SURREY PLACE

Fetal Alcohol Spectrum Disorder

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FASD Diagnostic Team

Overview

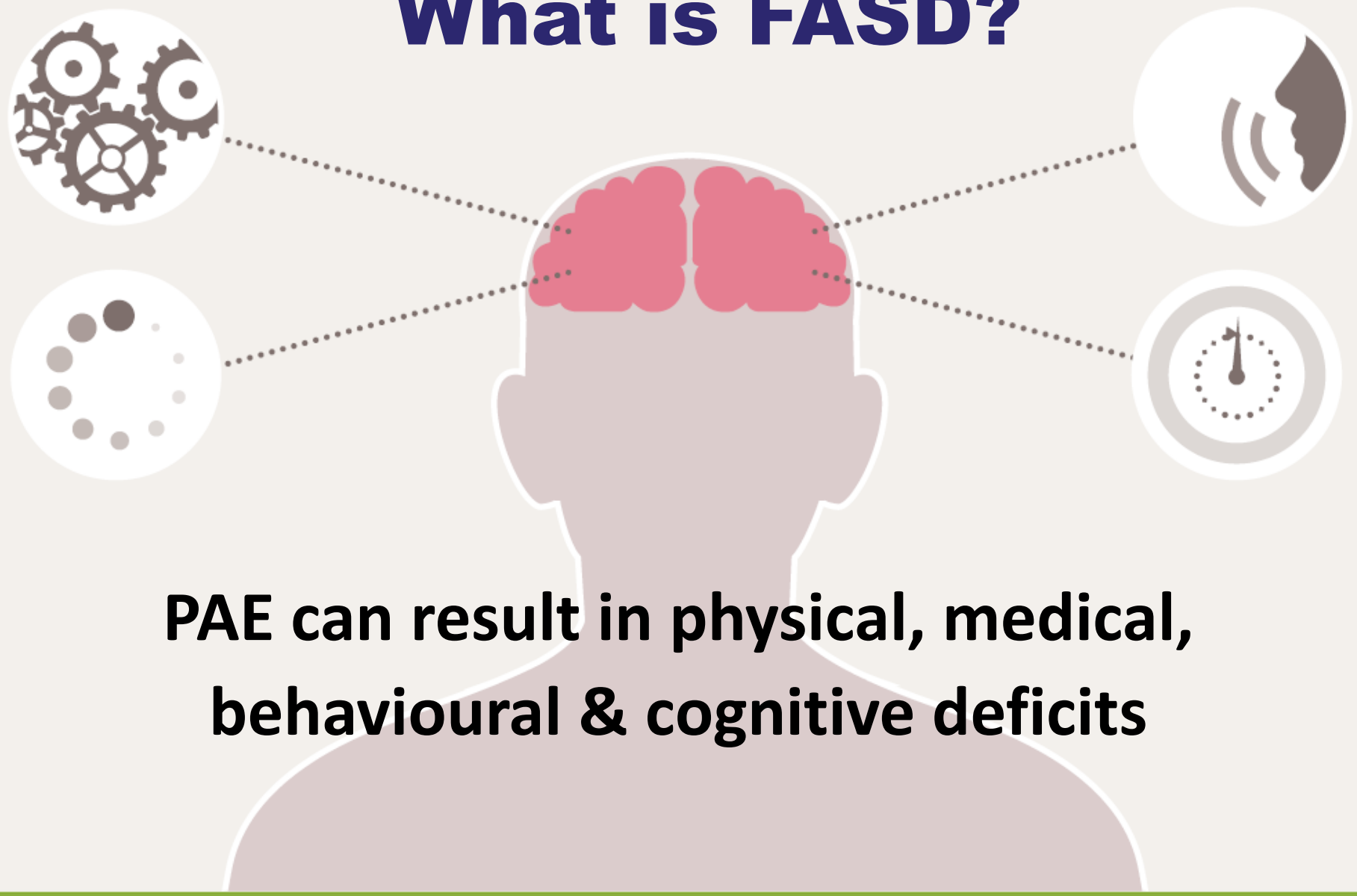
- What is FASD?
- How do we diagnose it?
- What does it look like?
- What are common challenges?

