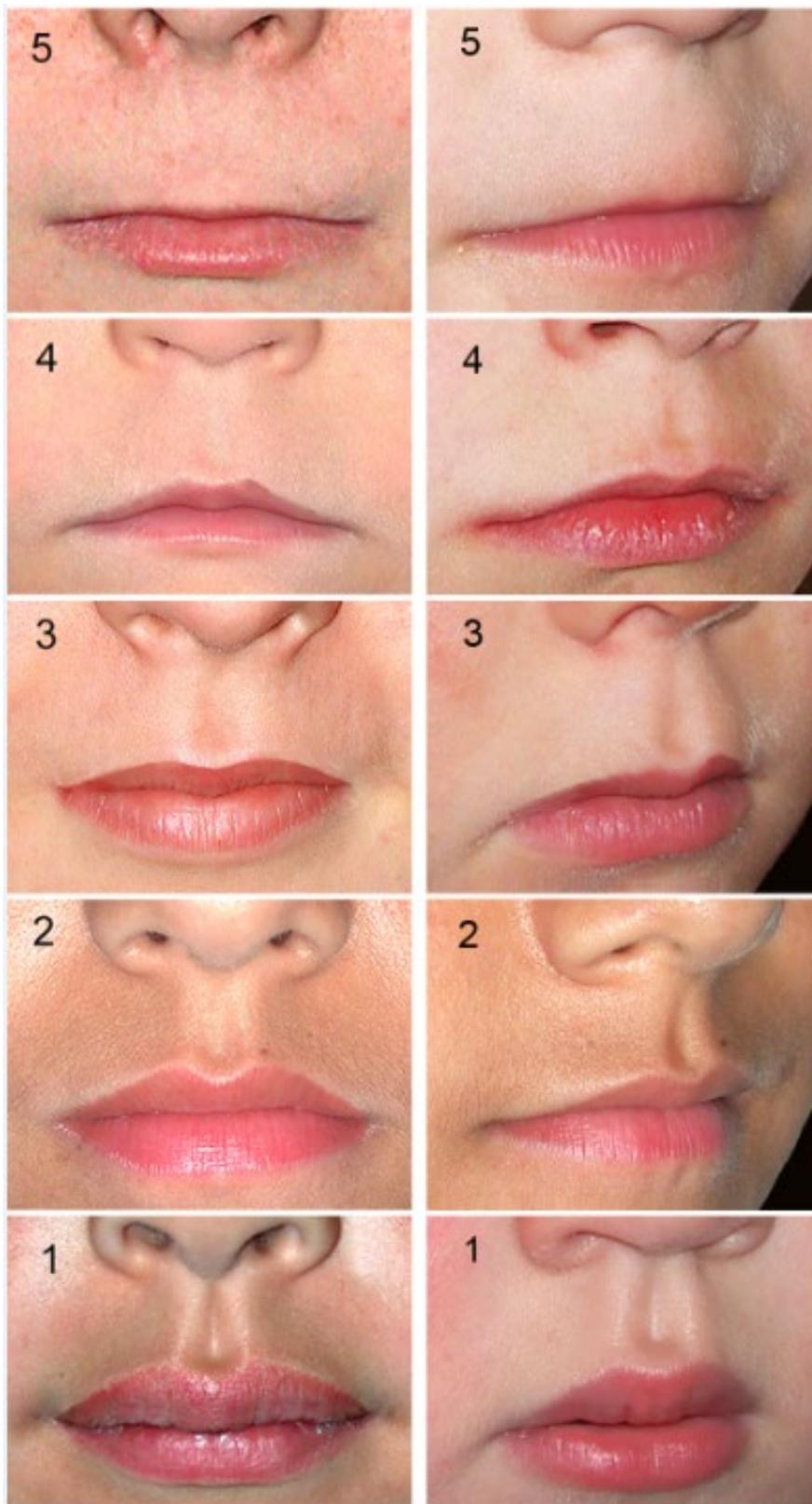
- Congenital *abnormalities in the structure, size, growth and/or function of the brain and central nervous system.*
- Difficulties with *development, learning and/or behaviour.*

But we need to remember:

- FASD is a whole body diagnosis – affecting more than just the brain and nervous system

Significant  
dysmorphology

Normal



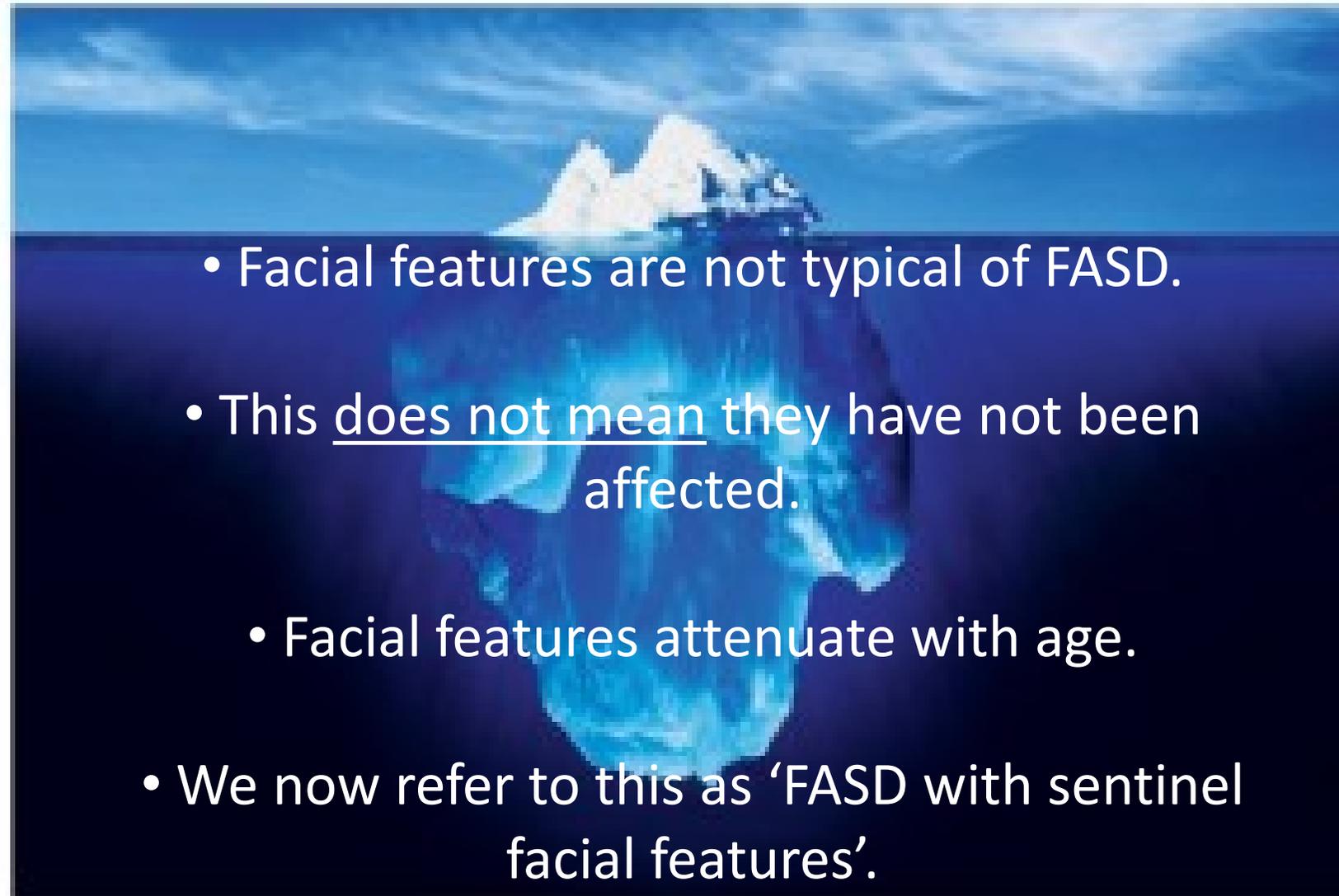
Lip-Philtrum Guide I

Philtrum Guide



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# FAS is only the tip of the iceberg



# FASD brains struggle to attain

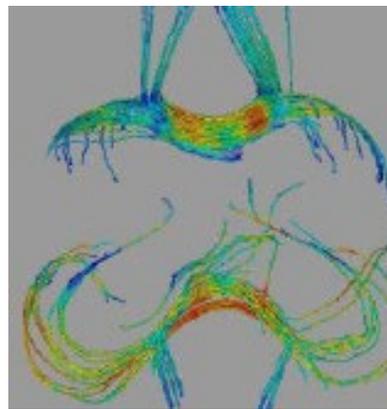
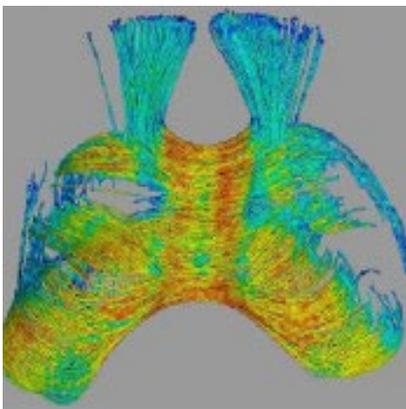


## Less connections

## FASD Brains Work Harder

Control

FAS

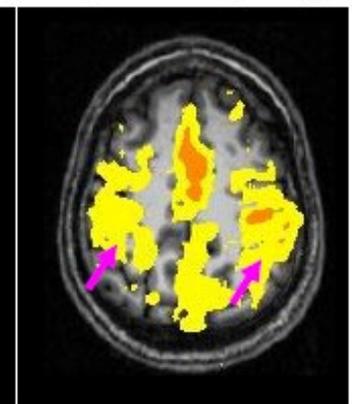
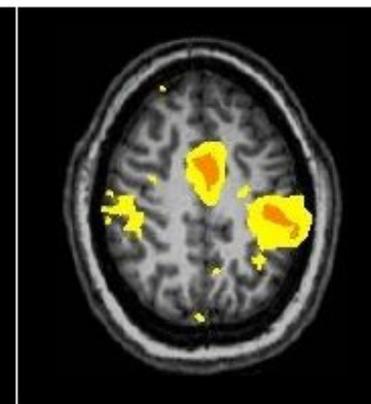
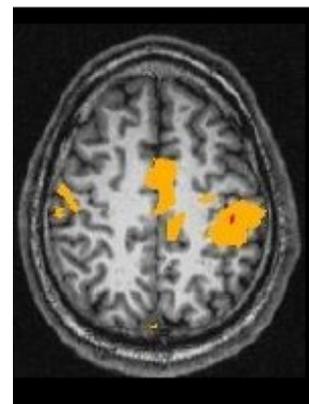


Diffuser Tensor Imaging studies (CIFASD)

Control

ARND

FAS



Functional MRI

*“10-second children in a 1-second world”*

Images used with permission of Dr Edward Riley & the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD).



# FASD affects multiple brain areas



**FASD is a whole body diagnosis, affecting the brain, central nervous system and physical development.**

**Features include:**

- A 'patchy' cognitive profile (not necessarily globally / Intellectual Disability)
- 3 or more affected brain domains indicating CNS impairment.
- High variability from individual to individual.



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# This means that what you see is not always what you get - an example profile



Profiles can differ significantly from individual to individual:

- An individual's **actual age** may not be an indicator of functioning in key areas of their life.
- Individuals may function well in some areas, yet poorly in others.
- Building up a strengths & difficulties profile is key – both diagnostically, and for intervention.

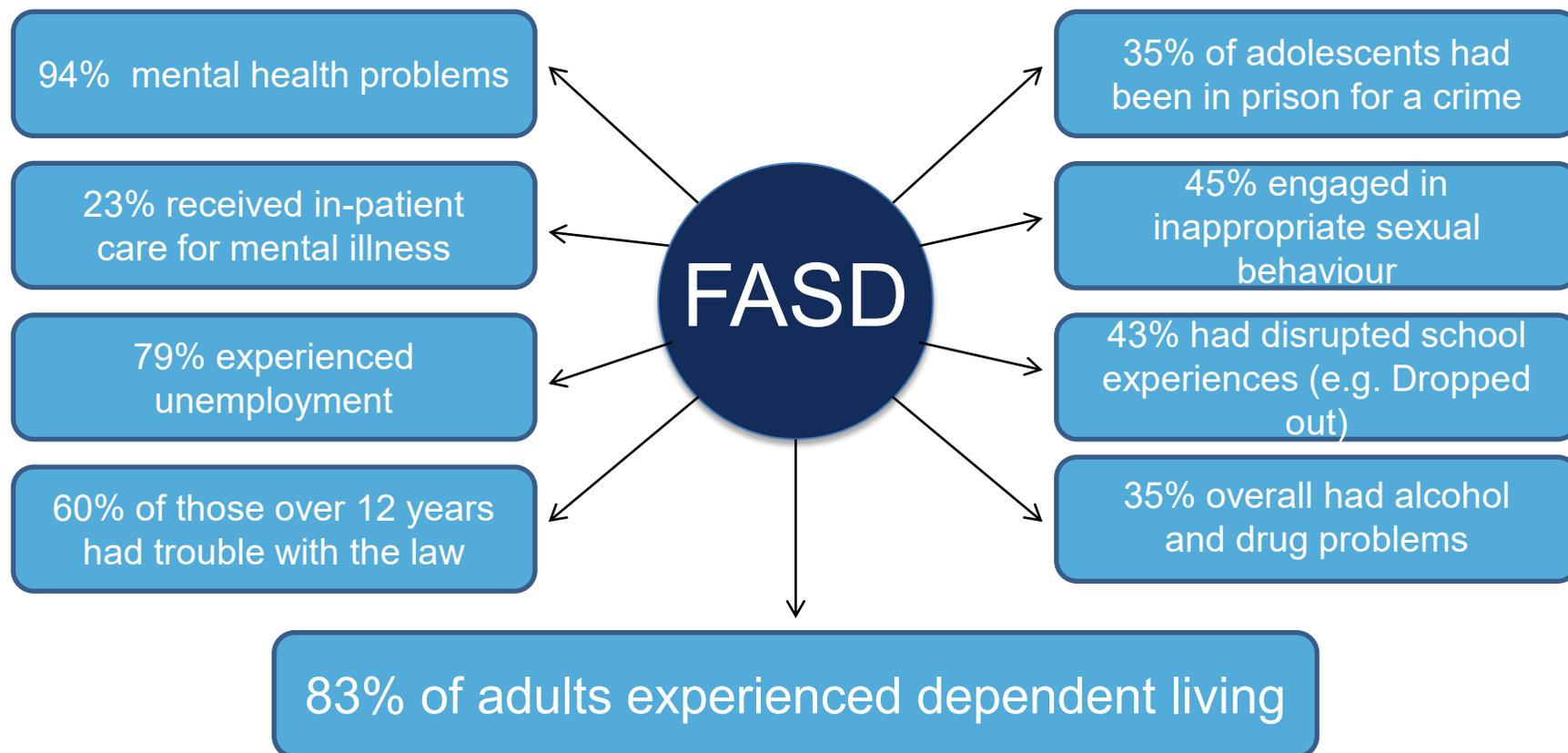


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# These profiles lead to many secondary difficulties



In a study of over 600 individuals, Streissguth and colleagues found that FASD was associated with a host of secondary disabilities, including: *mental health problems, unemployment, poor educational outcomes, homelessness, addiction, criminal justice system involvement* and more...



Streissguth, Barr, Kogan, & Bookstein (1996)

# The impact of unrecognised FASD



- **FASD affects neurodevelopment, attainment, physical & mental health**
- It is thought to be one of the most common, yet unrecognised, neurodevelopmental conditions in the Western World.
- **Individuals struggle to access the correct assessment & diagnosis** and subsequently will not receive the correct support
- **Individuals acquire alternative descriptors** - *“additional support needs child, learning disabled adult, addict, prisoner, homeless person, economically inactive.*
- The average **lifespan for an person with FASD (when not identified or supported) is 34 years** (due suicide, accidents & poisoning by alcohol & illicit drugs) (*Thanh & Jonsson, 2016*)





# How might I recognise FASD?

# FASD Assessment Overview



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## Evaluation of the Fetal Alcohol Assessment & Support Team

Summary Report  
August 2018

Author: **Dr Fiona McGruer**

Supervised by Dr Jennifer Shields

Fetal Alcohol Assessment and Support Team, Rainbow House, Community Paediatrics, Ayrshire Central Hospital, Kilwinning Road, Irvine, KA12 8SS



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# Communication



## Led by Speech & Language Therapist

- Individuals have significant expressive and receptive language difficulties.
- Yet, they may come across able to 'chat' very well, but on testing this often lacks content.
- Many mask difficulties – may not or 'parrot back' but do not fully understand

*"If our daughter hears a conversation and you ask what was said, she usually can't tell you..she makes it up!"*

*"Our daughter has trouble telling people what is wrong with her, what she needs or if she is struggling with anything. She just smiles and keeps it to herself."*

# Sensory and Motor



## Led by Occupational Therapist

- Individuals may (but not always) have issues with fine and or gross motor skills
- They may struggle with co-ordination and might have appeared delayed in walking, riding a bike for example and may often trip, fall.
- Sensory differences are common, although may not be recognised until testing by OT



# Cognition



## Led by Clinical Psychologist

- **Cognitive Assessment**

Many individuals score in low average, average or borderline

**Very few individuals have an IQ <70 (at Intellectual Disability level) on this test alone.**

**This can mislead professionals to assume this would correspond with actual levels of function**



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# Focus and Attention



## Led by Clinical Psychologist

- Sustained Attention is usually a strength....but may not appear this way because of sensory overload.
- Two thirds of children had a diagnosis of ADHD but on testing had fairly good attention...
- Highly related to motor & sensory



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# Memory



## Led by Clinical Psychologist

- Children's Memory Scale

(not to be confused with working memory)

Highly interlinked with communication ability

Memory can often be patchy, and visual is not always better than verbal.

*"Lots of times I forget as soon as you say what I'm supposed to do. I look at others, not because I want to cheat, but because I want to work out what I'm supposed to do!"*

# Executive Functioning



## Led by Clinical Psychologist

- Often individuals have difficulties in ability to learn from mistakes (consider CJS link here)
- Issues with planning & organising – seeing cause and effect.
- Managing time & money
- Impulse control (can't put on the breaks!)
- Emotion regulation



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# Adaptive Living skills



## Led by Clinical Psychologist

- Day to day living skills are often significantly lower than expected for age & stage.
- Issues with maintaining personal hygiene & self care skills
- Can't budget money or sustain tenancies
- May not understand rules of safety etc.

**Results are often in the intellectual disability range (not matching cognition). Very much like an acquired brain injury profile.**



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# Academic Skills



## Led by Psychologist

- May attend mainstream but may have struggled in various subjects
- May have had strengths in some too.
- School exclusion or behavioural difficulties are the norm.

**Training provided to all schools in Ayrshire aid understanding about FASD.**

- Allowances for extended time on tests and assignment
- Early intervention – support for education staff

*“Invest time in developing relationships with the school”*

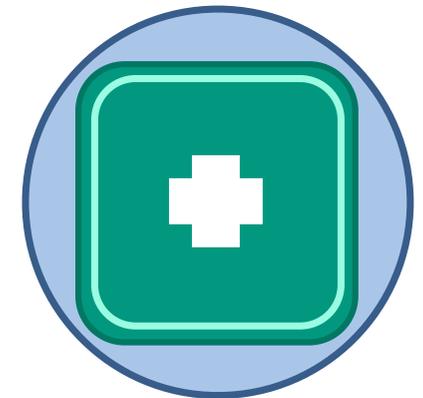
*“Our daughter has extra support at school but struggles at home.”*

Because FASD is largely unidentified, individuals struggle to manage the expectations of them...

- **30.6%** required mental health risk assessment.
- **16.7%** referred on to CAMHS  
: sample of <12's (Shields & McGruer 2018)
- Higher self-reported depression scores related to: higher social anxiety, higher risk-taking, higher hyperactivity.

**31.8%**

“I think about suicide,  
but wouldn't do it”



**4.5%**

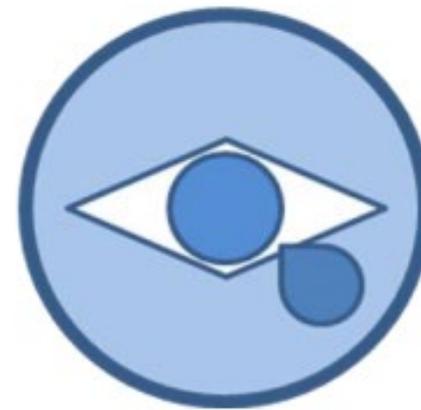
“I want to kill myself”

# Trauma: Key Findings

- FFAST group children have high rate of trauma, neglect, attachment difficulties
- 50% of children had previously been referred to services
- Average of 4 years between 1<sup>st</sup> referral and when FASD was considered
- Many children had been through ADHD assessment pathway.



**63.9%**  
Attachment  
Difficulties



**66.7%**  
Trauma



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The Finished Article  
Available online

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### NHS Ayrshire & Arran website

- All resources available to be freely downloaded

<https://www.nhsaaa.net/services-a-to-z/fetal-alcohol-spectrum-disorder-fasd/>



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# The Alcohol Strategy Commitments - Scottish Government (2018)



“We aim to improve support for individuals and caregivers to give all children the best start in life and throughout their life course. We will continue to build on our progress to date and move to implement the next phase of actions which will include:

Continuing to **raise awareness** and focus on prevention through national and local strategies including preconception messaging;

**Improving early identification, assessment and diagnosis** through up-skilling of all practitioners, professionals and partners working with women, children and families within 3 years;

Working to set up **a third sector hub** that will focus on both preventing instances of FASD arising in the first place and supporting families following diagnosis;

**Standardising education and training provision** and input to all health and social care professionals, education, third sector and across the youth and criminal justice system within 3 years;

**Improving recording of accurate alcohol use during pregnancy** and supporting appropriate information sharing to aid diagnosis at any stage within 3 years”

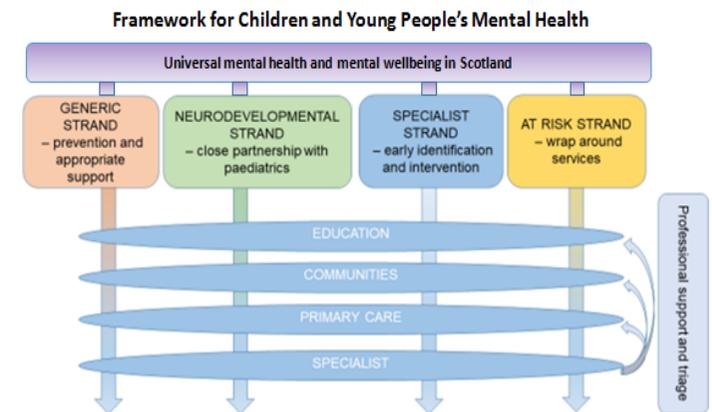
(Scottish Government, 2018)

# Scottish Government Strategy for our Neurodevelopmental Services



- The Children and Young People's Mental Health (C&YPMH) Taskforce recommended that (i) a **national Neurodevelopmental (ND) service specification be developed and implemented.**
- The group agreed that this would include the widest range of ND profiles **including those children affected by Fetal Alcohol Spectrum Disorder (FASD).**
- That ND Services would contribute to the taskforce recommendations of whole system working, and that the system would reduce the numbers of C&YP who sought help but were not seen – a **'No Wrong Door' approach to seeking help**

## Initial recommendations for the Taskforce



(McLeod, 2019) [www.scot.gov](http://www.scot.gov)

# Next Steps for the FAAS Team



Follow us: [@FASDAdvisoryAAA](https://twitter.com/FASDAdvisoryAAA)

The FAAS Team are now in the process of bridging with the School of Health in Social Science, University of Edinburgh.

- Our team hope to expand over the next 3 years to facilitate capacity & sustainability
- Plan is to to enhance access to FASD knowledge & evidence for FASD in Scotland.

FAAST are:

- Founding members of the **UK FASD Research Group**
- Member of **Scottish FASD Criminal Justice Research Group** (began 2018)
- **Co-Authors of BMJ publication:** Schölin L, Mukherjee RAS, Aiton N, *et al*  
Fetal alcohol spectrum disorders: an overview of current evidence and activities in the UK *Archives of Disease in Childhood*, 2021. doi: 10.1136/archdischild-2020-320435

# FAAST: Prevention & Post Diagnostic Resource Development resources



## Local and national prevention input

- Alcohol screening of all pregnant women
- Antenatal Alcohol Brief Interventions
- Contribution to FASD Campaigns
- Multi-disciplinary FASD training

## Provision of FASD resources

- Alcohol & Pregnancy resource
- Understanding FASD summary guide
- Train the Trainer Programme – FASD Awareness
- Parents and Carers resource
- Understanding FASD Educators resource
- FASD Family resource pack
- Diagnostic Support for Clinicians

# Thank you for listening.



## Any Questions?

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