SEPLA Conference 2023

Supporting Young people with Fetal Alcohol Spectrum Disorders (FASD)

Robyn Smith

Dr Vanessa Spiller

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Acknowledgement

NOFASD Australia acknowledges and pays respect to present and future Traditional Custodians and Elders of this nation and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

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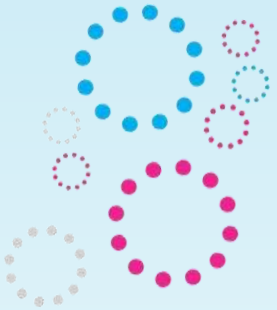
How many people have completed 2 or more hours of formal FASD training?



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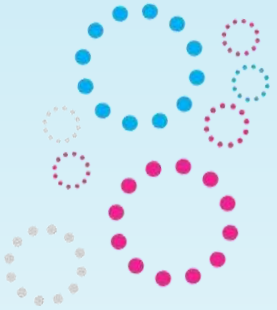
How many people have completed 2 or more hours of formal Autism training?



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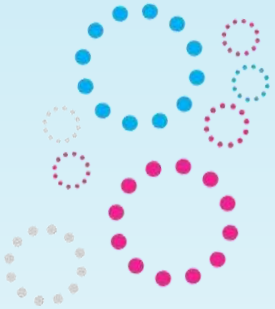
FASD is up to 2.5 X more common than autism

(and more prevalent than Autism, Cerebral Palsy, Spina Bifida and Down Syndrome Combined)



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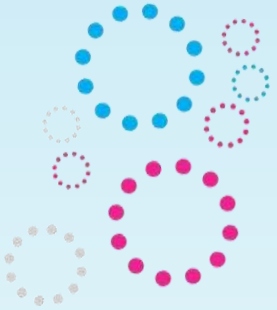
FASD is the leading preventable cause of developmental disability in the world



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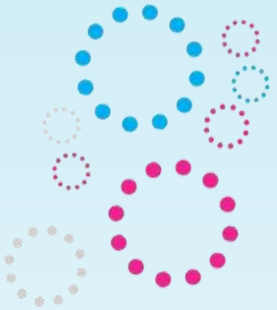
How many people have a child diagnosed with FASD in your class/school?



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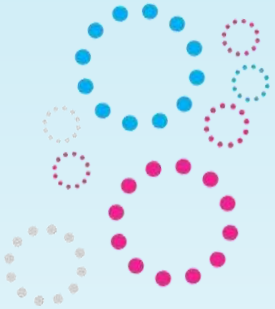
Most people with FASD will not be not be diagnosed or will be diagnosed with another condition



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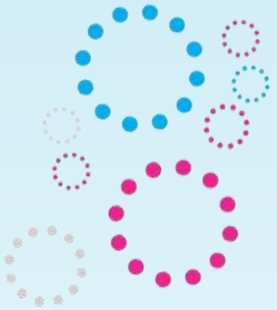
Why does this matter?



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OUTCOMES

Individuals with FASD have elevated rates of:

- disrupted education (60%)
- unemployment
- involvement in the legal system (60%)
- addictions/substance use (35 - 50%)
- mental health issues (50-90%) particularly ADHD
- inappropriate sexual behaviours (49%)
- physical health issues (38%)
- involvement with child protection (75%)
- shortened life expectancy

Barr et al, 2006; Popova et al, 2021; Streissguth et al, 2004; Streissguth & O'Malley, 2000

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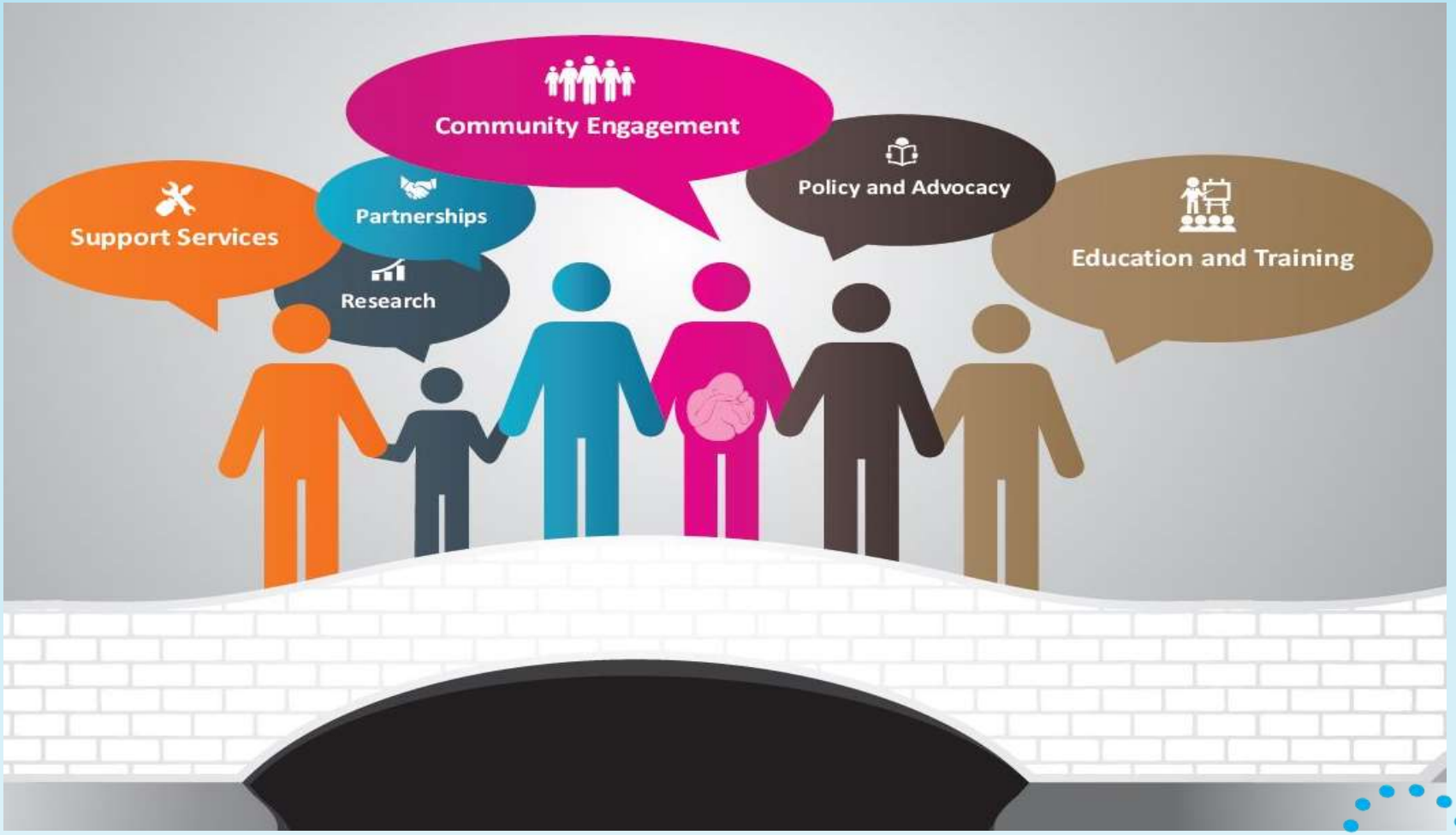

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1800 860 613
www.nofasd.org.au

What is FASD?

Fetal Alcohol Spectrum Disorder

FASD is the term used to describe the physical and/or neurodevelopmental disorder that can result from prenatal alcohol exposure.

What Causes FASD?

FASD is caused by alcohol exposure during pregnancy

- Alcohol is a neurotoxin (poison) and a teratogen (an agent that is known to cause birth defects and permanent brain injury in the fetus)
- Alcohol is a substance that can cause harm to the developing baby at any time during the pregnancy

Estimated 2-5% of population

Specialist Population prevalence study 12%

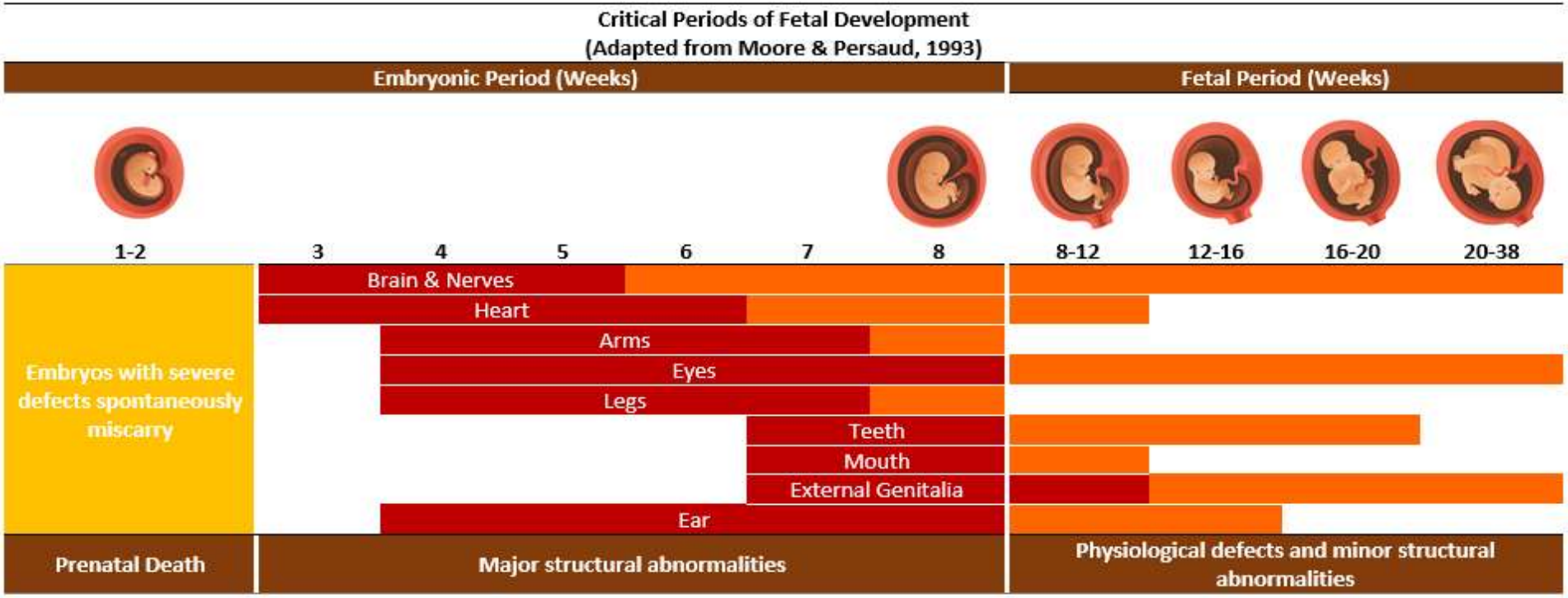
Specialist Population prevalence study 36%

Alcohol consumption - Australia

- 59% of Australian women drank at some point during their pregnancy. (Muggli et al., 2016)

- Estimated that 1 in 13 alcohol exposed pregnancies result in FASD. (Lange et al., 2017)