What is FASD?

Damage due to alcohol exposure in utero

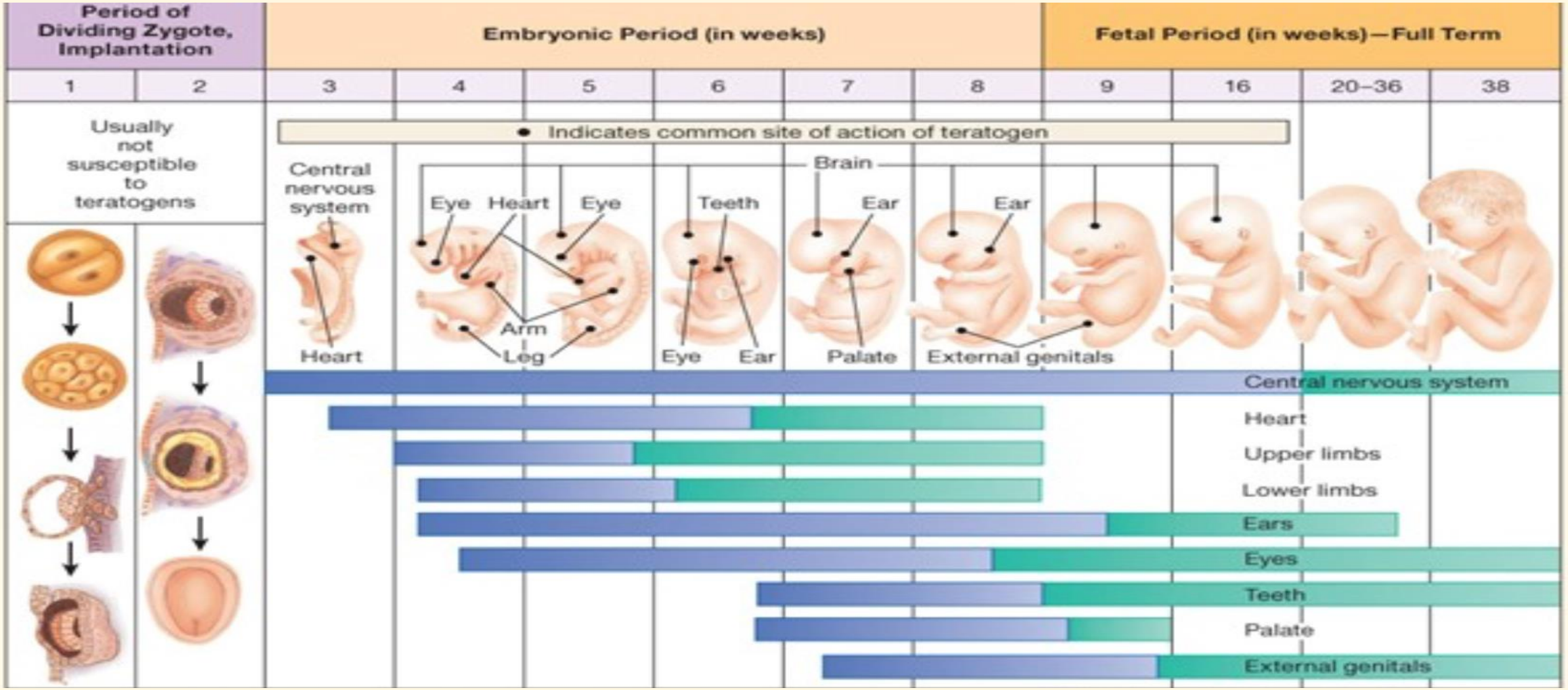
Prenatal Alcohol Exposure (PAE)

What is FASD?



PAE can result in physical, medical, behavioural & cognitive deficits

Sensitive Periods for Development



What is FASD?

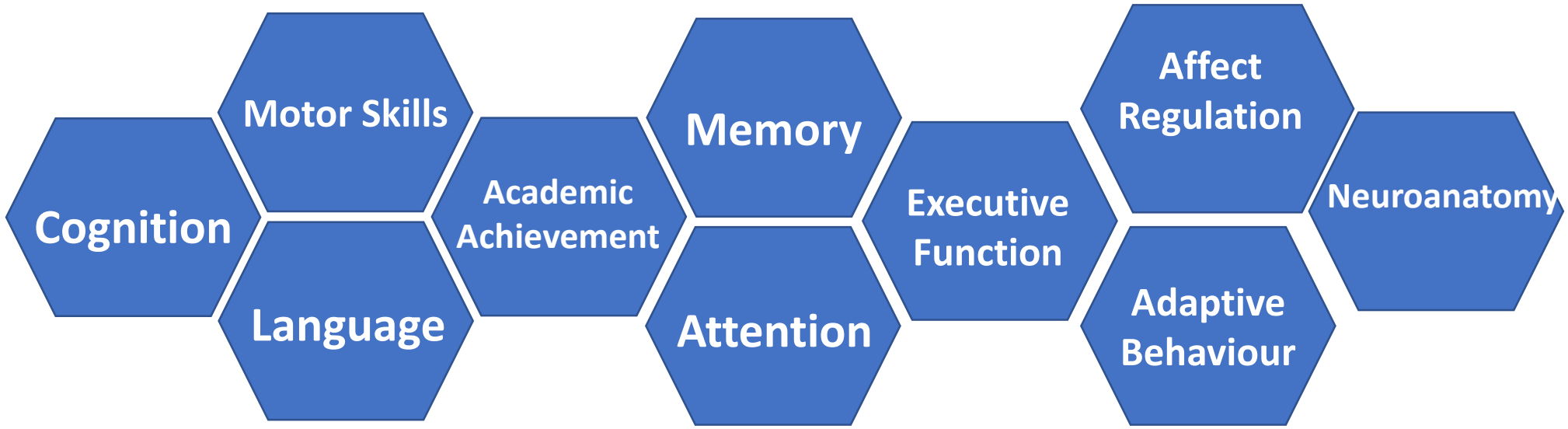
Symptoms and presentation of FASD vary based on the amount of alcohol consumed, when and how it was consumed, pre-existing genetic factors & environmental interactions across the lifespan.

What is FASD?

New population-based prevalence study estimated a rate of 2%-3% for FASD in Canada **(Popova et al. 2018)**

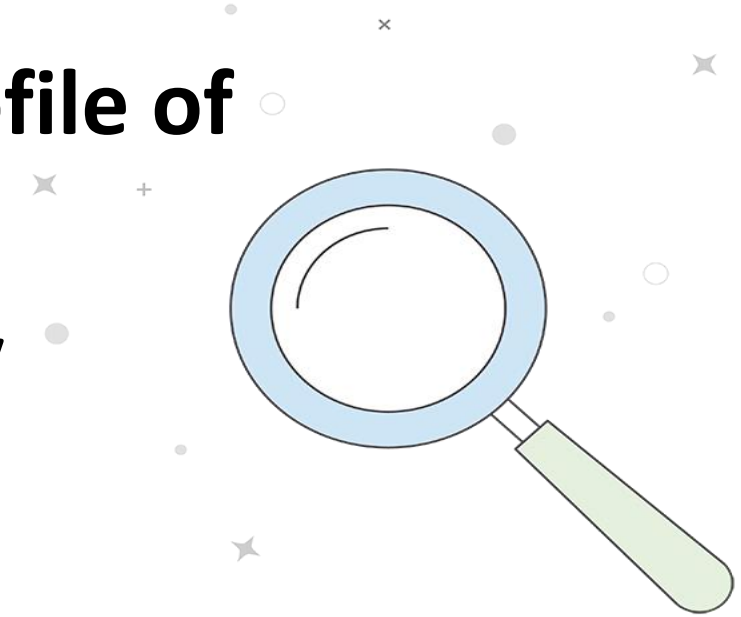
How do we diagnose FASD in Canada?

