

# AN INTRODUCTION TO FASD

DIAGNOSIS, MANAGEMENT, SUPPORT

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# PLAN

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- Defining FASD and its co-occurring conditions.
- Diagnosis and what gets in the way.
- Post diagnostic support.
- Specific challenges for education.

# FASD IN A NUTSHELL

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- Fetal Alcohol Spectrum Disorder can result from **any amount** of exposure to alcohol in utero, at **any time** during pregnancy.
- Directly teratogenic, but also changes in gene expression > multi-generational neurodevelopmental impact.
- Twin studies > modified genetic susceptibility.
- FASD can occur with and without sentinel facial features (only 10%).
- FASD results in life-long neurodevelopmental disorder, in addition to a number of possible physical effects (428 conditions associated with PAE).

## Sentinel Facial Features

- ▶ Only ~10% of children with FASD
- ▶ Three primary diagnostic features:
  - ▶ Palpebral fissures <3<sup>rd</sup> centile
  - ▶ Grade 4/5 upper lip (Washington lip/philtrum Guide)
  - ▶ Grade 4/5 philtrum



# TEXTBOOK NEUROCOGNITIVE PRESENTATION

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- A WISC is not enough – full neuropsychological assessment needed.
- **IQ is not a reliable predictor of functioning in FASD**
- Spiky cognitive profile more common than IQ in LD range. >2SD between domains.
- Working memory vs. episodic memory.
- Receptive/expressive language deficits.
- Executive functioning impairment > poor adaptive behaviour.
- Often present as more capable than they are – pass the ‘mingle’ test.

# SPEECH AND LANGUAGE PRESENTATIONS IN FASD

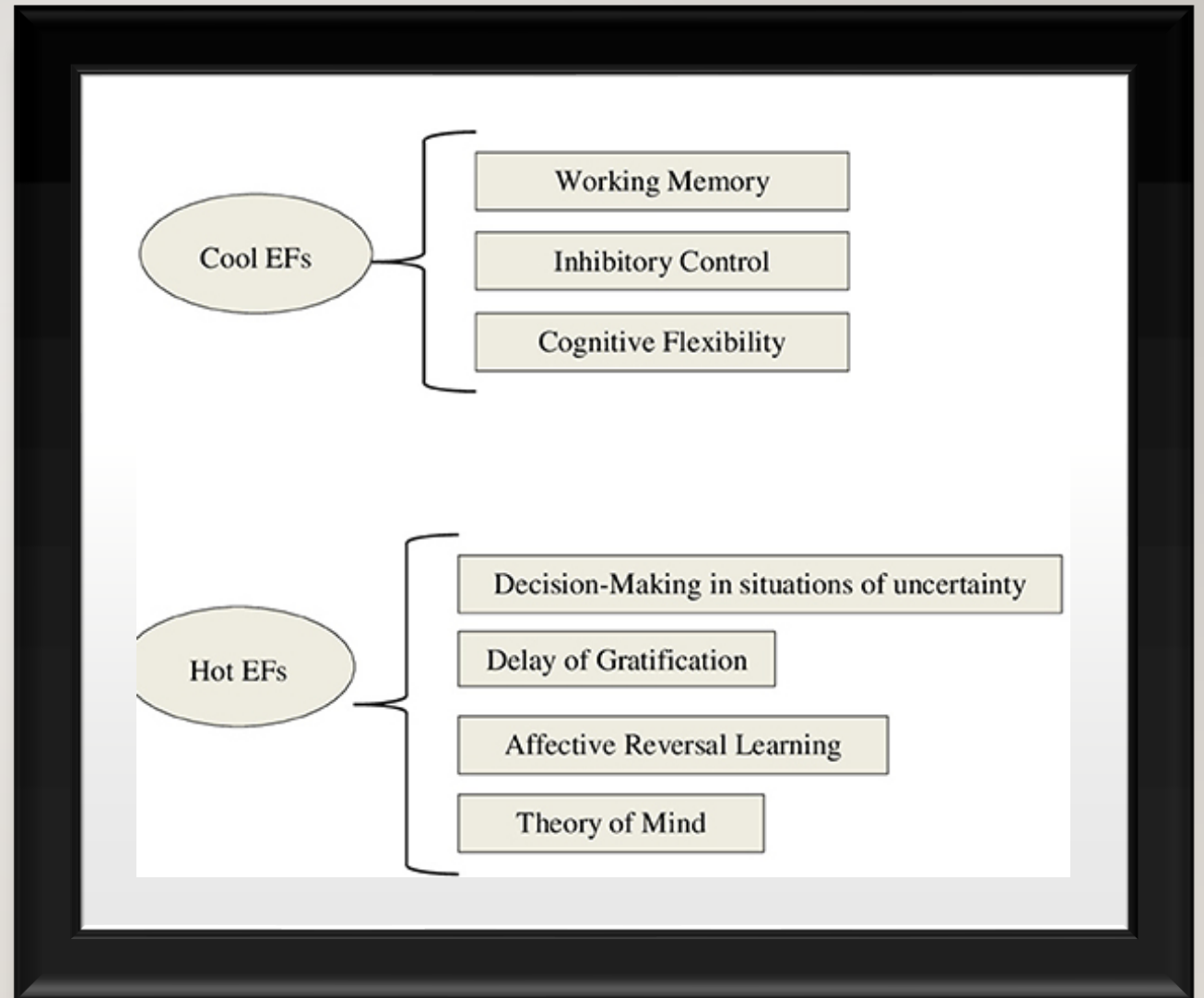
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- 80-86% of children with FASD have SL challenges.
- Deficits are heterogenous, but receptive language generally more severely affected.
- Expressive language skills often used to mask poor comprehension (children with FASD are often very pro-social and over-familiar).
- Poor inference skills, very literal understanding of world.
- Winnipeg et al (2014) – CELF-4 with 124 children with FASD aged 5-18.
  - 80% had significant SL problems.
  - Two thirds = 'severe' rating.
  - Difficulties appear to become more severe and more specific with age.
  - Only one third had ever received SLT intervention despite most having a high level of need.

# EXECUTIVE FUNCTION

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- The managing director of the brain – independent of IQ
- Hot vs. cold functions
- Dysfunction only explicit from school age onwards (esp. from year two)
- At risk of being interpreted as ‘trauma’ (more on this later)



# ADAPTIVE FUNCTIONING

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- Poor executive functioning > poor adaptive skills
- Increasingly explicit from high school onwards

## FASD AND ADAPTIVE FUNCTIONING

Adaptive functioning involves an individual's practical, social and mental capacities to deal with everyday challenges and tasks (hygiene, finances, social interactions). Without appropriate accommodations, consequences can range from difficulty maintaining employment to struggles with caring for one's self.

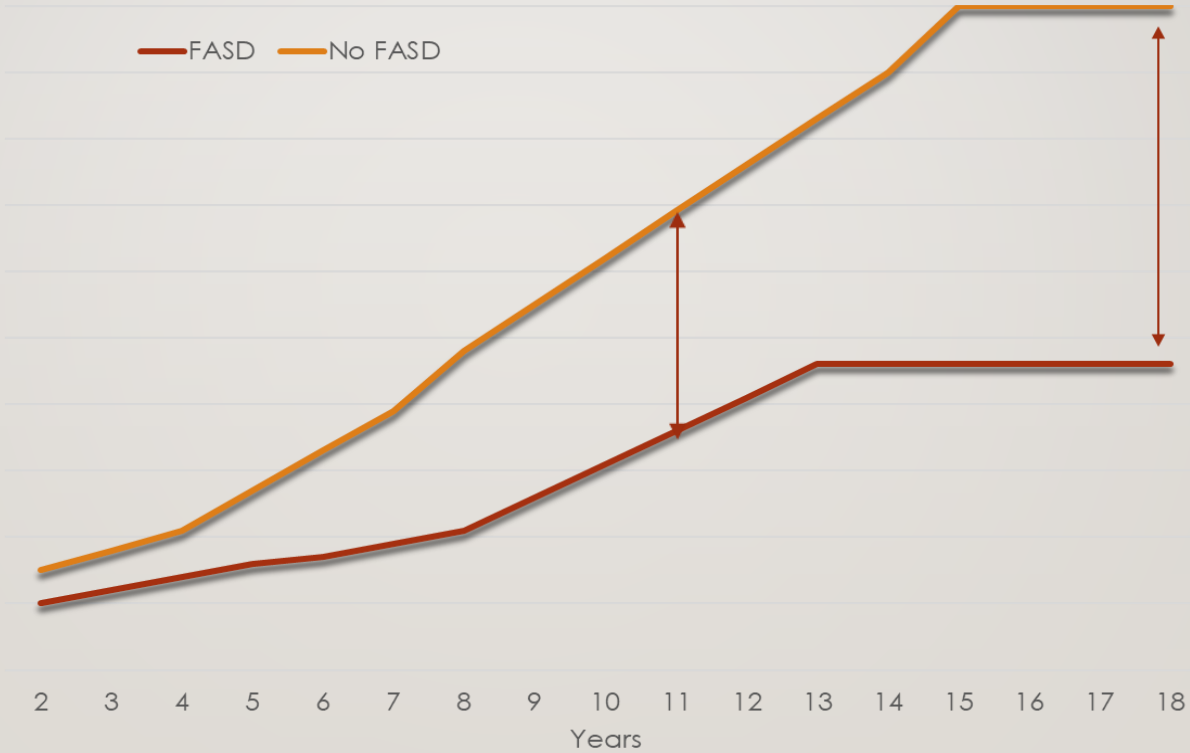
Source: FASD: A guide for mental health professionals by Jerrod Brown (Counselling Today: July 10, 2017)





# DEVELOPMENTAL DIVERGENCE BY AGE

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# THE SPIKY PROFILE OF FASD

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- Mismatch between:
  - IQ and functioning
  - Superficial presentation vs. functioning



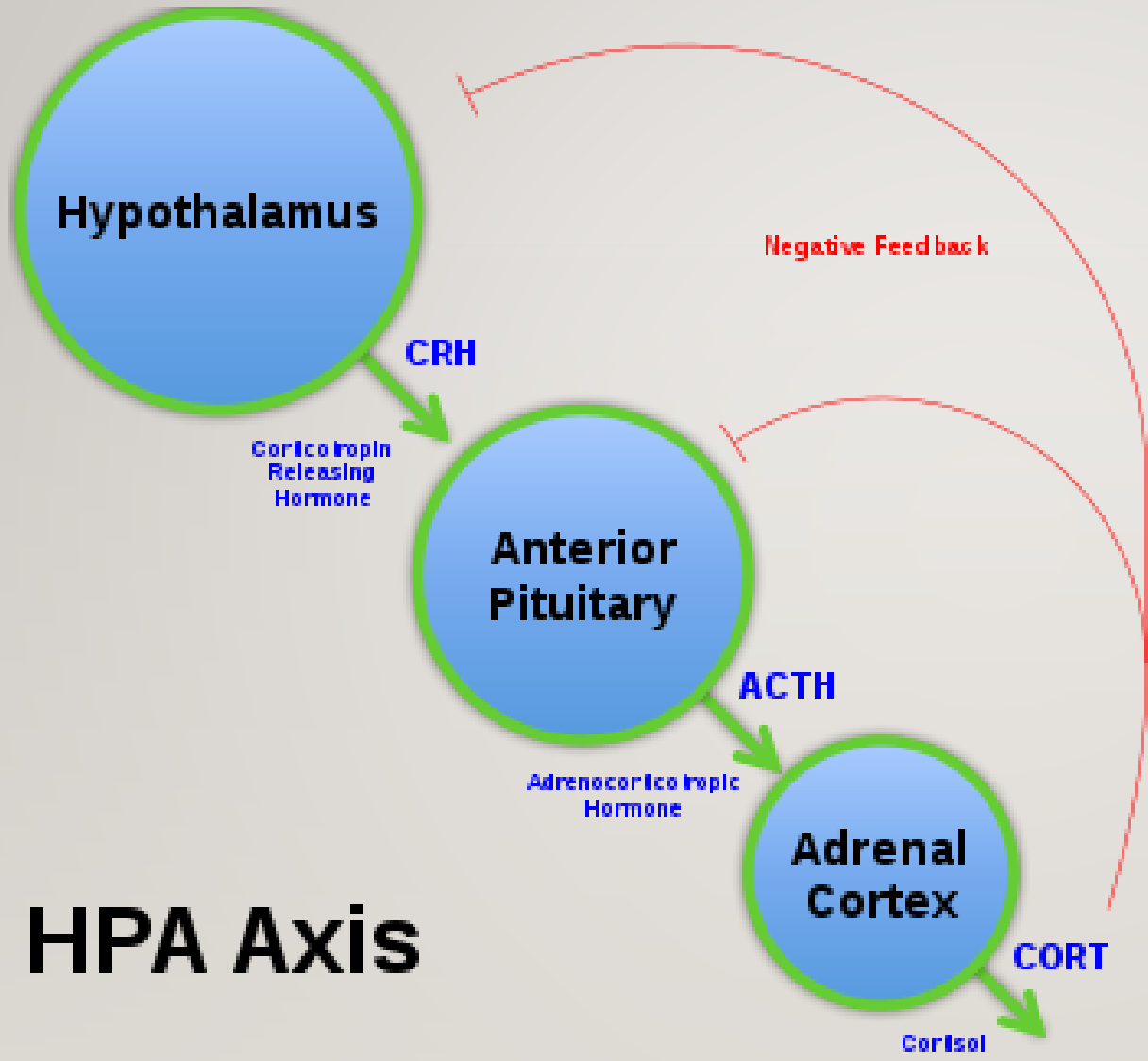
# COMMON COMORBIDITIES I

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Popova et al (2016) – 50-91% pooled prevalence in FASD:

- Conduct disorder/challenging behaviours - 91%!
- Sensory integration/processing disorders
- Expressive and receptive language disorders
- Disorders relating to hearing and eyesight.

# COMMON COMORBIDITIES 2



## HPA Axis

- Damage to HPA Axis
- Poor affect regulation > sensory and behavioural challenges (that look like attachment disorder)
- Life-long increase in risk of regulatory disorders including depression and anxiety
- More likely to diagnosed with BPD, EUPD, etc.

# COMMON COMORBIDITIES 3

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## **ADHD ~75%**

- Medical management differences – Ritfeld et al (2021)
- Girls often inattentive
- ADHD 'plus' presentation

## **Autistic Spectrum Disorder (ASD) ~50%**

- Pro-social variant more common
- Sensory processing problems significant
- ASD 'plus' presentation

## **General Learning Needs**

- Below ARE
  - Poor literacy and numeracy (often misdiagnosed as dyslexia, dyscalculia etc)
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# UK PREVALENCE STUDY

PROF PENNY COOK, UNIVERSITY OF SALFORD, 2020

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- First study in the UK to directly assess for FASD in a sample of children in Greater Manchester.
- Based on finding 4 cases in a baseline of 220 children, this research shows that FASD is likely to affect 1.8% (1.0%-3.4%) of children in the **general** population.
- If this was extrapolated to the whole of Greater Manchester alone, it would suggest that 619-1,238 affected live births and a similar number of affected children would start school each year.
- Results may be an underestimate, as many children considered most at risk were not made available to be assessed.

# PREVALENCE STUDIES OF CHILDREN IN CARE / ADOPTED CHILDREN

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- Data collected from 547 foster and adopted children - 156 met criteria FASD (29%), of which 86.5% were undiagnosed (Charnoff, 2015).
- Meta analysis found 16% of children in care had FASD (Popova 2015).
- Peterborough 55/160 (34%) children in care group, and 34/45 adoption reports (75%) met criteria for FASD (Gregory 2015).
- I have seen ~400 adopted children in the last three years alone, and had to turn many away.

# MEETING THRESHOLD FOR FASD AS PRIMARY AETIOLOGICAL DIAGNOSIS: SIGN 156

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- Evidence of prenatal alcohol exposure (PAE).
- Absence of SFF is the norm.
- Normal/clinically insignificant chromosomal microarray
- MRI is not diagnostic
- SIGN 156 – ten cognitive domains: must have **significant** impairment (2SD below mean) in three or more:
  - Neuro-anatomy/neurophysiology (inc. HC and MRI abnormality)
  - Sensory-motor skills
  - Language - receptive and expressive.
  - Cognition (IQ and composites within IQ)
  - Executive functioning, including impulse control and hyperactivity
  - Memory
  - Attention
  - Adaptive behaviour, social skills, social communication
  - Academic achievement.
  - Affect regulation



# OTHER THINGS TO CONSIDER

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- Prematurity (paradoxically sometimes protective)
- Neglect and trauma (but does not preclude diagnosis)
- Medication (e.g. sodium valproate, antidepressants)
- Smoking
- Other substances (heroin, cocaine, cannabis, etc)

**TABLE 2** Summary of Effects of Prenatal Drug Exposure

	Nicotine	Alcohol	Marijuana	Opiates	Cocaine	Methamphetamine
Short-term effects/birth outcome						
Fetal growth	Effect	Strong effect	No effect	Effect	Effect	Effect
Anomalies	No consensus on effect	Strong effect	No effect	No effect	No effect	No effect
Withdrawal	No effect	No effect	No effect	Strong effect	No effect	*
Neurobehavior	Effect	Effect	Effect	Effect	Effect	Effect
Long-term effects						
Growth	No consensus on effect	Strong effect	No effect	No effect	No consensus on effect	*
Behavior	Effect	Strong effect	Effect	Effect	Effect	*
Cognition	Effect	Strong effect	Effect	No consensus on effect	Effect	*
Language	Effect	Effect	No effect	*	Effect	*
Achievement	Effect	Strong effect	Effect	*	No consensus on effect	*

\* Limited or no data available.

BEHNKE ET AL 2013  
(PEDIATRICS)

# DIAGNOSTIC PROCESS IN AN IDEAL WORLD

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- Specialist FASD pathway or general neurodevelopmental pathway (currently neither exists or is commissioned in most regions).
- MDT – including medical, psychology, SLT and OT (see SIGN 156) > detailed diagnostic report including all aspects of functioning to support EHCP application.
- FASD assessment should also include assessment for ASD and ADHD.
- Assess to post-diagnostic support – workshops, therapies, etc.

# 'BUT WE DON'T HAVE AN MDT!'

## PRAGMATIC ADVICE FOR COMMUNITY PAEDIATRIC TEAMS

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- If you can diagnose, don't delay due to imperfect/absent team or pathway.
- In presence of known PAE and no other primary aetiological factors, you only need to tick three boxes.
- A full neuropsychological assessment could be a post-diagnostic action point if needs be. Could educational psychology/school assessment/reporting help?

## PRAGMATIC APPROACH 2 – HOW EDUCATION COULD HELP

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- Neuro-anatomy/neurophysiology (inc. HC and MRI abnormality) – easy to do, but usually normal.
- Sensory-motor skills – Sensory Profile questionnaires, fine/gross motor assessment in clinic.
- Language - receptive and expressive – School SLT?
- Cognition (IQ and composites within IQ) – information from school, have they been seen by an EP?
- Executive functioning, including impulse control and hyperactivity – teacher and parent BRIEF-2 as minimum, SNAP-IV.
- Memory – school reporting.
- Attention – SNAP-IV, school reporting.
- Adaptive behaviour, social skills, social communication – ASD assessment, teacher and parent ABAS.
- Academic achievement – school reporting.
- Affect regulation – parent and teacher report, SNAP-IV teacher and school.

# POST DIAGNOSTIC SUPPORT

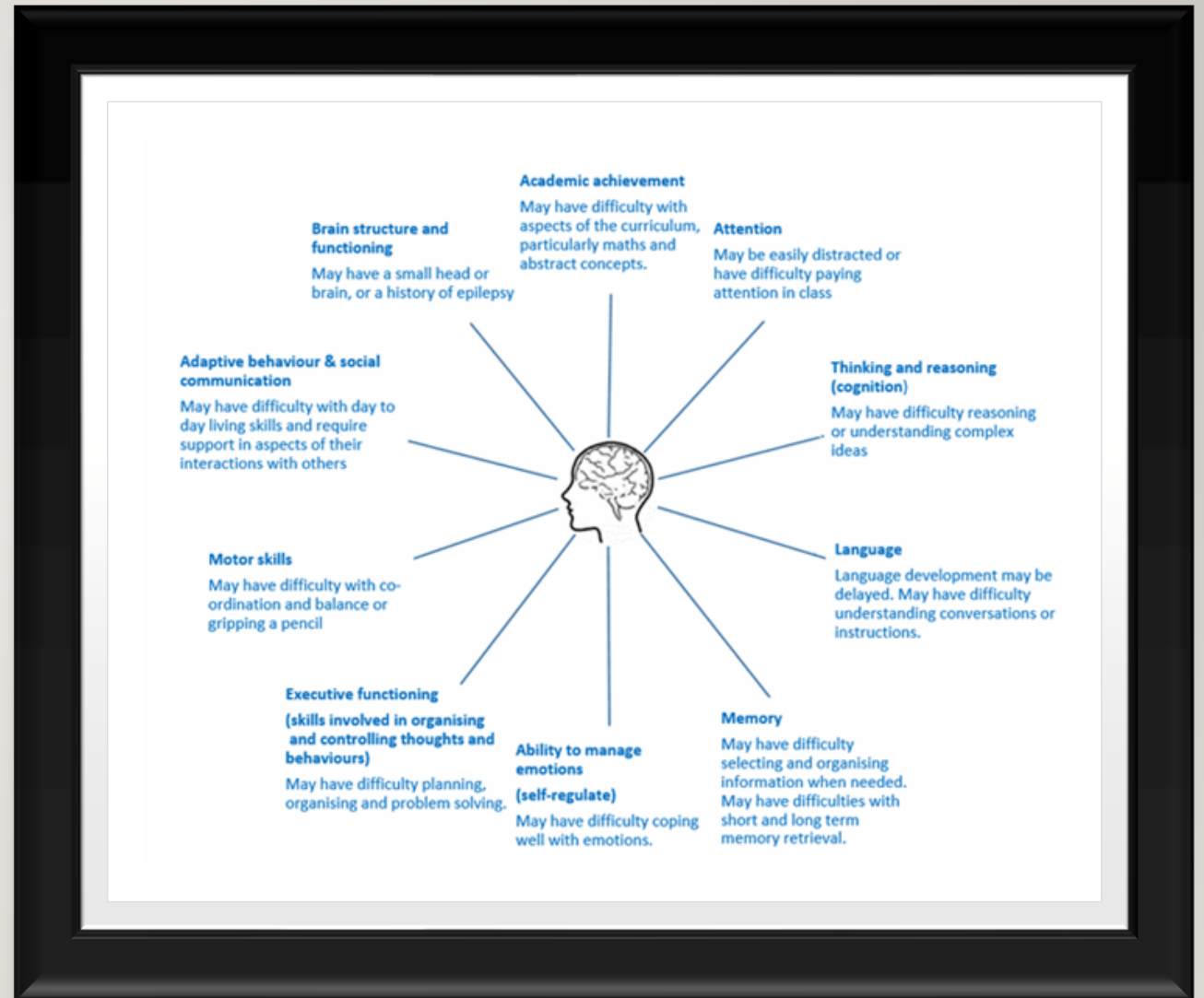
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- Developmental divergence > need and vulnerability increases with age.
- Multi-agency working:
  - Education > EHCP
  - Social care, e.g. post adoption support, therapies (sensory integration, sensory attachment)
  - Community therapies – SLT, OT, psychology
  - Sometimes YOT, probation
- Therapies to optimise functioning and regulation. Expectations to be realistic. Many FASD-related behavioural difficulties are quite resistant to change.
- Working with the family system. FASD creates systemic problems – change at environmental level rather than expectations of child changing/'growing out of it.'

# EDUCATING CHILDREN WITH FASD

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- Best fit provision dependent upon:
  - Primary presenting problem (ASD? LD? Externalising behaviour?)
  - Availability of provision locally
- Needs relating to FASD span all four key areas of need in EHCP



# FASD IS AN ACQUIRED BRAIN INJURY > EMPHASIS ON ENVIRONMENTAL ADAPTATION

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- Support for co-occurring conditions – ADHD *plus*, ASD *plus*.
- Mismatch between IQ and functioning.
- Variable performance day-to-day.
- Increased levels of tiredness requiring more frequent breaks.
- Increasing divergence from normative population with age.
- Social and life skills and supervision re social vulnerability.
- Appropriate behaviour management strategies.



# KEY POINTS FOR TEACHING STAFF

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- Scaffold and support without expectation of future mastery (important point for EHCP outcomes).
- Poor grasp of cause and effect – but may verbalise otherwise.
- Difficulty applying learning from one context to another.
- Repetition and over-learning.
- Supervision
- Manage own expectations: FASD is a complex life-long neurodevelopmental disorder, not just a behaviour problem.
- Trauma and FASD often co-occur – don't merge the two together.
- Don't assume intentionality - think 'can't' not 'won't'.

# DYSREGULATION AND EXTERNALISING BEHAVIOUR

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- Damage to PFC and HPA axis > toddler-like responses to anxiety, frustration and anger.
- Frequently in a state of hyper-arousal > small triggers > dysregulation.
- Preventative measures include scaffolding, containment and support.
- Have a plan. Visual emotions dictionary with options can be useful.
- Have a safe space / de-escalation environment.
- A key person as an attachment figure in school.
- A child with FASD is likely to need ++ co-regulation throughout the day.
- If you don't see externalising behaviour, consider the possibility of masking in school.

# CAPITALISE ON STRENGTHS

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- Use special interests to spark interest and engagement.
- Encourage creativity.
- Regulating activities/placements to facilitate success.
- Allow every day to be a new day.



# SUMMARY

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- FASD is more common than you think (up to 75% in some populations of children).
- Even a severe trauma history is not a reason to avoid assessment and diagnosis where there is known PAE.
- FASD is a brain injury and needs supporting as such.
- The way a child with FASD is supported can be the making (or breaking) of them.
- Appropriate support completely changes long term outcomes for the better.