Alcohol and the developing fetus



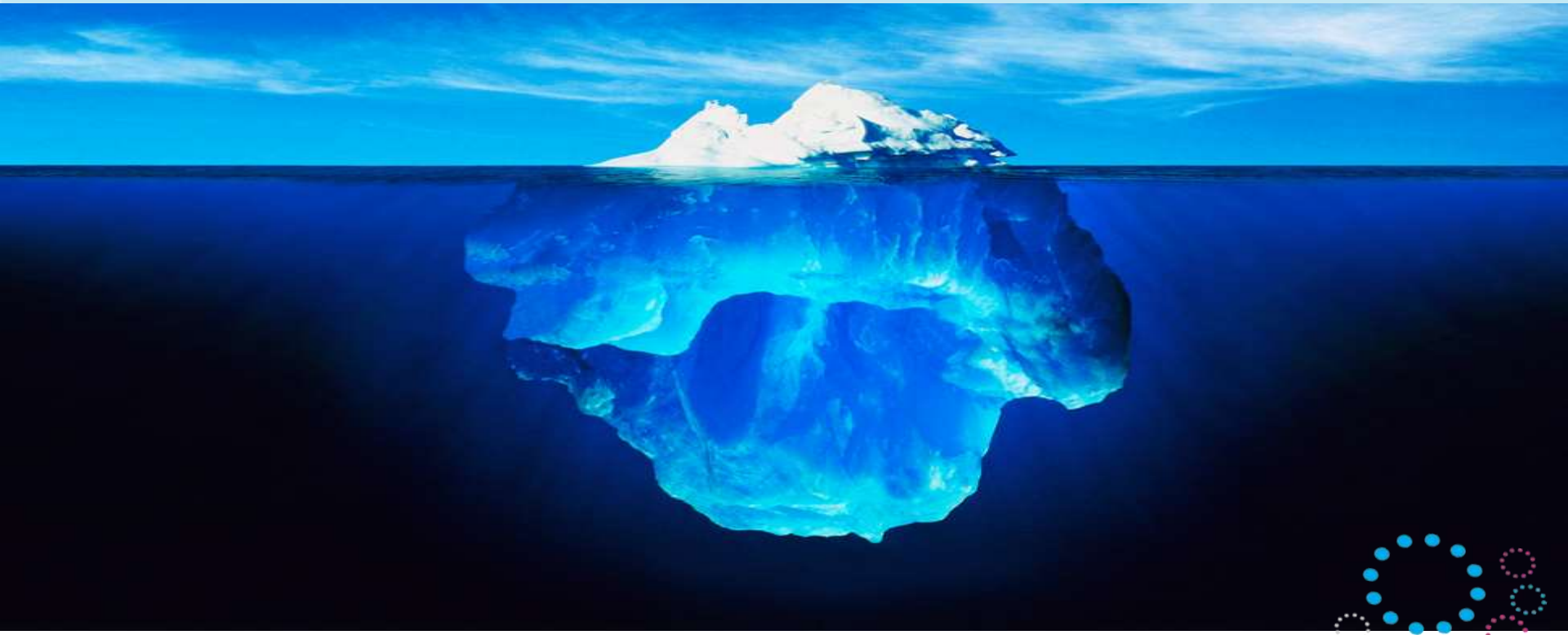
Periods when teratogens may cause abnormalities

Highly Sensitive

Sensitive

FASD Facial features

83% of individuals with FASD do not display sentinel facial features. (Kuehn et al., 2012)



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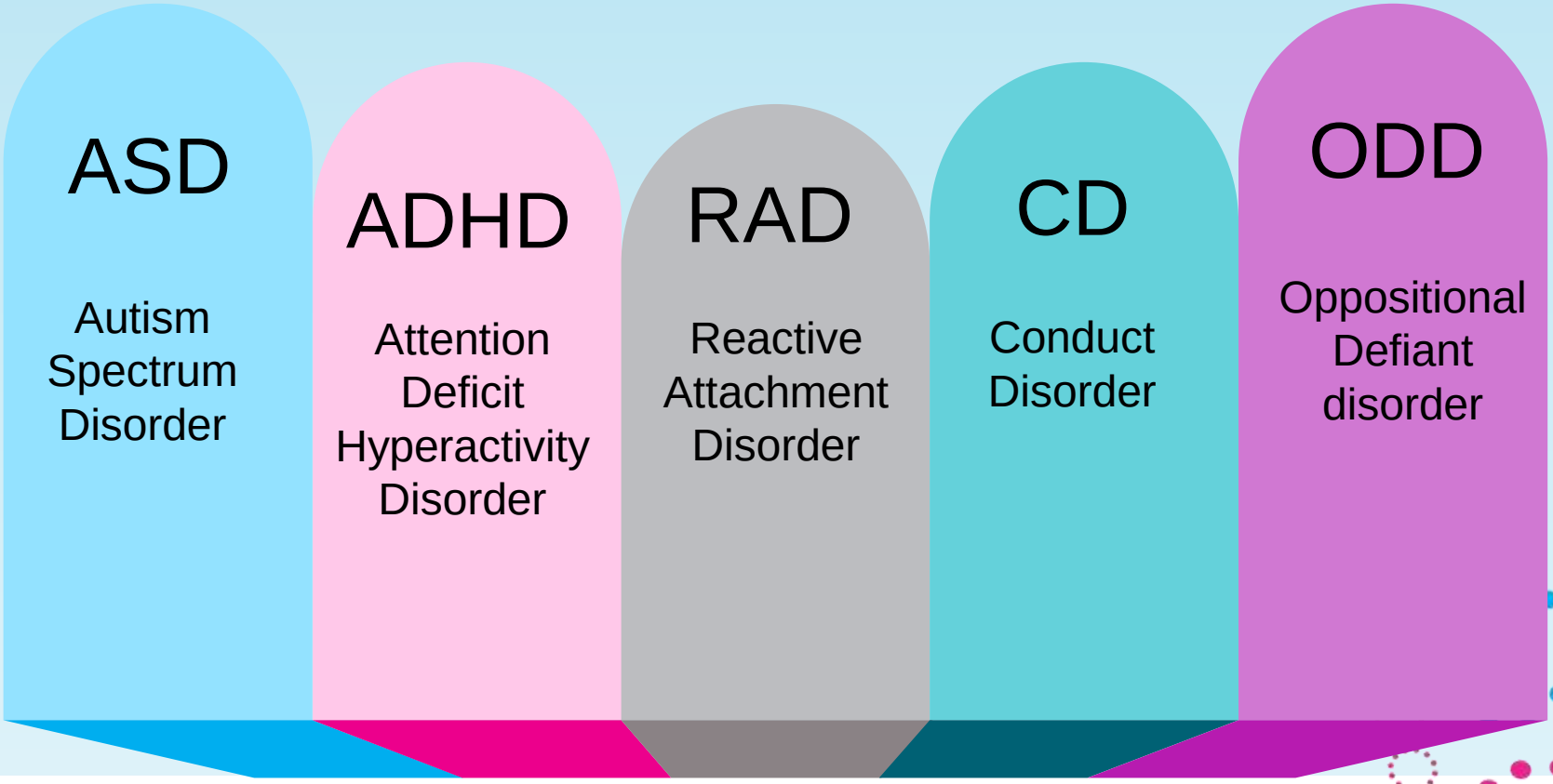
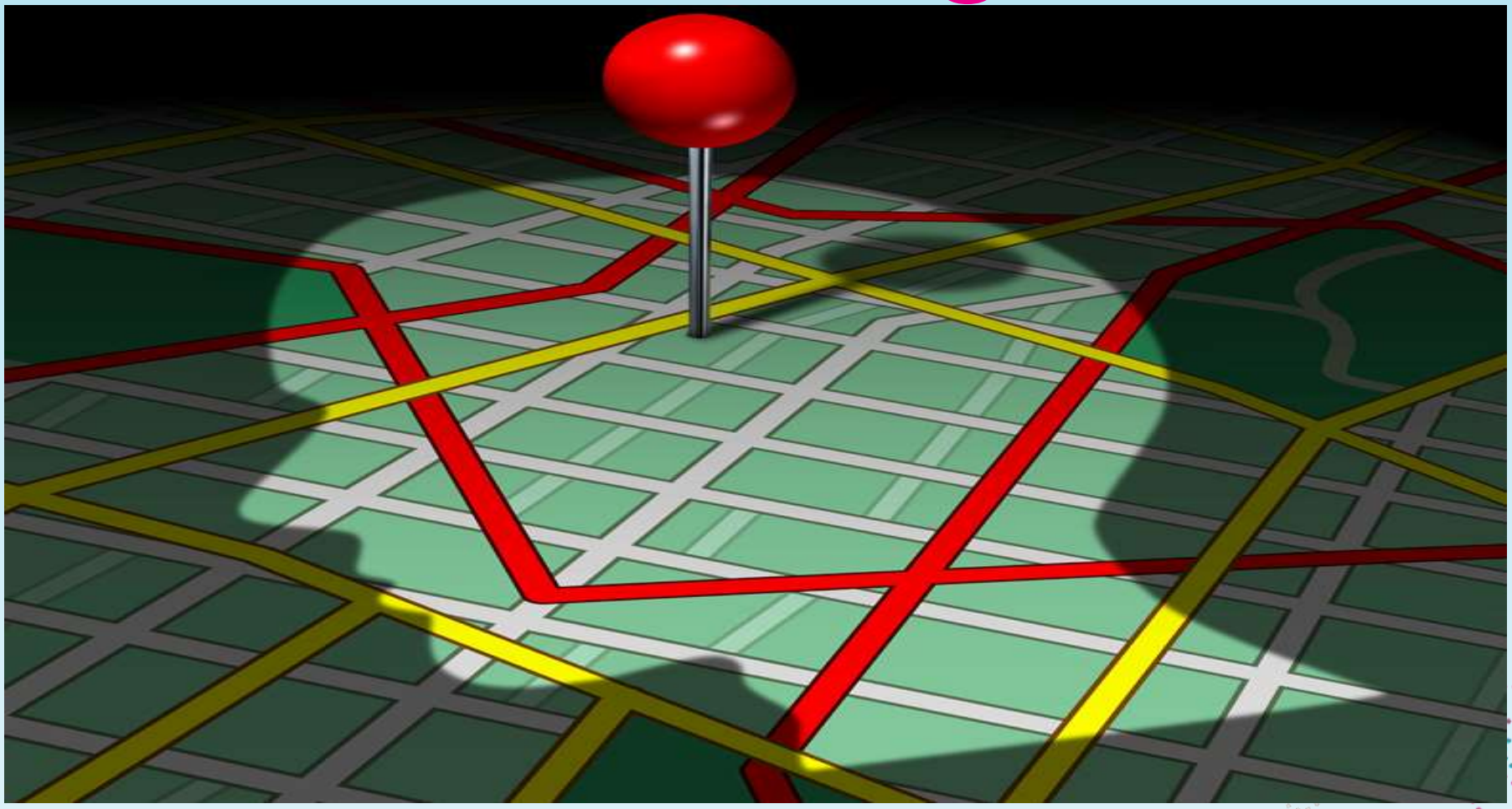
Mis-diagnoses & co-diagnoses

People with FASD may also be diagnosed with the following disorders: (National Institute of Alcohol Abuse and Alcoholism, 2015)



Benefits of diagnosis



Benefits of diagnosis

- → Early diagnosis – reduce secondary conditions
- → Aware of potential needs and accommodations
- → Work with individuals to reduce environmental triggers
- → Access FASD specific clinicians and services
- → Reduce incorrect prescription of medication
- → Awareness = advocacy “can’t not won’t”

Permanent brain damage

- The changes in brain development are permanent.
- The brain does not repair itself over time.

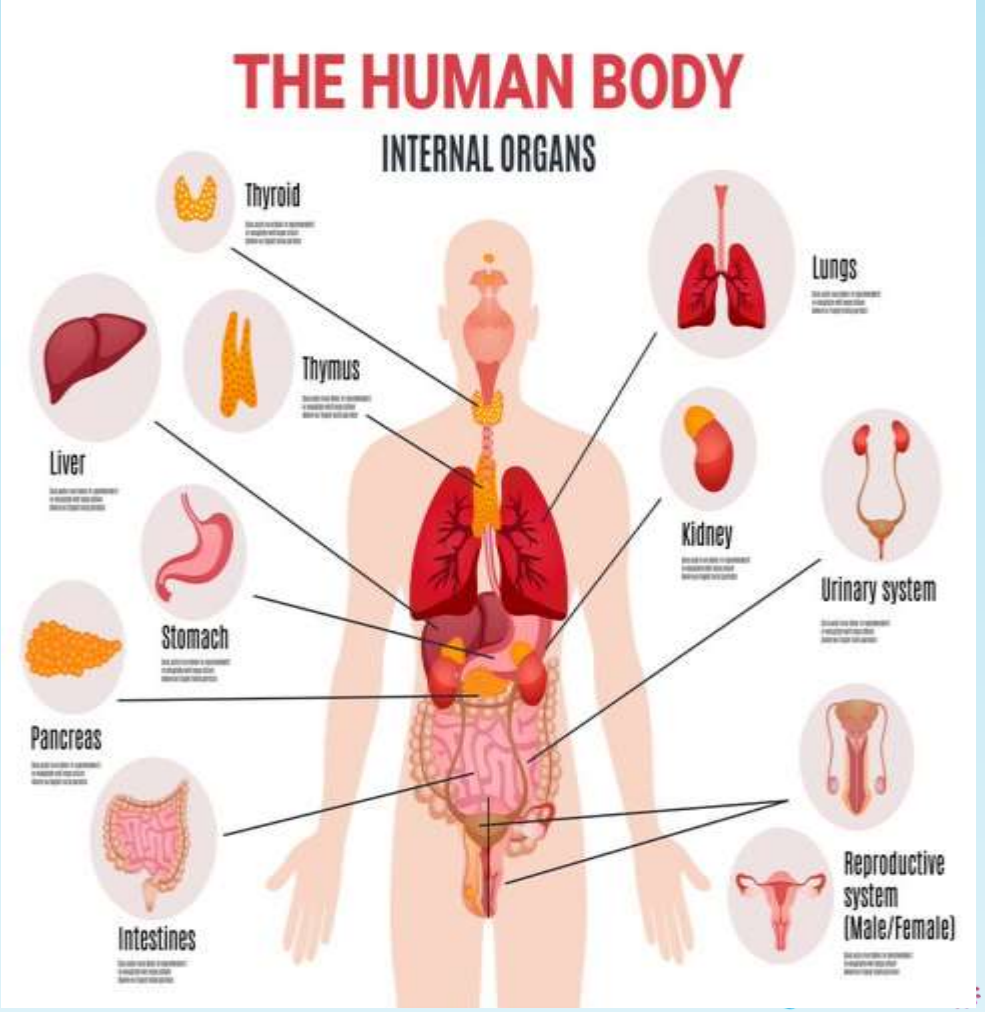
However,……..

Permanent brain damage

- People with FASD are able to learn! (differently)
- Appropriate supports have a huge impact on learning and life outcomes.

Impact on Individuals - Physical

- → Poor growth
- → Physical abnormalities: body or major organs
- → Problems with vision and hearing



FASD and IQ

Research found an IQ range of 45 – 120:

34% Had an IQ below 70

76 Average IQ

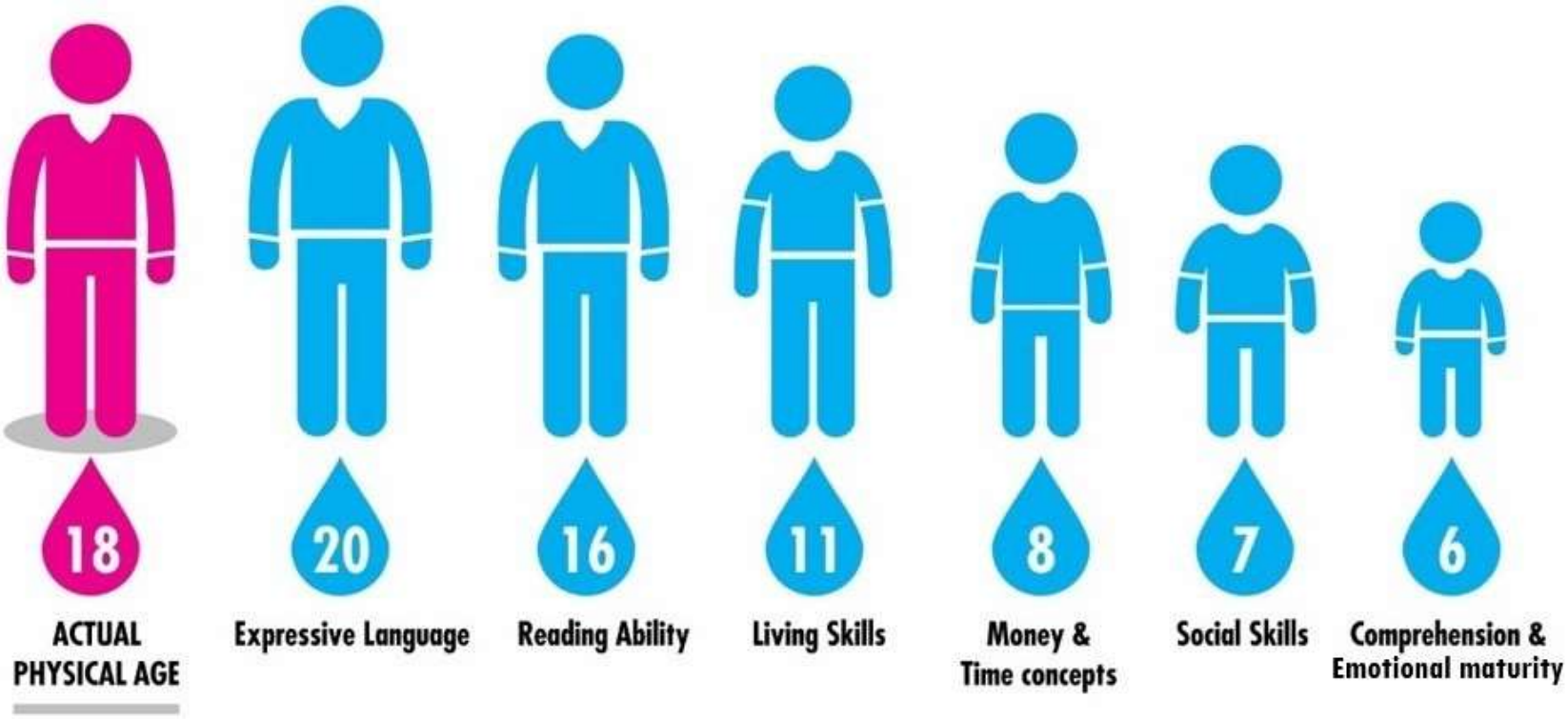
IQ below 70 was not significantly associated with secondary conditions

(Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004)

Developmental Delay

Individuals with FASD (children and adults) often function socially, emotionally, and mentally at a much younger developmental age than their chronological age.

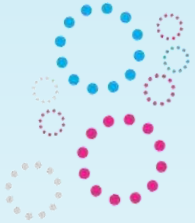
Age Dysmaturity



Impact on Individuals - Behavioural Symptoms

- Cannot stay focused
- Acts impulsively without thinking
- Difficulties with age appropriate tasks such as toileting
- Can't remember things even with lots of repitition
- Slow to learn but seems bright enough
- Wants friends but can't keep them
- Difficulties problem solving
- Anxious
- Constantly irritable and frustrated

- Lots of big emotions and outbursts
- Difficulties using or understanding language
- Clumsy and uncoordinated
- Academic difficulties
- Repeats the same mistakes over and over again
- Sensory seeking or avoiding
- Sleep problems
- Doesn't respond to usual behavioural management approaches



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MY JOURNEY

Clinical Psychologist
Child Protection and
Family Counselling

Foster Carer

FASD Educator and
Trainer

Our stories,
shared experiences

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- self disclosure
- documented use
- reliable report

DIAGNOSIS

Confirmed Prenatal Alcohol Exposure

Severe impairment in at least 3/10 brain related domains

With or without 3 facial features

- Adaptive Functioning
- Executive Functioning
- Affect & Emotional Regulation
- Attention
- Memory
- Language
- Cognition
- Academic Achievement
- Motor Skills
- Brain Structure

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CHALLENGES

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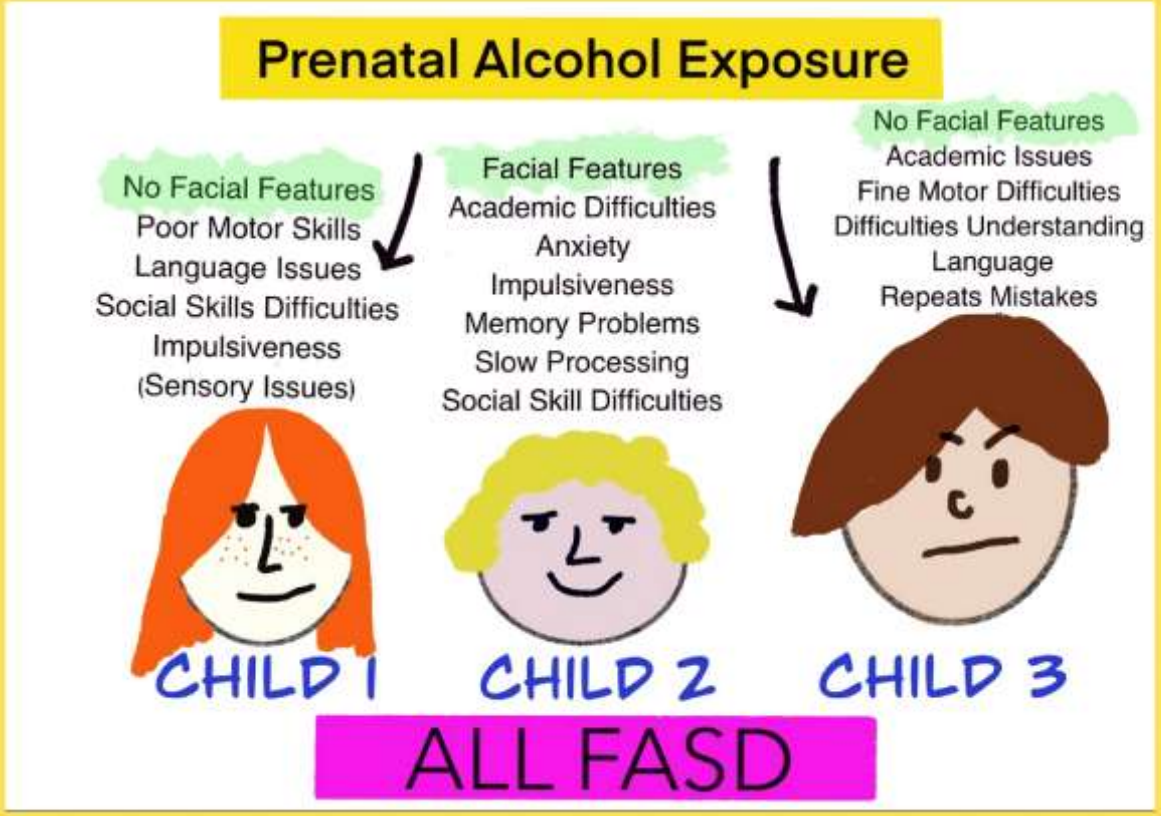
CHALLENGES



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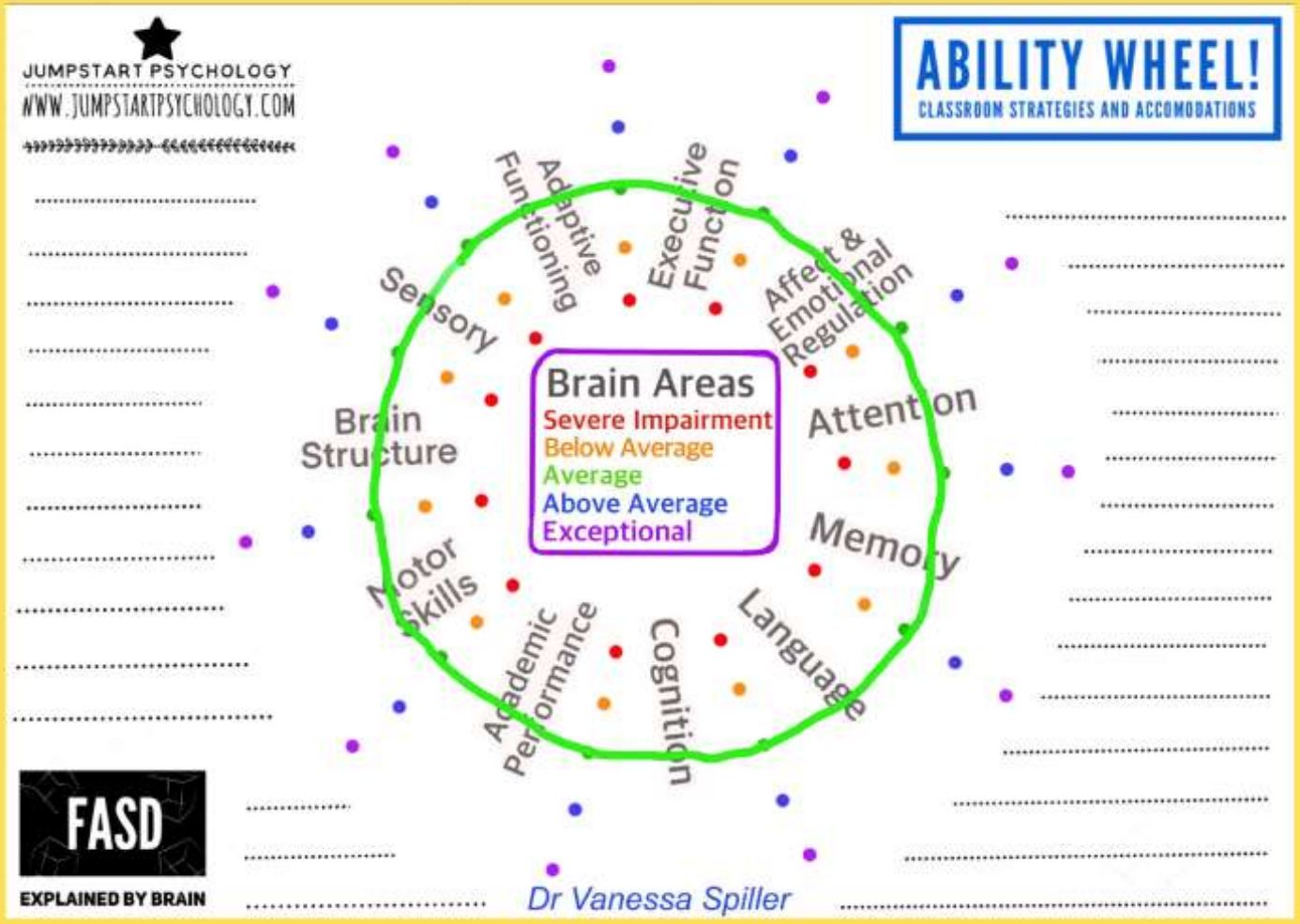
FASD & INTERVENTION

There is no single intervention or technique possible due to the diversity of presentation and differences in underlying brain issues

- there is no cure
- it is a permanent, life-long, brain and body injury
- individuals with FASD will need appropriate supports across the life-span
- improvement is possible but progress is slow and within limits depending on the extent of original brain injury
- interventions should target the whole family and support-system not just the child (parenting stress is exceptionally high).
- intervention must fit the brain of the individual (apply a framework)



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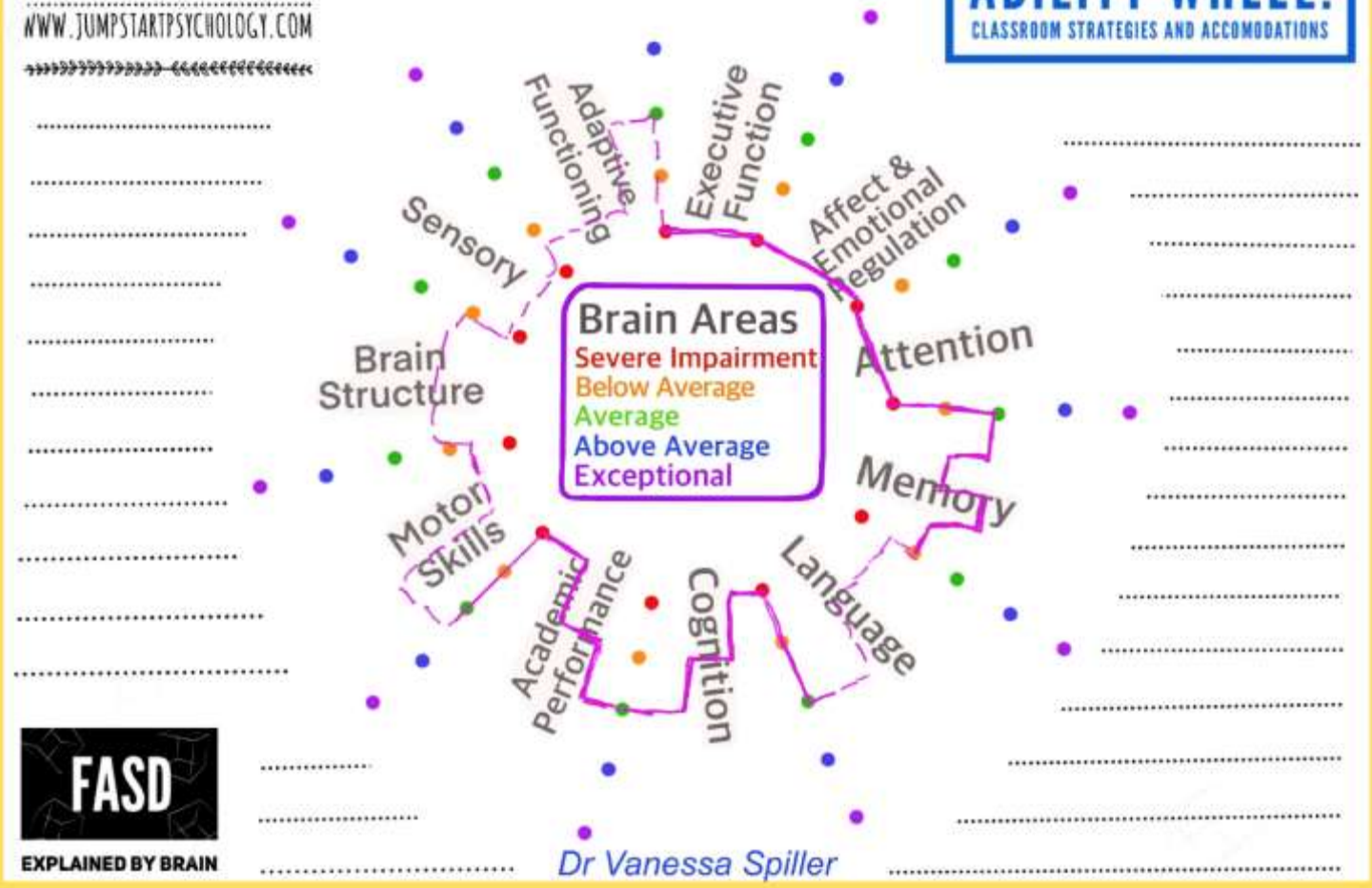
ABILITY WHEEL!

CLASSROOM STRATEGIES AND ACCOMODATIONS



FASD

EXPLAINED BY BRAIN

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SUPPORTING FASD IN THE CLASSROOM

Be proactive rather than reactive

Don't rely on parenting and behaviour management strategies that they don't have brain functioning to benefit from e.g., sticker charts, consequences, natural consequences, suspensions, yelling

Target lower level skills first (e.g., executive functioning, emotional regulation) over high level skills (e.g., academic learning).

Modify the environment, expectations and approaches to maximise the chances of success

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STEP AWAY FROM THAT STICKER CHART!

Why common behaviour management strategies often don't work for people with FASD (and other neurodiverse people)!

CONDITION	BRAIN AND BODY DOMAINS											
	ADAPTIVE FUNCTION (everyday skills of life e.g., social skills, self-care, concepts of time and money etc)	EXECUTIVE FUNCTION* (e.g., impulsivity, organisation, linking cause and effect, working memory)	ATTENTION*	AFFECT (e.g., depression, anxiety, emotional regulation)	ACADEMIC (numeracy and literacy)	LANGUAGE (use and understanding)	COGNITION (e.g., IQ, processing speed, problem solving)	MEMORY	MOTOR SKILLS (fine and gross motor, visuo-motor)	BRAIN STRUCTURE	SENSORY	PHYSICAL HEALTH ISSUES (e.g., malformations and deformities, heart issues etc)
FETAL ALCOHOL SPECTRUM DISORDER	Impairment in a minimum of three brain related domains is required for diagnosis of FASD in Australia but most children with FASD have more (average = 4)											
MY CHILD WITH FASD	✗	✗	✗	✗			✗					
BRAIN DOMAINS REQUIRED TO BENEFIT FROM THE TECHNIQUE												
STICKER CHARTS	✔	✔	✔	✔	✔	✔	✔	✔				
TIME OUT	✔	✔		✔		✔	✔				✔	
REMOVAL OF FAVORITE TOY		✔	✔	✔		✔	✔	✔	✔			
MISSING OUT ON DESIRABLE ACTIVITY		✔		✔			✔	✔				
PHYSICAL DISCIPLINE	✔	✔		✔		✔	✔	✔			✔	
NATURAL CONSEQUENCES		✔	✔	✔			✔	✔				
IGNORING	✔	✔	✔	✔			✔					
SUSPENSION/ EXPULSION	✔	✔	✔	✔	✔	✔	✔	✔				
YELLING	✔	✔		✔		✔	✔				✔	

ALTERNATIVE STRATEGIES THAT DON'T RELY SO HEAVILY ON EXECUTIVE FUNCTIONING AND OTHER ABILITY AREAS INCLUDE

Remember giving consequences for impairments and missing skills is the same as giving a child consequences for not listening when they are having a seizure!

Strategies that **DON'T** rely on skills in executive functioning (i.e., the ability to link cause and effect or the ability to manage your impulses), the ability to self-regulate your emotions or other brain areas are likely to be most successful!

These can include: Supervision, Time In, Praise, Distraction, Redirection, Humor, Role Modelling, and Role Play and remember Pick your battles wisely!

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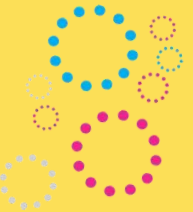

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PRIORITISE

Games and activities that practice stopping and starting, transitioning, mental flexibility e.g., Simon says, Red light, green light, Beat Saber, BJJ (Executive functioning)

Continuously teach emotional literacy (Emotional regulation)

Focus on social skills (Adaptive functioning)

Avoid any strategies that rely on brain development or abilities they don't have

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MODIFY THE ENVIRONMENT

Supervise, supervise, supervise

Adequate staffing

Low stimulation and distraction teaching environments

Have use concrete items to practice and teach skills

Equipment and items for sensory soothing

Maximise structure, predictability and consistency

Use prompts and visual aides

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MODIFY EXPECTATIONS

Symptoms not behaviours

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MODIFY EXPECTATIONS

Symptoms not behaviours

Developmental age not chronological age

Can't versus won't

Missing skills and abilities not willful defiance

Interdependence not independence

Change within limits

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MODIFY EXECUTION

Strategies that fit the brain

Repeat, repeat, repeat

Praise

Do-over's

Time-in and co-regulation

Role model

Role play

One-step instructions

Humor

Distraction and redirection

Leave scaffolding in place

Focus on strengths

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Brain-based strategies for support and understanding

My clients/young person's/student's ability to understand and complete required tasks.

Person's name: DOB:

Completed by: Date:

Task or activity: *Attending and participating in therapy*

BRAIN DOMAINS:	Adaptive Functioning	Executive Functioning	Attention	Affect	Academic	Language	Cognition	Memory	Motor Skills	Brain Structure	Sensory
DESCRIPTOR:	Everyday skills of life e.g., social skills, self-care, concepts of time, money etc	Impulsivity, organisation, linking cause and effect, working memory, mental flexibility self monitoring etc	Remaining focused, switching focus, focusing on multiple things	Emotional regulation – self-soothing, getting yourself going, depression, anxiety etc	Numeracy and literacy skills	Ability to understand language, ability to use language	Comprehension, problem solving, IQ, processing speed, etc	Visual, audio, memory for places, motor memory etc	Fine motor, gross motor, visuo-motor etc	Hearing and vision issues, seizures etc	Sensory seeking, sensory avoiding, interoception, proprioception
Brain domains required for this task or activity:	✓	✓	✓	✓		✓	✓	✓			✓
My client's brain-based functioning:											

Comments:

Brain based accommodations or scaffolding required for equity and success:

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RESOURCES

https://www.earlychildhoodaustralia.org.au/through-different-eyes/

Marula Strategy

https://learningwithfasd.org.au

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Dr Vanessa Spiller is a clinical psychologist and the parent to a young adult with FASD. She blends 20 years of clinical work with lived experiences to deliver practical framework and strategies to help young people and their families to achieve success.

The Explained by Brain approach utilises multiple well-researched frameworks to provide parents, carers and educators the tools they need to better understand and support young people with FASD.

I am the mother of two adult children with this condition. Our lives could have been much easier if Dr Spiller had written this book twenty years ago. With appropriate strategies and an understanding of the way the FASD brain works, my boys' lives could have been so different and much of the stress of parenting could have been alleviated. I encourage any parents who have tried everything – or don't know where to start, to read Dr Spillers book.

Elizabeth (Anne) Russell – Parent, FASD educator and advocate

Explained by Brain

- Real stories, real world strategies!
- Brain wiring explained
- Understand complex behavioural symptoms
- Parenting approaches and school-based strategies
- Build on strengths and talents

Strategies for success

Explained by Brain

Dr Vanessa Spiller

Explained by Brain

The FASD Workbook for Parents, Carers & Educators

(who have tried everything or don't know where to start)

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