- Process includes multi-disciplinary assessment of medical, cognitive/functional abilities and confirming PAE
- Diagnosis requires impairments in at least 3 of 10 domains

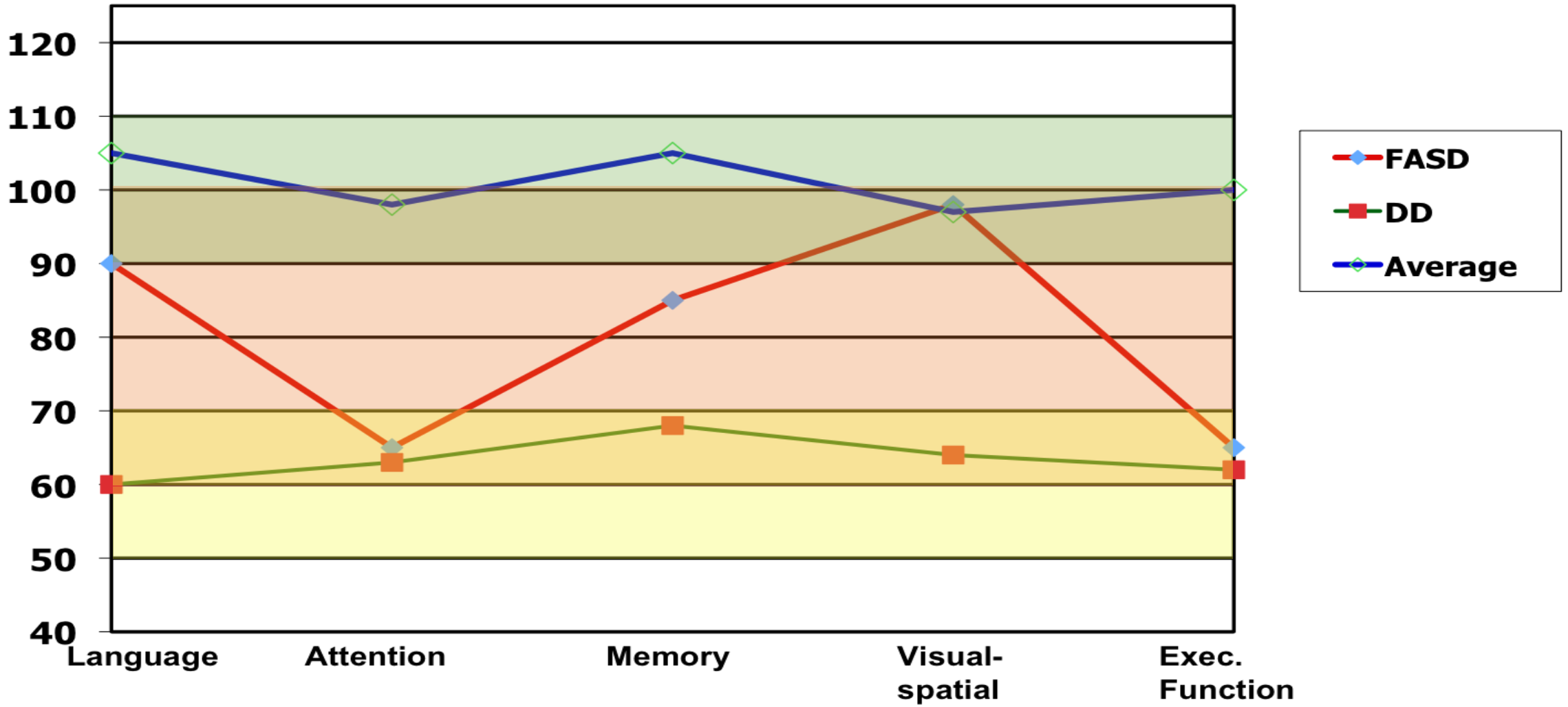


What are the most common/important challenges in FASD?

- There is a scattered or uneven profile of abilities
- Deficits in Affect regulation ability
- Deficits in Executive functioning



The Scattered Profile: IQ Scores for 3 Groups



Affect (Dys) Regulation

- Difficulty controlling, modulating, regulating emotional reactions
- Excessive reaction to environmental stress compared to others

Affect (Dys) Regulation

- Researcher at UBC showed PAE results in changes to hypothalamic-pituitary-adrenal axis (HPA)
- HPA= “Central stress response system”
- These changes sensitize person to stress; hyper-reactive emotionally
- Increases vulnerability to mental health problems later in life (depression, anxiety)

Executive Functioning Deficits

Impairments in working memory, impulse control, planning & problem solving, predicting consequences, and mental flexibility

Executive Functioning problems

Working Memory problems

- *Like a mental sticky note; ability to hold a small amount of info and immediately use it*
- *Result: problems following instructions & making good decisions*

What happens when you have executive function & affect regulation deficits?

Impulsivity

over spending, alcohol/drug use, problems delaying gratification, risky sexual behaviours

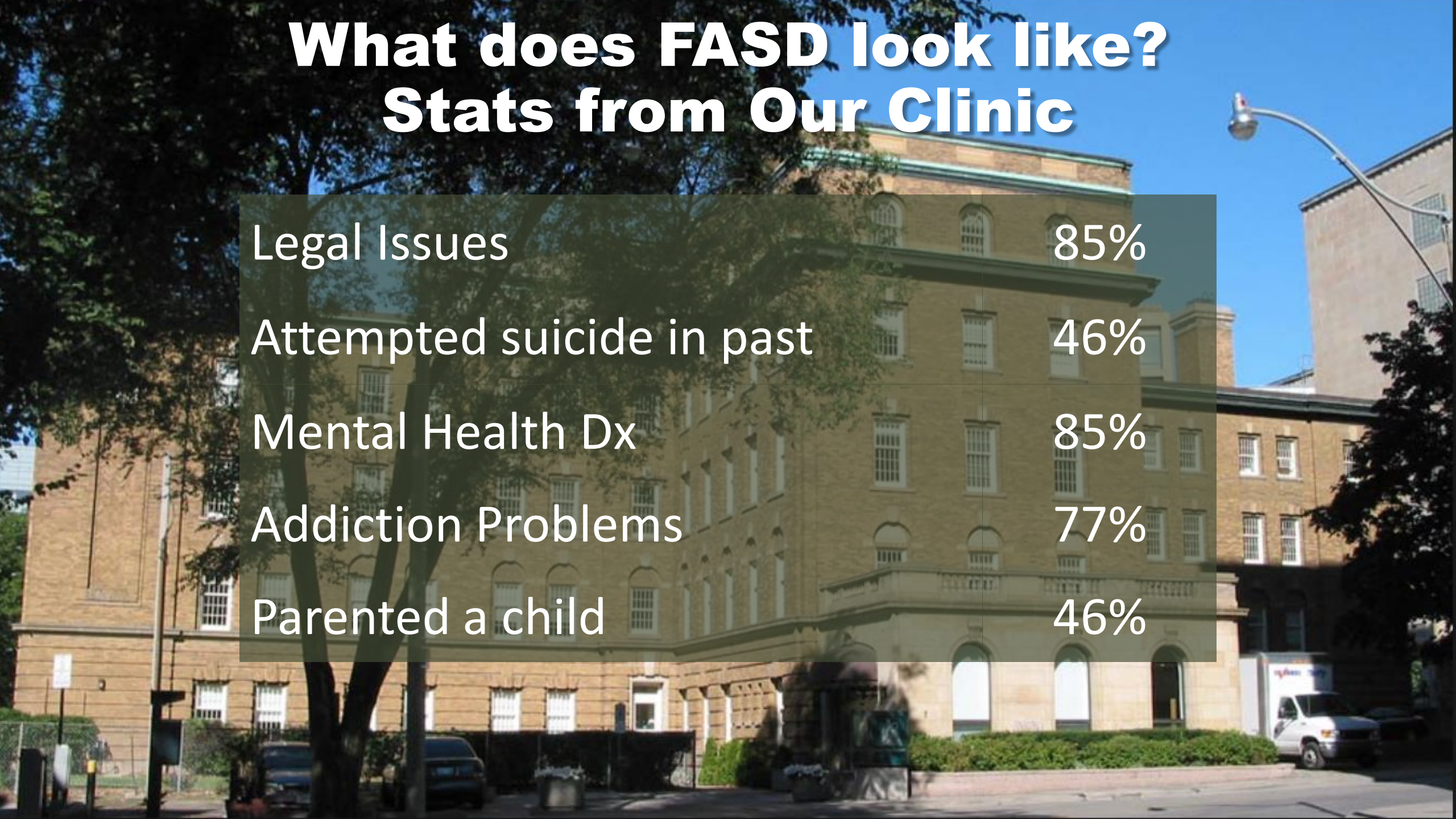
Organization & Attention problems

missed appointments, no planning for future, loss of jobs & homes, no ability to prioritize

Affect (dys) Regulation

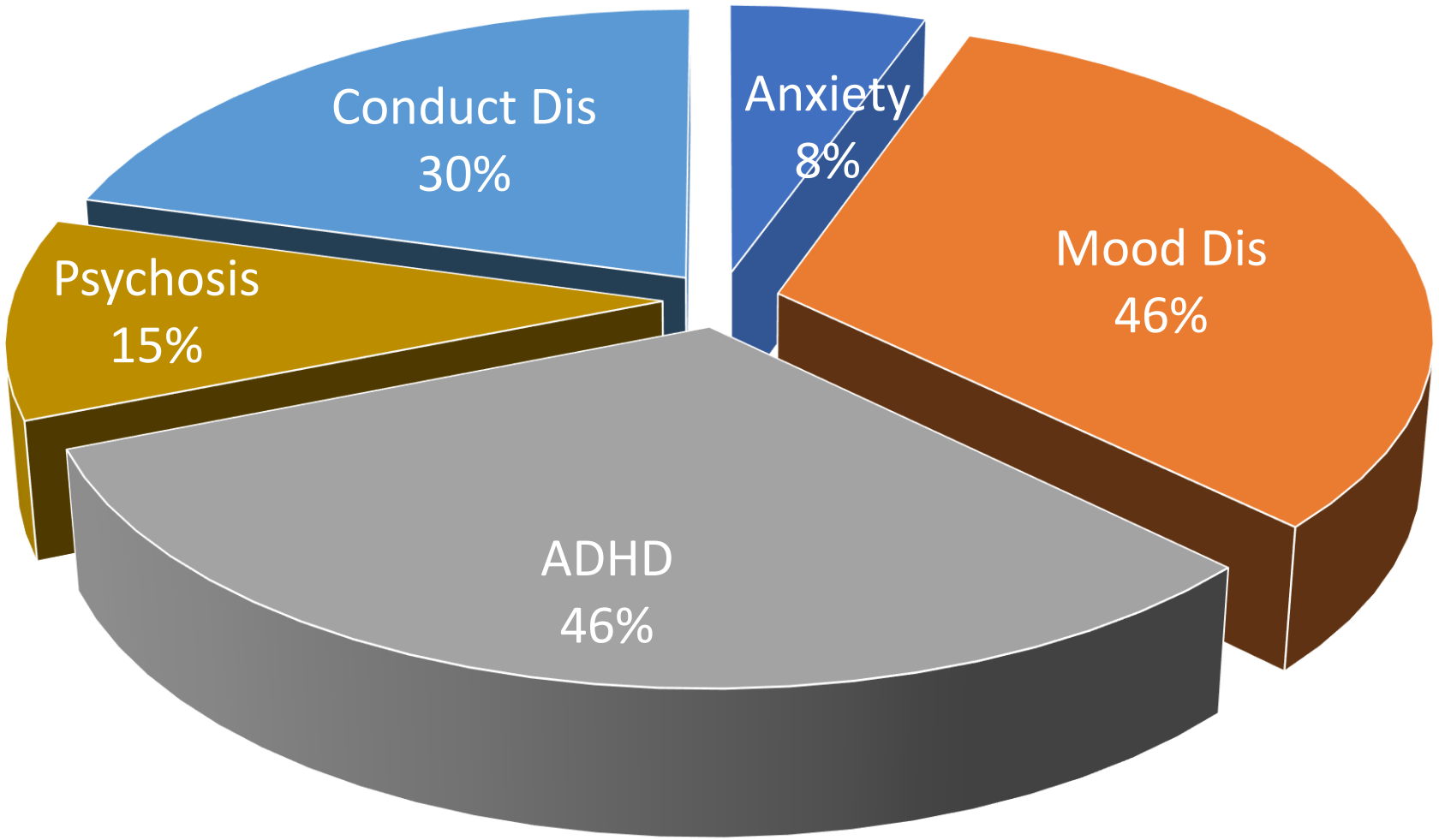
anxiety, depression, loss of temper, low threshold for frustration, self-harm, mental health diagnoses

What does FASD look like?
Stats from Our Clinic



Legal Issues	85%
Attempted suicide in past	46%
Mental Health Dx	85%
Addiction Problems	77%
Parented a child	46%

Mental Health Diagnoses



Resources for FASD Online

FASD-ONE, clinics, justice, education

- http://www.fasdontario.ca/cms/

POPFASD Educational Videos

- https://www.fasdoutreach.ca/

FASD workers embedded in communities across Ontario

- *at Surrey Place and other agencies*

Resources: Surrey Place Diagnostic Clinic

The Stages of Diagnosis for

Fetal Alcohol Spectrum Disorder (FASD)

These stages of diagnosis were described by Jan Lutke the adoptive mother of many adults with FASD. They may not be the same for everyone. But they may give you some ideas about what other people felt after they got a diagnosis of FASD.

Validation: "I was right. Something is wrong".

At first, people often feel relieved and happy that they received a diagnosis. It proves that all those problems were not the result of bad parenting, bad behaviour, or not trying hard enough. They were because of FASD.

Disbelief : "No way!"

Later, people sometimes become angry or refuse to accept their diagnosis. "That's not me. I'm not like that. This isn't fair. Why did this happen?" Sometimes people feel angry with their birth mother too.

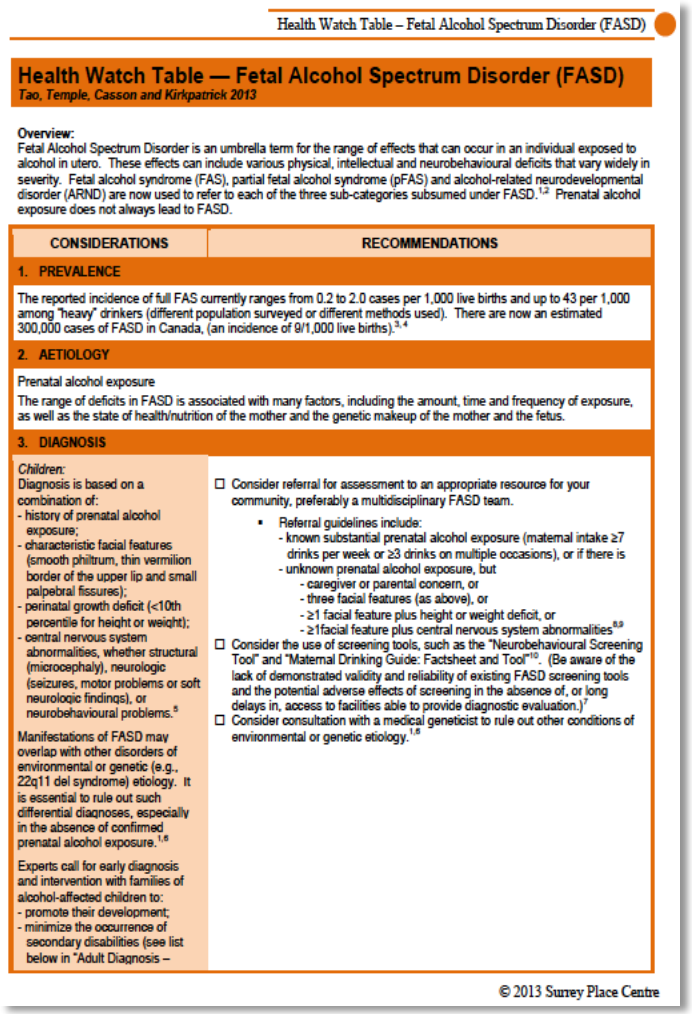
Confused: "How should I feel about this?"

Sometimes people go back and forth in how they feel. Sometimes they feel sad and feel like they have lost something. Sometimes they feel discouraged and want to give up. They think: "why try? I'll just fail". They may feel like they have no energy to go on.

Reaffirmation: "I'm ok!"

It may take some time, but gradually most people begin to feel better and happier. They learn that accepting support is smart. Accepting help doesn't define who you are. Support is what you have-- not who you are. Most people learn to accept this and look to the future with hope.

Everyone has different experiences in their life and this may or may not be how things happen for you. Surrey Place Centre and other agencies offer counselling services where people can talk about these feelings and work towards a good outcome.



Health Watch Table – Fetal Alcohol Spectrum Disorder (FASD)

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Tao, Temple, Casson and Kirkpatrick 2013

Overview:
Fetal Alcohol Spectrum Disorder is an umbrella term for the range of effects that can occur in an individual exposed to alcohol in utero. These effects can include various physical, intellectual and neurobehavioural deficits that vary widely in severity. Fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS) and alcohol-related neurodevelopmental disorder (ARND) are now used to refer to each of the three sub-categories subsumed under FASD.[1,2] Prenatal alcohol exposure does not always lead to FASD.

CONSIDERATIONS	RECOMMENDATIONS
1. PREVALENCE	
The reported incidence of full FAS currently ranges from 0.2 to 2.0 cases per 1,000 live births and up to 43 per 1,000 among "heavy" drinkers (different population surveyed or different methods used). There are now an estimated 300,000 cases of FASD in Canada, (an incidence of 9/1,000 live births).[3,4]	
2. AETIOLOGY	
Prenatal alcohol exposure The range of deficits in FASD is associated with many factors, including the amount, time and frequency of exposure, as well as the state of health/nutrition of the mother and the genetic makeup of the mother and the fetus.	
3. DIAGNOSIS	
Children: Diagnosis is based on a combination of: - history of prenatal alcohol exposure; - characteristic facial features (smooth philtrum, thin vermilion border of the upper lip and small palpebral fissures); - perinatal growth deficit (<10th percentile for height or weight); - central nervous system abnormalities, whether structural (microcephaly), neurologic (seizures, motor problems or soft neurologic findings), or neurobehavioural problems.[5] Manifestations of FASD may overlap with other disorders of environmental or genetic (e.g., 22q11 del syndrome) etiology. It is essential to rule out such differential diagnoses, especially in the absence of confirmed prenatal alcohol exposure.[1,6] Experts call for early diagnosis and intervention with families of alcohol-affected children to: - promote their development; - minimize the occurrence of secondary disabilities (see list below in "Adult Diagnosis –	☐ Consider referral for assessment to an appropriate resource for your community, preferably a multidisciplinary FASD team. ