

# Fetal Alcohol Spectrum Disorder (FASD)

**Dr Jennifer Shields**  
Principal Clinical Psychologist



**Scottish Government funded Fetal Alcohol Advisory & Support Team**

# Hopes for today

- Provide a background to the FASD pilot project in NHS Ayrshire & Arran.
- Offer a brief overview of alcohol use in Scotland, and in pregnancy.
- Outline prevalence & features of FASD
- Relay findings regarding mental health and learning difficulties of affected individuals
- Reflect upon service structures and diagnosis
- Consider how prevention can effect real change

# Background



## The Scottish Government funded **Fetal Alcohol Advisory & Support Team**

- Attended specialist training (from Canada) in Nov 2013
- Ayrshire awarded 3-year pilot funds-> small diagnostic team
- Expertise and knowledge gained (now >200 cases)
- Impact evaluated and implementation sustained
- Further 3 years of funding -> dissemination of learning

# Setting the Scene

## What we know so far...

- Patterns of alcohol use have changed significantly over the past 30 years
- In 2015 wine sales in Scotland reached their highest level for over 20 years
- Women regularly binge drink to levels which would be teratogenic to a fetus - a binge is classified as 6 units of alcohol in one sitting
- 46% of pregnancies in the UK are unplanned/ambivalent (Wellings et al 2013)
- **The UK has the 4<sup>th</sup> highest rate of drinking in pregnancy in the world (41.3%, 32.9–49.%)**

*The Lancet Global Health 2017*





# Alcohol guidelines - pregnancy



The new guidelines bring the rest of the UK in line with Scotland:

The CMO guideline 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**.
- Despite this, however, many individuals drink in pregnancy



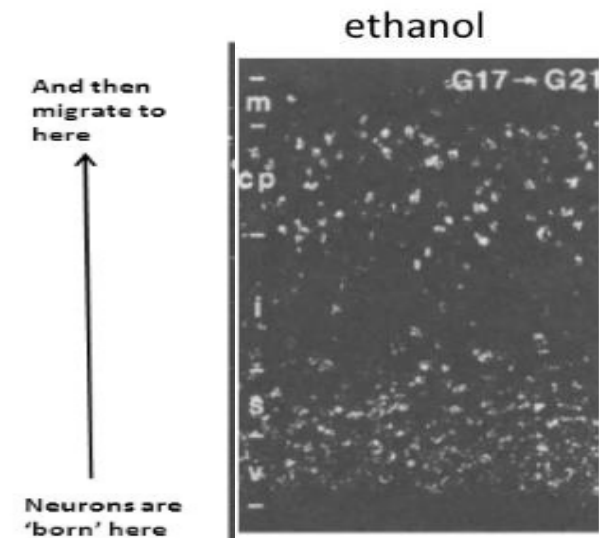
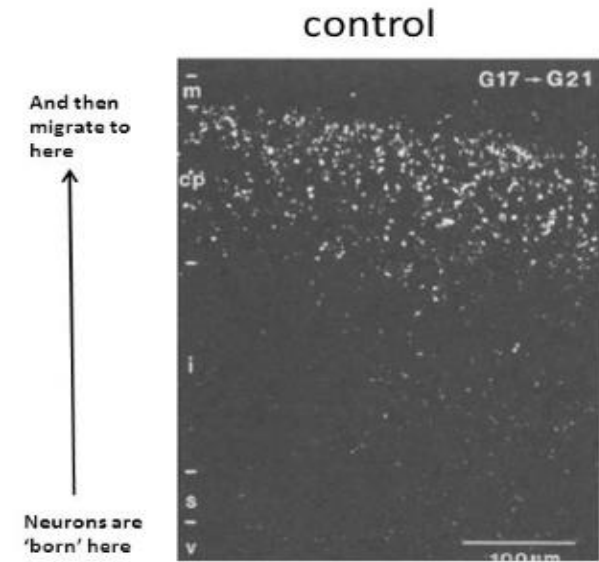
# Alcohol and pregnancy



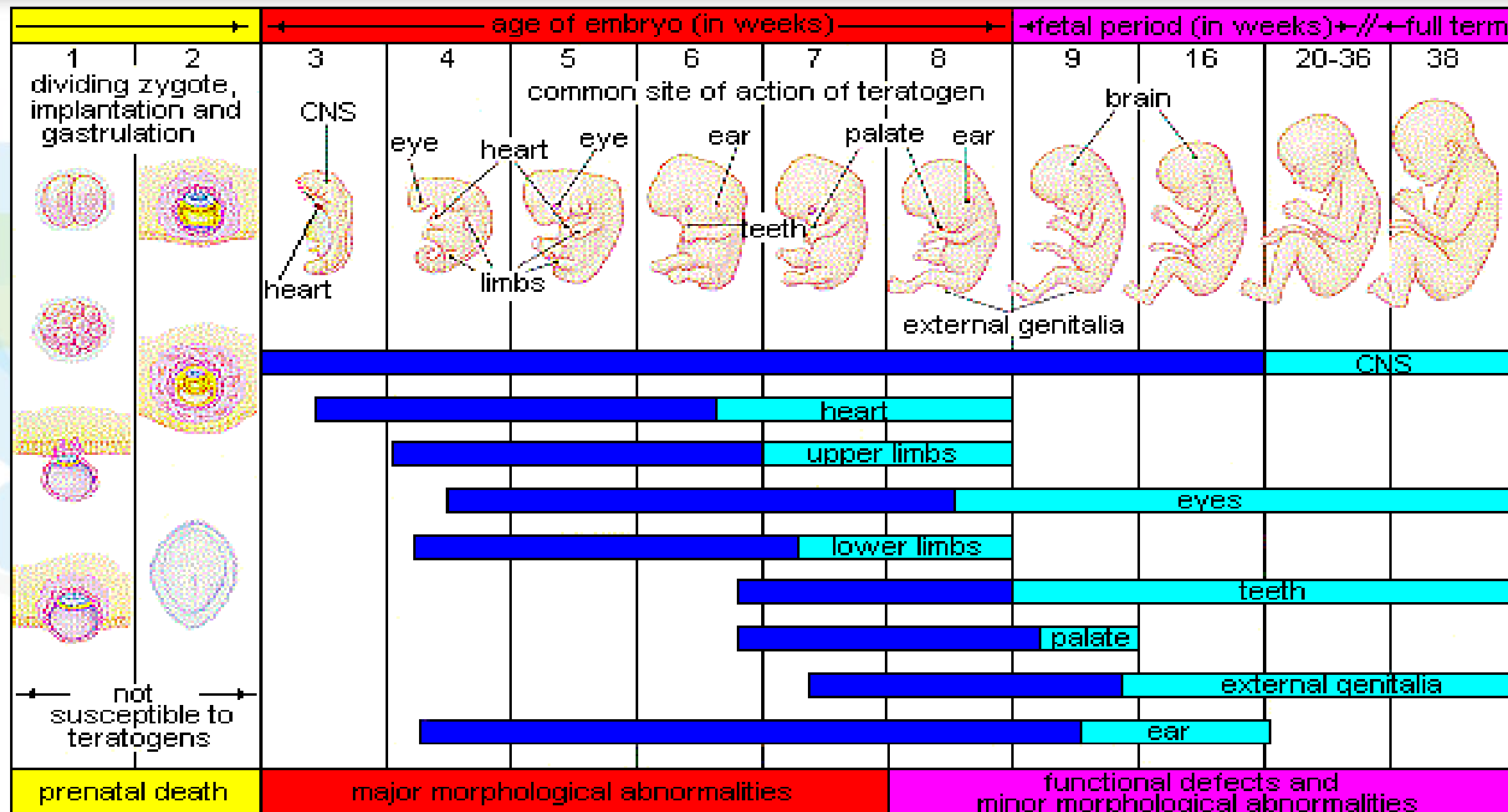
- Alcohol can destroy brain cells and damage the nervous system and other organs
- Drinking in pregnancy can lead to long-term harm to the baby, with **the more you drink the greater the risk.**
- 3-4 drinks on 3-4 occasions is enough to do so

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

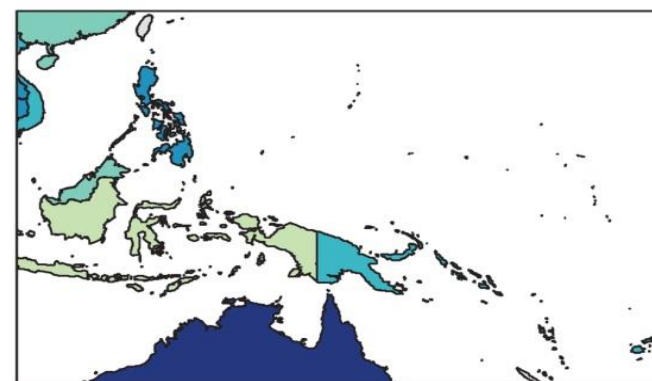
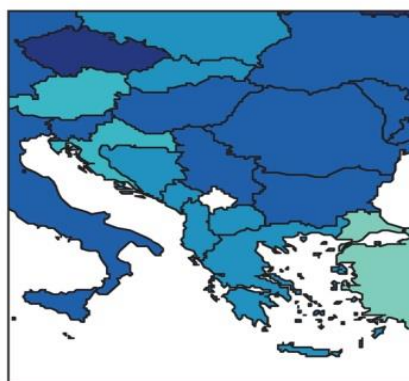
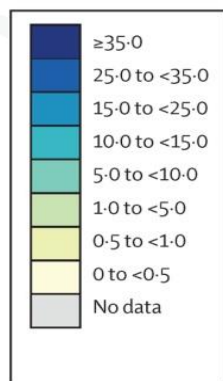
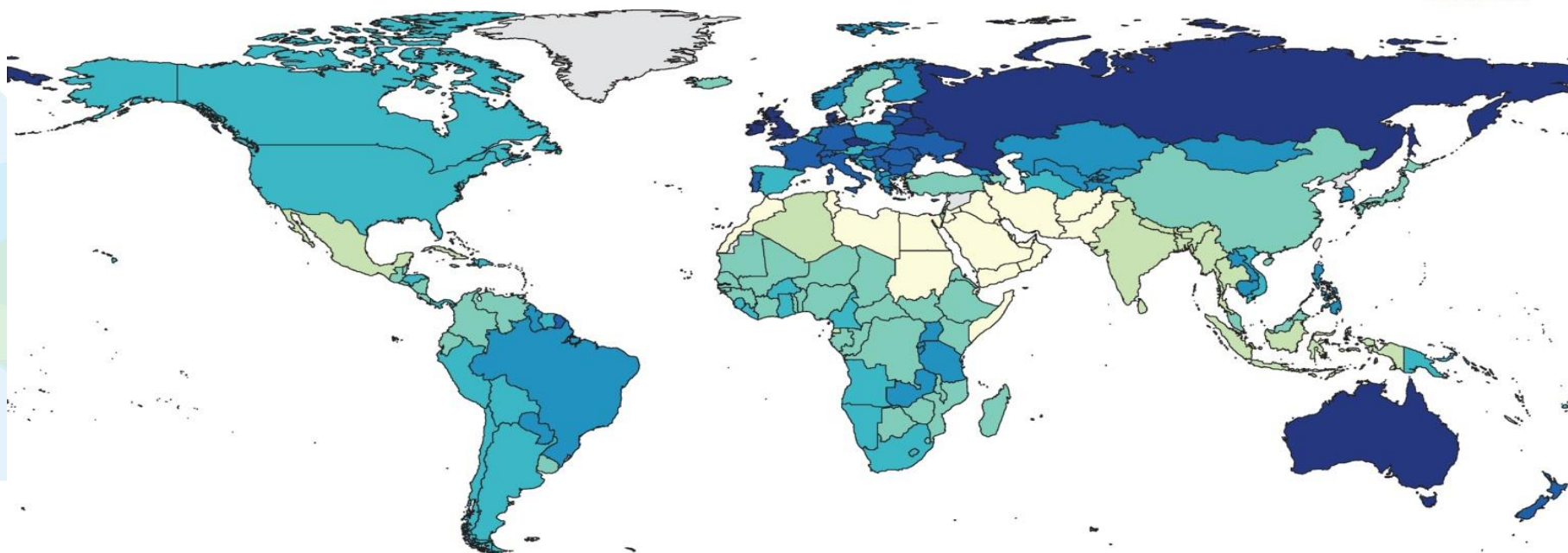
*American Institute of Medicine Report to Congress, 1996*



# Alcohol & Fetal Development



# ***Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome***





# Prevalence of Alcohol Use in Pregnancy in Scotland

## Study at Princess Royal Maternity

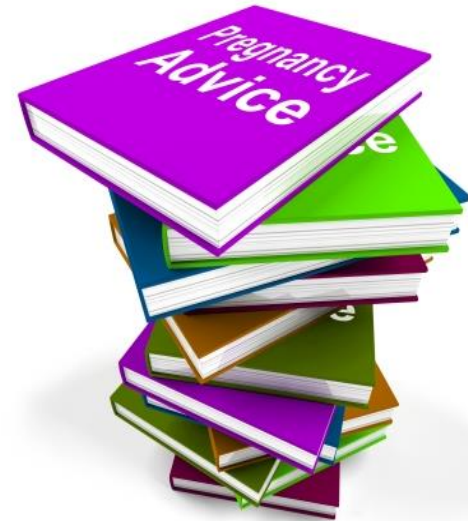
- Methodology involved sampling of meconium for presence of ethanol biomarkers - these indicate significant intake of alcohol use **from** 20 weeks.
- Data suggests 40% of women in West of Scotland are consuming alcohol during pregnancy, significant quantities in 15% of babies: 1 in 7 babies significantly alcohol exposed.
- No association between biomarkers and age, ethnicity, parity, postcode, smoking status, birth weight or head circumference.



Abernethy C, McCall KE, Cooper G, et al  
Determining the pattern and prevalence  
of alcohol consumption in pregnancy by  
measuring biomarkers in meconium  
Archives of Disease in Childhood - Fetal  
and Neonatal Edition Published Online  
First: 04 July 2017. doi:  
[10.1136/archdischild-2016-311686](https://doi.org/10.1136/archdischild-2016-311686)

# Prevalence in Scotland

- Thought to be at least 5 times the prevalence of autism (autism 1:100)
- FASD likely to be more like **5% + of population**
- This suggests over 330,000 affected individuals in Scotland.
- Over lifetime estimated cost of 2.9 Million
- Numbers continue to grow in today's context



# Prevalence in the care system



- **73-80%** of children with full-blown FAS are in foster or adoptive placement [Burd, 2001]
- FASD is **10-15 times** more prevalent in the foster care system than in the general population.[*Streissguth 1998*]
- Current discussions in literature in relation to the need to screen individuals who have a history of being in care.

# Prevalence in Justice System



## Individuals with FASD are over-represented in the justice system

- FASD youth 19-40 times more likely to be in criminal justice system (Malbin, 2004; Popova et al, 2011).
- 23% of youth forensic inpatients affected by FASD (Fast et al, 2009)
- 60% of FASD-affected individuals over 12yrs old have criminal histories (Streissguth et al., 1996; Streissguth et al, 2004; Brown et al, 2010).

# Prevalence in Justice System



- FASD among the inmate population est. 28 x higher than in general population (MacPherson 2011)
- 50% of adolescents and adults with FASD displayed inappropriate sexual behaviour (Streissguth et al, 2004)
- 50% of individuals with an FASD have a history of confinement in a jail, prison, residential drug treatment facility, or psychiatric hospital (Streissguth et al, 2004).
- Average age of CJ involvement is 12.8yrs old (Streissguth et al, 2004).



# Prevalence



***“Alcohol is the most common cause of neuro-disability in the Western world”***



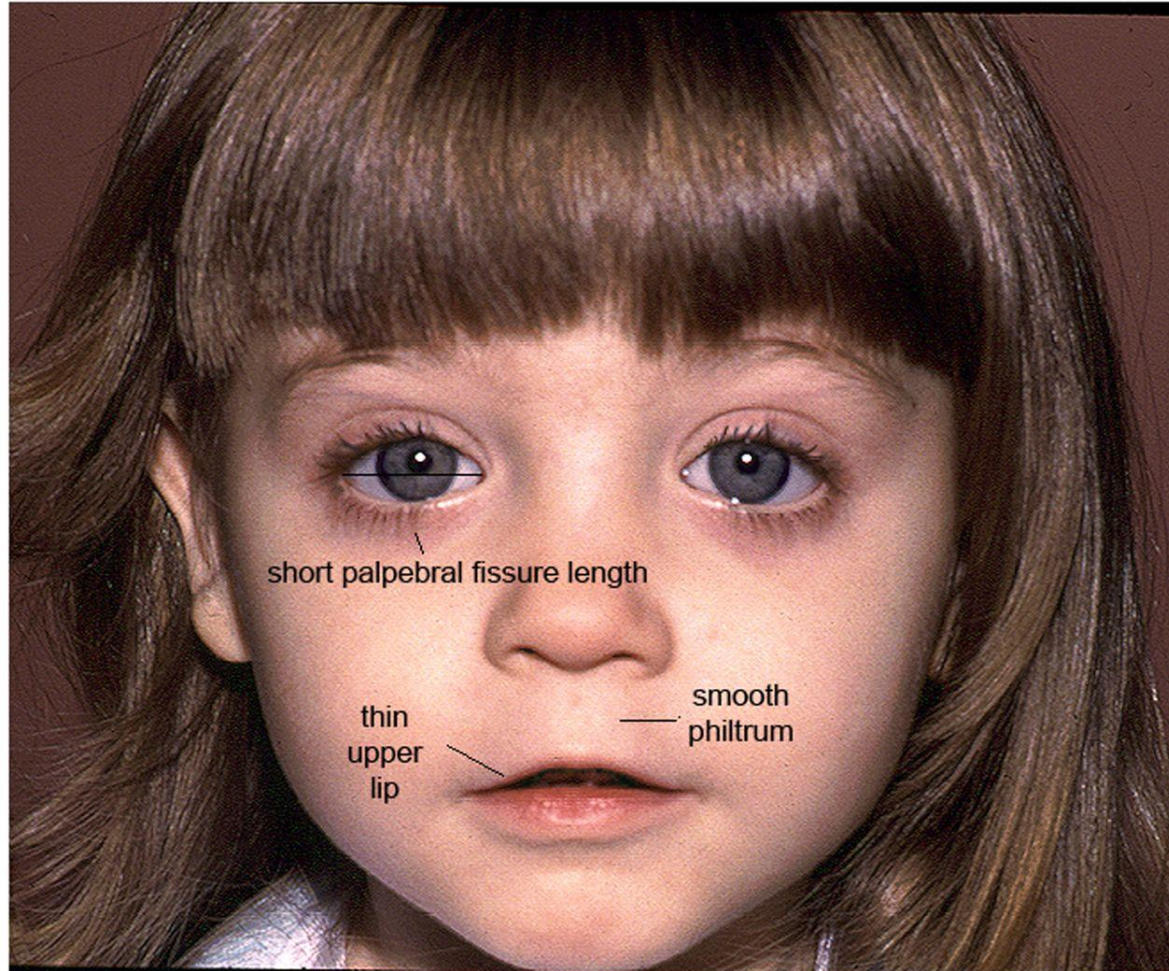
# What leads to a diagnosis of FASD? Why diagnose?



## *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.
- *May not be detected at birth but can become apparent later in life and carries lifelong implications.*

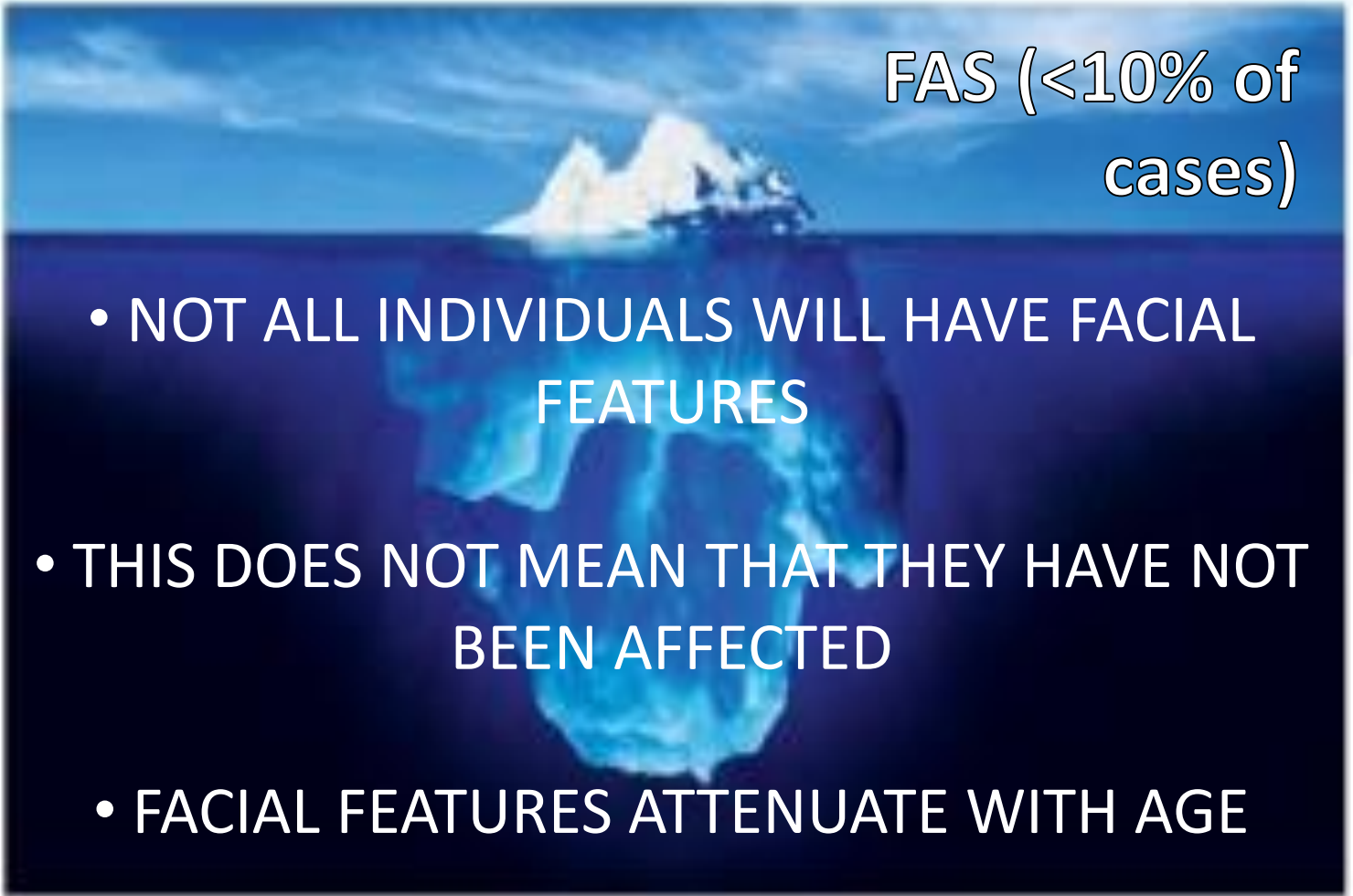
# Facial Features



Only 10% of  
FASD will have  
facial features



# Facial Features



FAS (<10% of cases)

The image features a large iceberg floating in a dark blue ocean under a light blue sky. The tip of the iceberg, which is visible above the water, is shaped like a small, white, triangular mountain. The much larger part of the iceberg, which is submerged and therefore invisible to the viewer, is shaped like a human head in profile, facing right. This visual metaphor illustrates that the visible cases of FAS are only a small fraction of the total number of affected individuals.

- NOT ALL INDIVIDUALS WILL HAVE FACIAL FEATURES
- THIS DOES NOT MEAN THAT THEY HAVE NOT BEEN AFFECTED
- FACIAL FEATURES ATTENUATE WITH AGE

# Nine brain domains affected by FASD



➔ 'Patchy' cognitive profile with a disorganised brain

➔ 3 or more affected Brain domains indicates CNS impairment

➔ Highly variable from individual to individual

➔ FASD is a whole body diagnosis

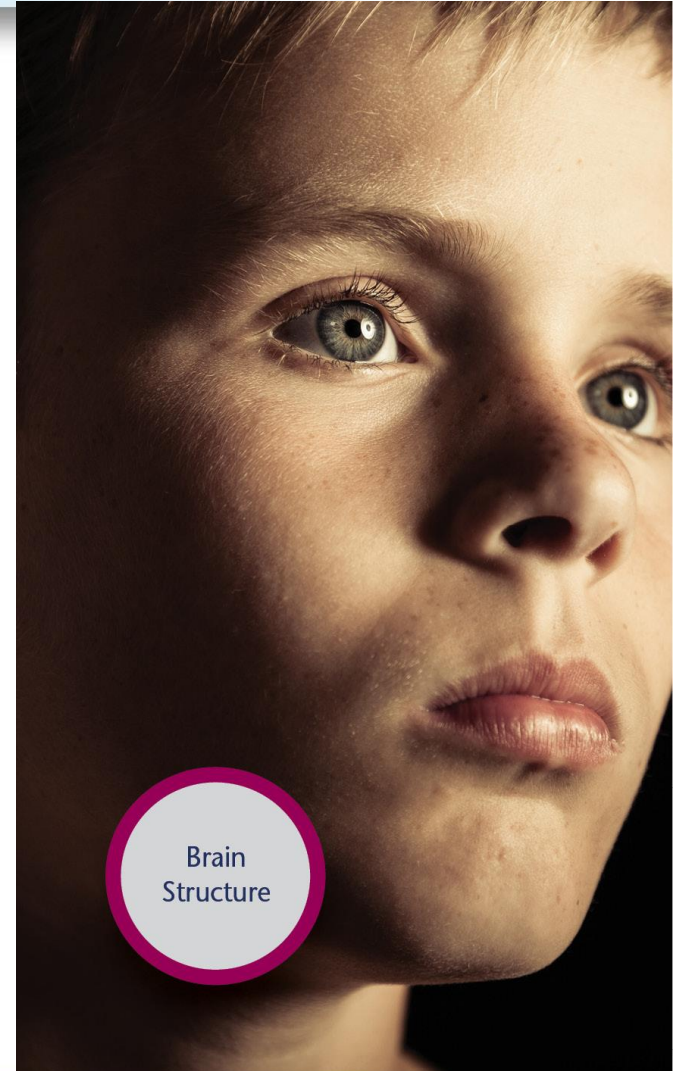




# Brain Structure

## *Difficulties:*

- Smaller brain
- Small head circumference
- Absent or partial absence of corpus callosum
- Neurologic problems (e.g. seizures)



Brain  
Structure

# Academic Skills



## *Difficulties:*

- Maths, reading, time & money
- Comprehension, organisation & abstract concepts
- Completing age appropriate academic tasks
- Learn better with visual or hands on approach



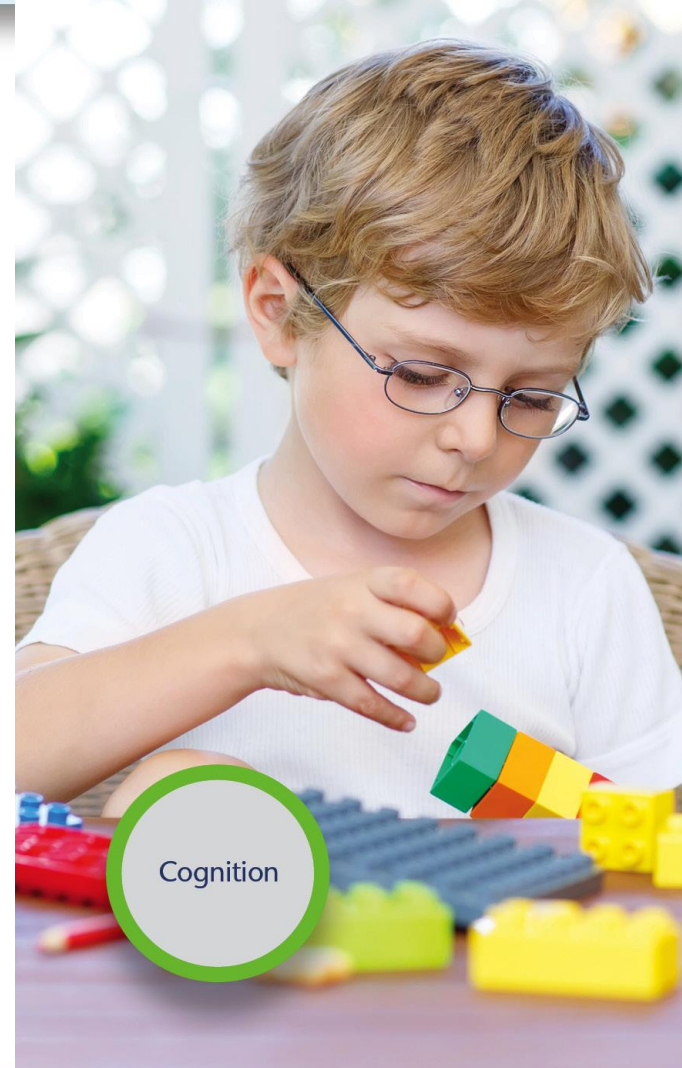
Academic  
Skills

# Cognition



## *Difficulties:*

- Thinking & reasoning
- Processing information
- Learning, working memory, planning & organisation.
- Problem solving
- Following complex instructions.



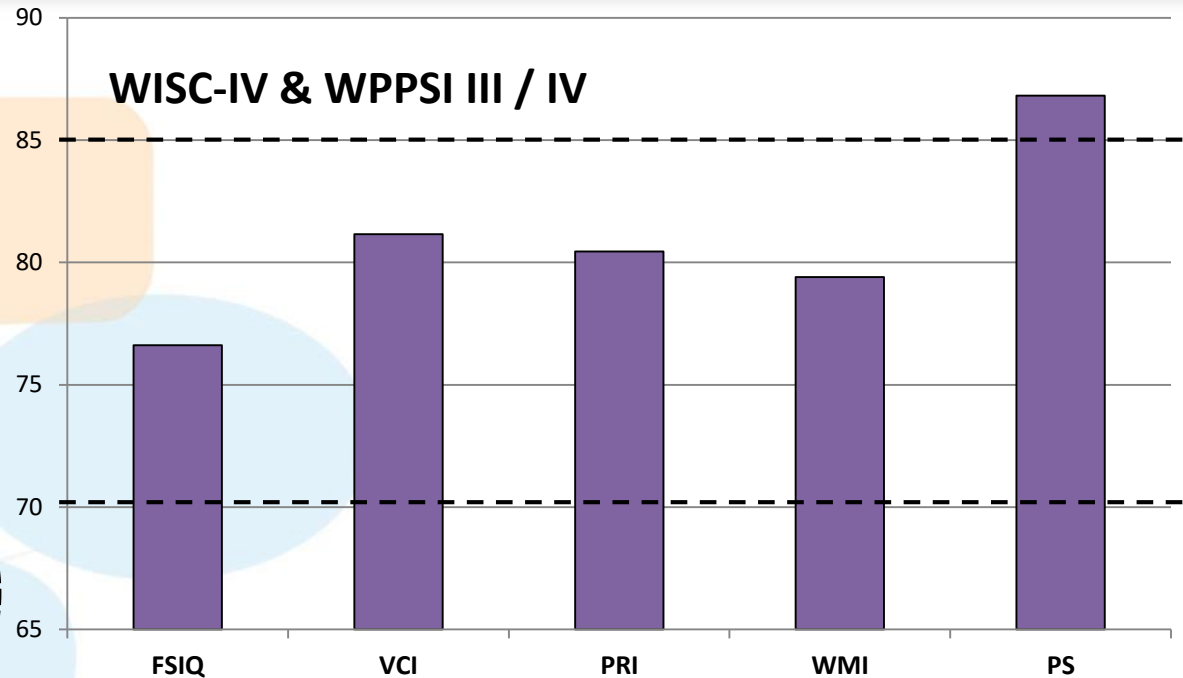
# Scores: Cognition

**Overall  
1.5 SD+  
below**

**30.7%  
FSIQ  
<70**

**7.7%  
FSIQ  
<50**

**7.7%  
Learning  
Disability  
Diagnosis**



- Most pilot children had a 'patchy' profile with few at LD level
- Higher Processing Speed anomaly - ? Trauma influence?



# Living & Social Skills



## *Difficulties:*

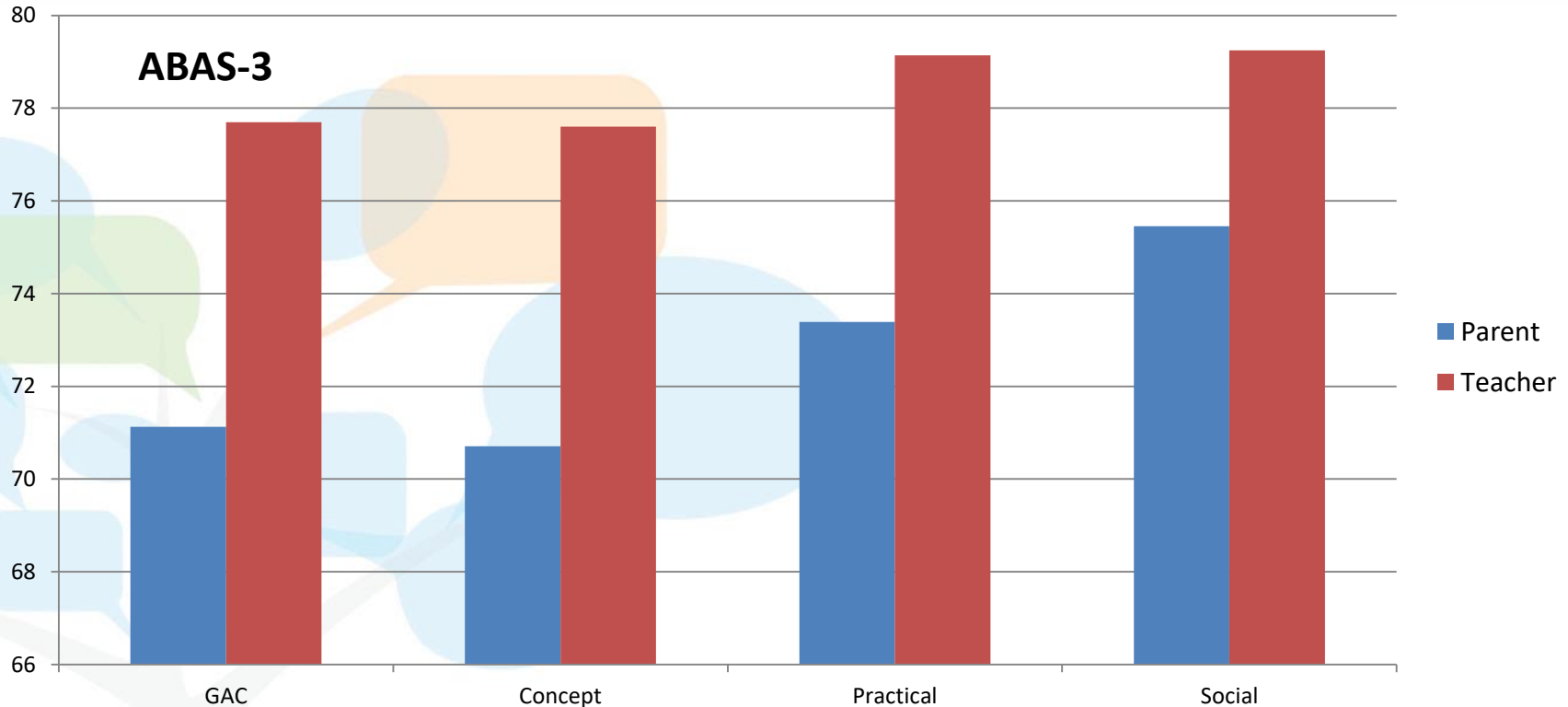
- Inappropriate responses in social situations
- Misunderstand social cues and personal boundaries
- Difficulty seeing things from another's perspective
- Socially & emotionally immature....behave younger than actual age
- Difficulty with functional life skills –own timeline, cooking, dressing appropriately, managing money



Living and  
Social Skills



# Adaptive Function



- Poor adaptive scores, but carers report poorer function than education.

# Cognition, Executive and Adaptive Functions

There are relationships between executive and adaptive function

## BADS-C and ABAS 3

- **EF correlated with ABAS**

( $r = 0.55$ ,  $p=0.02$ )

## Multiple Regression Analyses

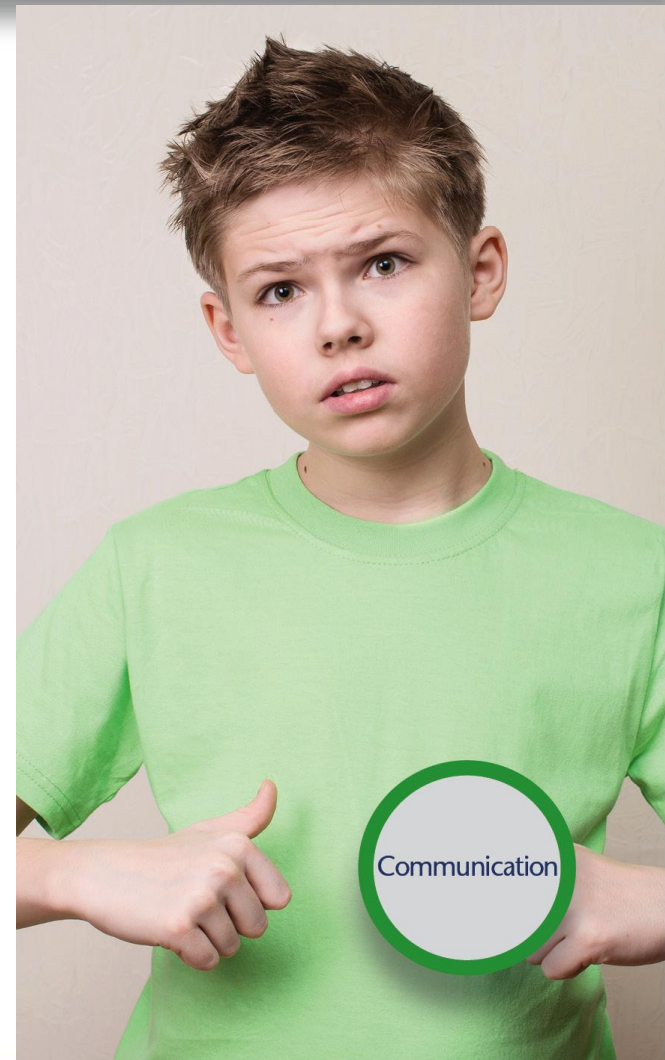
- Overall executive score is a predictor of ABAS ( $t = 2.3$ ,  $p = 0.04$ )
- **Full Scale IQ is not a predictor of General Ability Component of ABAS** in individuals with FASD (this would be the opposite for LD)
- Model explains 31.2% of the variance in General Adaptive Component



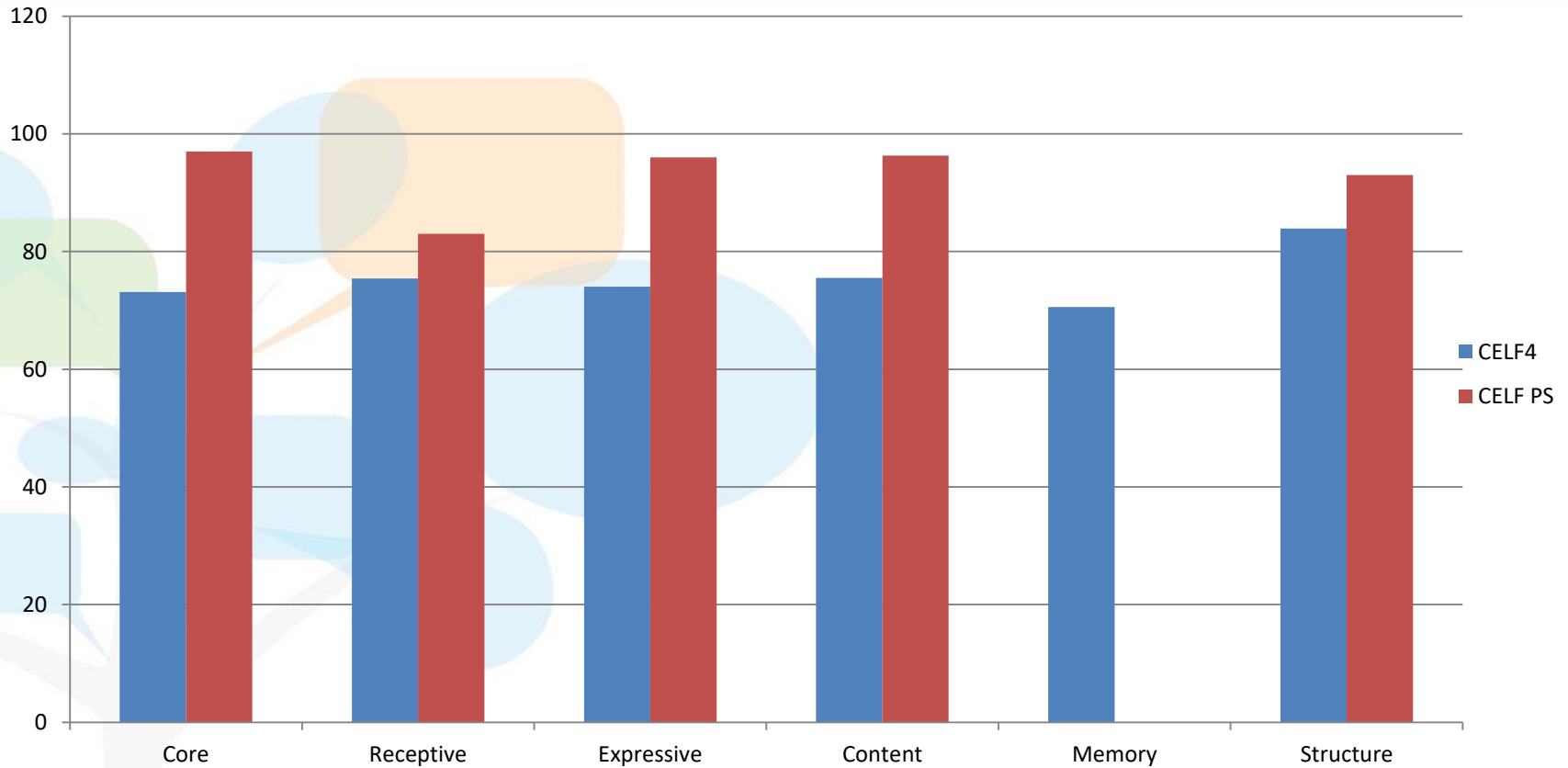
# Communication

## *Difficulties:-*

- Delayed language milestones for age
- May speak well but not grasp full meaning
- Difficulty understanding lengthy conversations
- Difficulty following instructions
- Can repeat instructions but then be unable to follow them through



# Speech and Language



# Sensory and Motor



## *Difficulties:*

- Sensitivity to light, sound, taste, smells & textures
- May over/under respond to stimulation
- May be unable to make sense of what is going on around them
- Difficulty with fine and gross motor skills



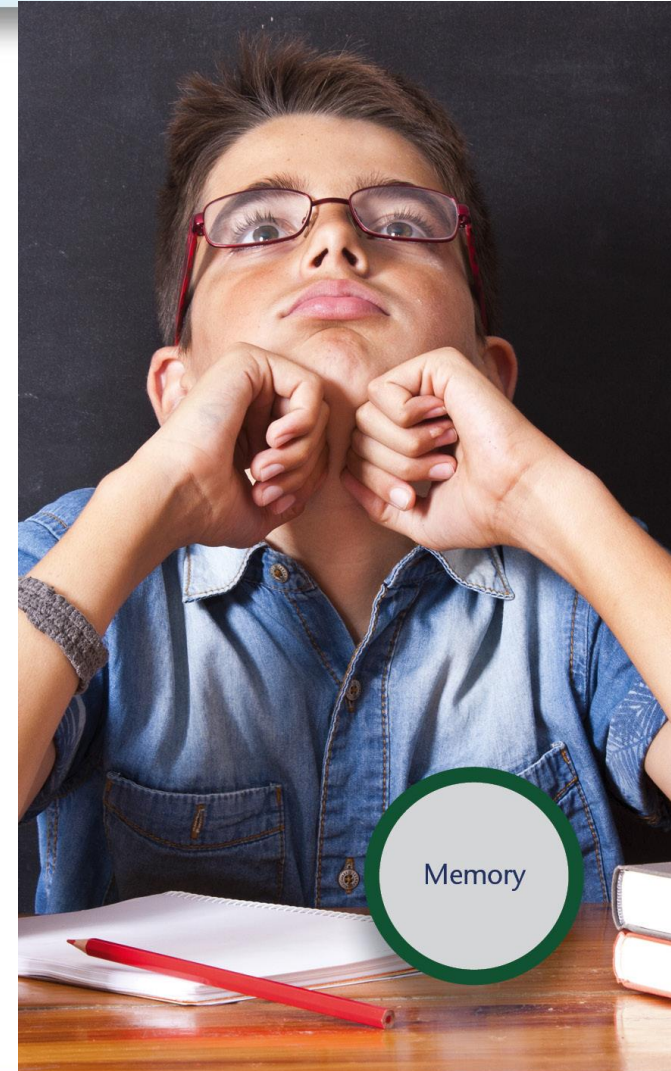
Sensory  
and Motor



# Memory

## *Difficulties:*

- Long and short term memory
- Verbal, working and visual
- Problems recalling sequences
- Recalling instructions given verbally
- Relatively better visual memory
- Easily forget steps in normal daily routine
- Appear to lie but is filling in blanks when unable to remember (confabulation)



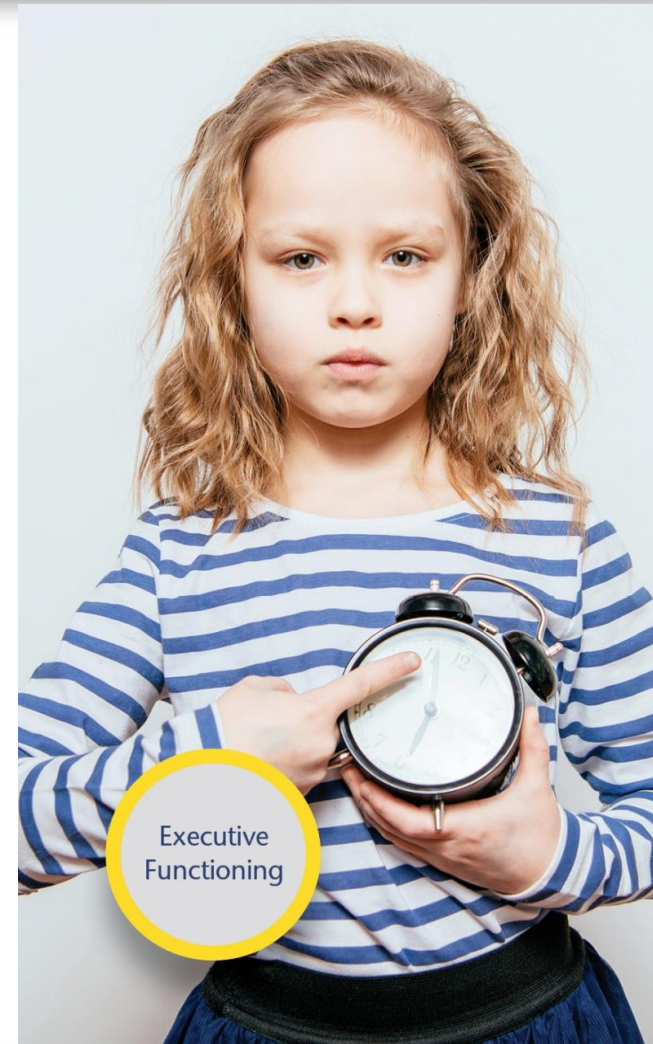
Memory

# Executive Functioning

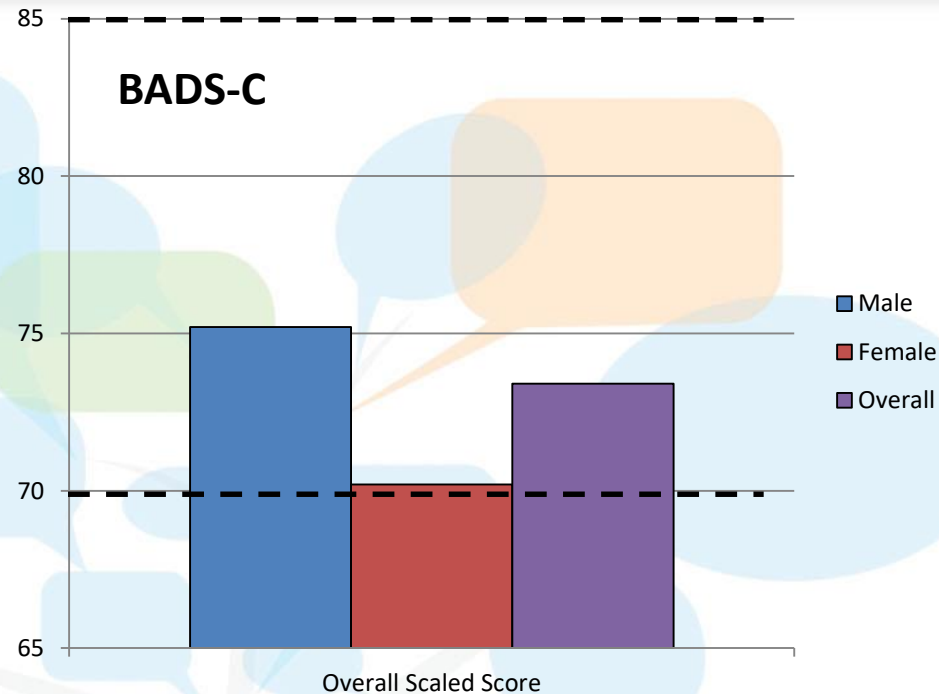


## *Difficulties:*

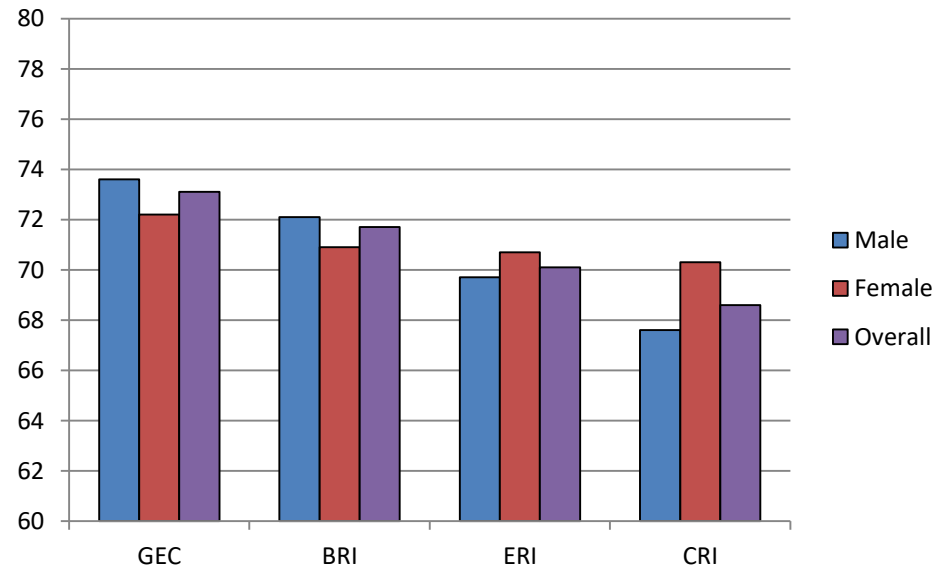
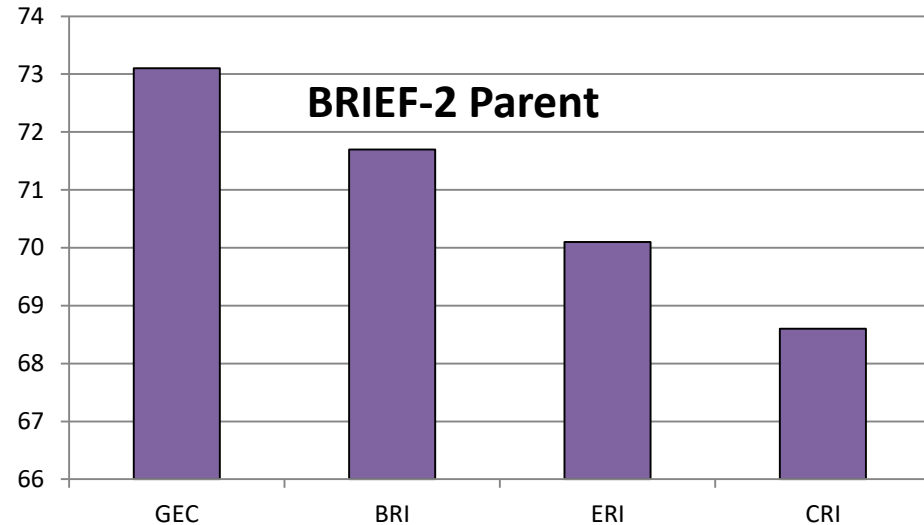
- Planning, sequencing, problem solving & organisation
- Controlling emotions; may be impulsive
- Transition and change and managing time
- Understanding cause & effect, consequences of actions and don't learn from mistakes
- Understanding concepts & abstract ideas



# Executive Function



- BADS-C score correlates with BRIEF 2 Parent GEC ( $r=-0.53$ ,  $p=0.02$ ) and CRI ( $r=-0.51$ ,  $p=0.03$ ).
- Exec Function a significant difficulty.

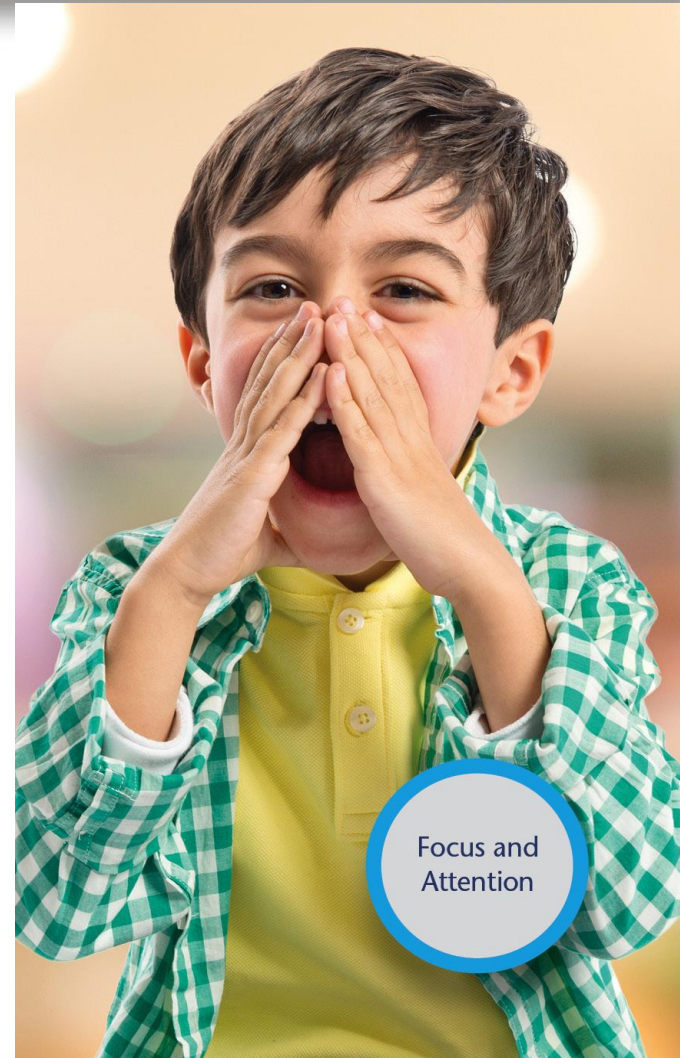




# Focus and Attention

## *Difficulties:*

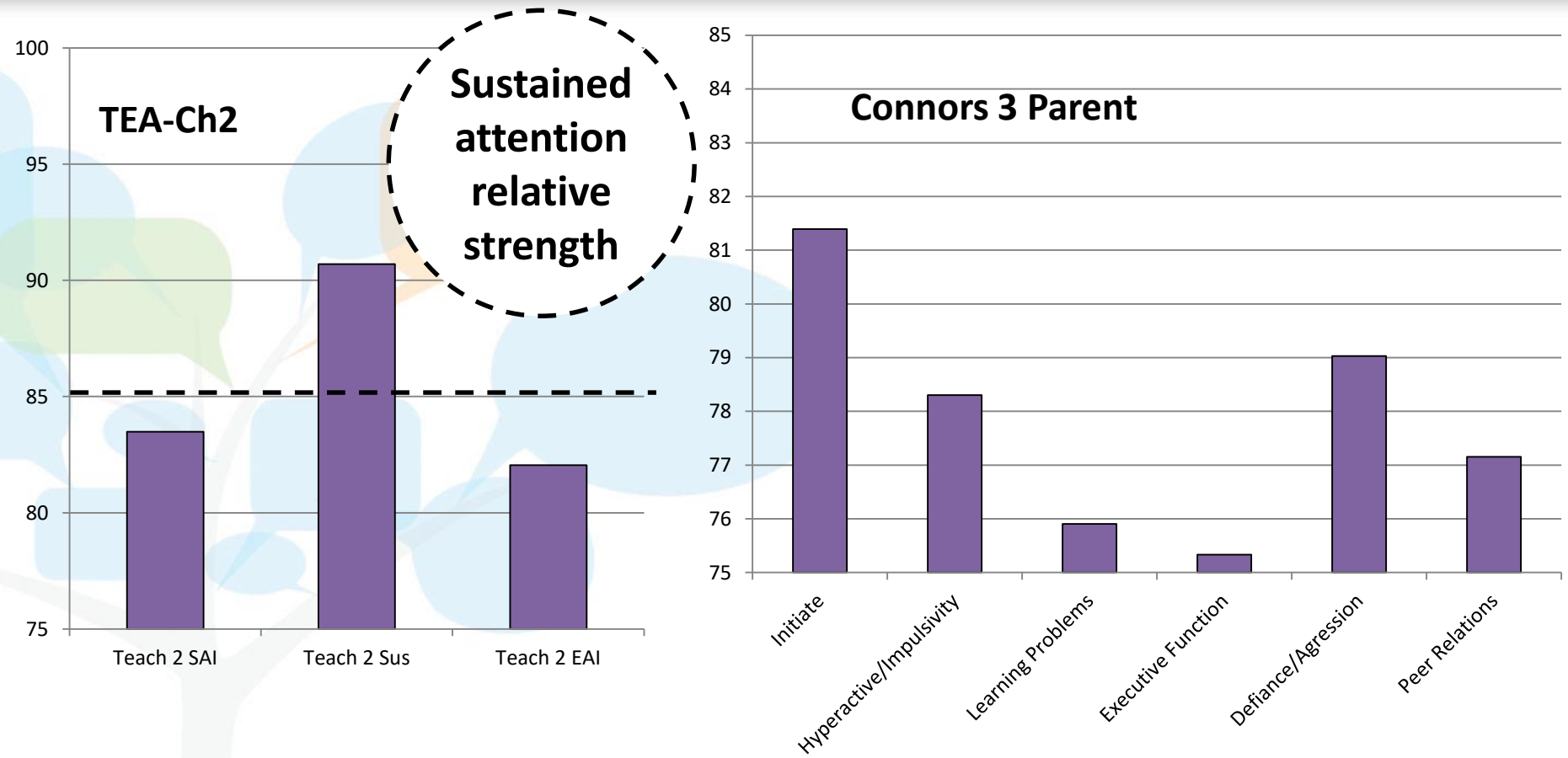
- Easily distracted
- Over stimulated
- Impulsiveness
- Inattentive
- Hyperactive
- 'Can't sit still'
- Hearing impairment/auditory processing problems



Focus and  
Attention



# Attention



- Formal testing of attention shows less deficit than behavioural report.
- Switching attention and everyday attention more of a difficulty than sustained attention.

# Nine brain domains affected by FASD



# What you see is NOT always what you get: *(an example profile)*



## Additional Support Needs

This high level summary page is no longer being updated. Please follow the below links to reach the most recent publications and datasets. The statistics for this topic can be found in the Summary Statistics for Schools in Scotland publication and the pupil census, supplementary data dataset.

[Publications](#)

[Datasets](#)

In 2016, 170,329 pupils (24.9 per cent of all pupils) had additional support needs, of which 60 per cent were boys. 5.3 per cent of pupils had social, emotional or behavioural difficulties and 2.1 per cent had a learning disability. 162,252 (95 per cent of them) spend at least some of their time in mainstream classes.

### Pupils with Additional Support Needs

	2011	2012	2013	2014	2015	2016
		118,034	131,621	140,542	153,190	170,329
Total pupils with Additional Support Needs	98,523					
With a Co-ordinated Support Plan (CSP)	3,617	3,448	3,279	3,128	2,716	2,385
With Individualised Education Programmes (IEP)	42,819	42,847	40,089	37,640	37,168	37,733
Assessed or Declared Disabled	14,682	15,368	15,510	15,156	15,899	16,265
With Child Plans	3,351	7,235	12,102	15,946	20,235	25,095
With any 'Other' type of support	58,256	77,892	94,090	103,568	115,527	131,042

In 2010, information on additional support needs was collected in a different way. Information on reasons for support and nature of support was collected separately for each type of additional support need. There was also inclusion of a new category, 'other' which include child plans (separate category for child plans introduced in 2011), short term or temporary support and any other support not covered under IEP and CSP. The inclusion of 'other' category contributed to



# Prognosis if not accurately understood.....

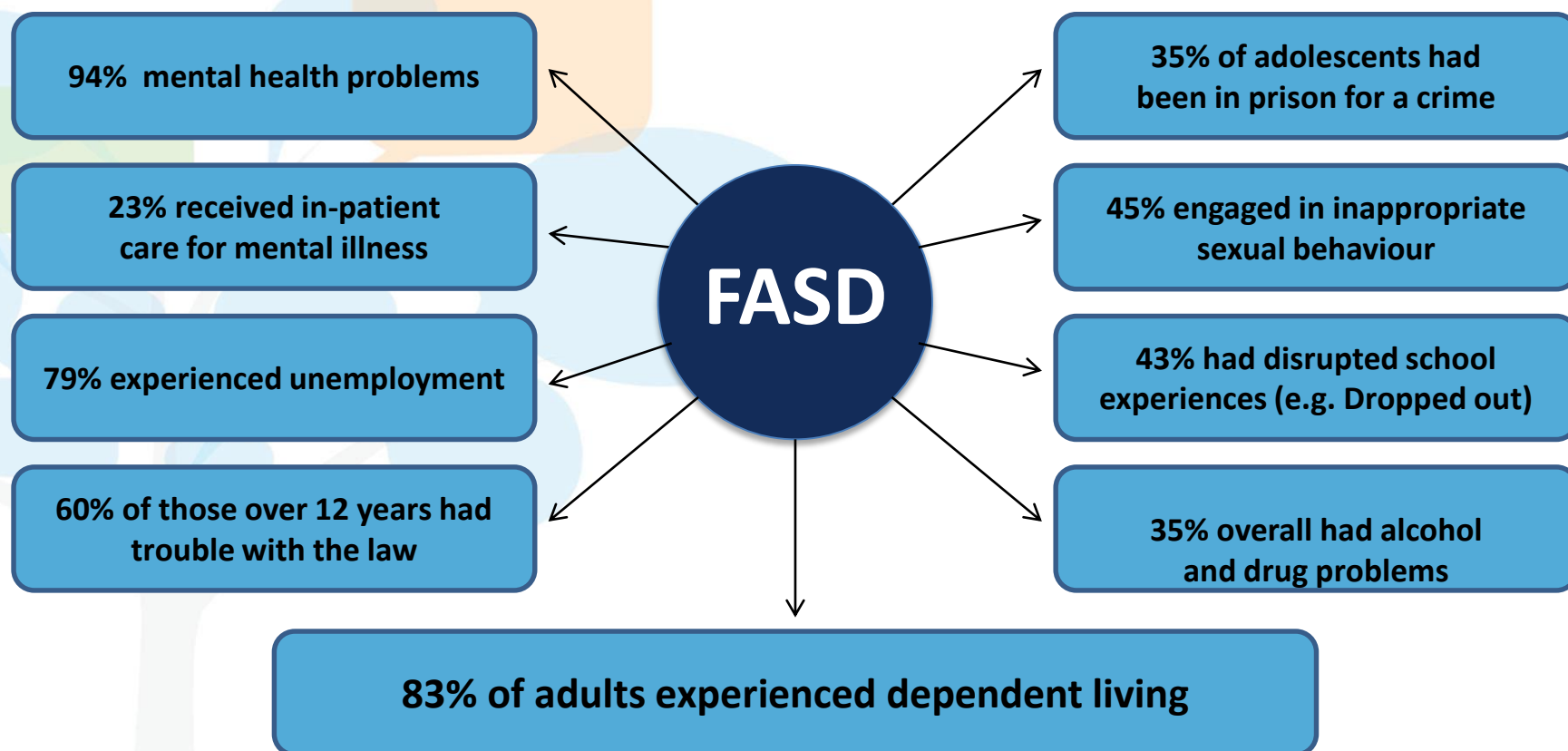
## *As the children with FASD grow older they experience:*

- Social difficulties in relating to their peer group and often face a traumatic path through adolescence and beyond
- Involvement with criminal Justice
- Homelessness
- Unemployment
- Dependent living
- Vulnerability to trauma - adults & due to brain differences are more likely to experience abuse & exploitation.



# The Evidence

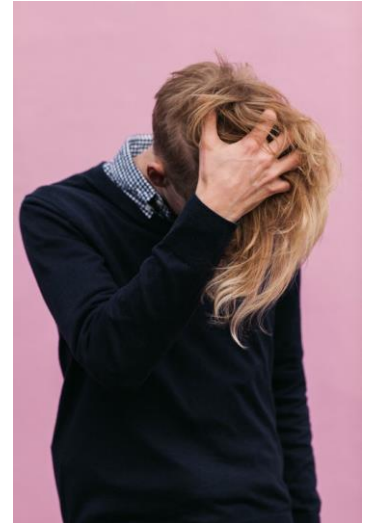
## Study of 500 adults with FASD (*FASD Centre of Excellence, Manitoba 2007*)



# Pilot Project Data

## Mental Health & Wellbeing

- Many of the children assessed within the Ayrshire pilot were looked after and accommodated.
- Attachment Difficulties evident in 64% of children.
- Adverse Childhood Experiences contained in 67% of the 36 pilot children's case histories (all under 12) - these were mainly for significant trauma and neglect.



# Mental Health Risk

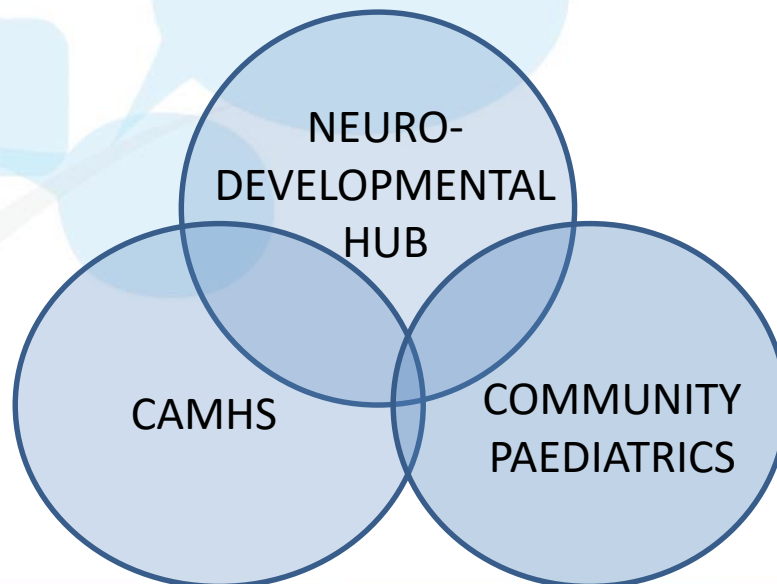
- **31% of children required risk assessment** due to disclosure of active self harm / suicidal ideation / planning / intent
- These children selected ***“I think about killing myself but I would not do it”*** to describe mood
- 2 children displayed **active suicidal behaviours** intended to end their life (both under 12yrs) – using ligatures, knives. Ongoing risk management was required with CAMHS.
- Overall, 5 children required referral to CAMHS. 5 others had previously had CAMHS input ( One third of pilot children)
- Children with FASD require both paediatrics and CAMHS.



# Diagnostic Pathway Suggestions....



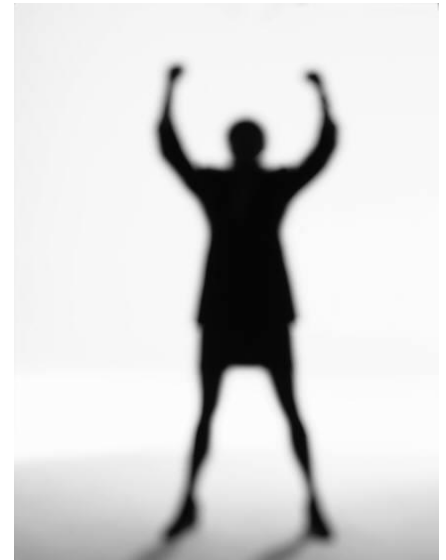
- **Disorder specific pathways are not the best fit (e.g autism vs ADHD vs FASD. Neurodevelopmental Assessment pathways appear a better fit – all conditions assessed under the same umbrella pathway.**
- **Service structures need to adapt to the co-occurrence of neurodevelopmental and mental health difficulties.**



# Successful Outcomes

Early identification and diagnosis provides a crucial window of opportunity:

- To educate
- To provide early intervention
- To link with resources
- To facilitate successful transition to adulthood



**“Diagnosis and early intervention  
is known to improve outcomes”**

(Streissguth 2004, Burd et al 2003)

# Prevention work



- Alcohol screening of all pregnant women  
*Alcohol discussed at booking appointment*

- Antenatal Alcohol Brief Interventions (ABI)

- Local/national FASD Campaigns

- FASD Awareness Day: 9 September annually
- Local FASD Conference March 2017
- ACAMH Conference 4<sup>th</sup> October 2018



# Prevention



Prevention is key to reducing prevalence of FASD.

We need education for all

**FASD is everybody's business.**





# To summarise.....

- Binge drinking and alcohol consumption by women is increasing
- Alcohol is a toxin against which the developing fetus has no defence. Yet 40% of babies have alcohol in meconium.
- Alcohol in-utero may cause brain damage which is permanent and has impact across the lifespan
- Severity of impact is linked to frequency and dose of drinking, in addition to maternal & paternal factors and stage of pregnancy
- No two children are affected the same & require individualised assessment to elicit profile of strengths & difficulties
- Prevention is key



**FASD is preventable.**

# Any questions?



## Thank you for listening

## Please share your knowledge

All materials within this presentation and available today belong to NHS Ayrshire and Arran. If you would like to reproduce any of this material for educational purposes, please contact [Jennifer.Shie;ds@aapct.scot.nhs.uk](mailto:Jennifer.Shie;ds@aapct.scot.nhs.uk) for permissions.

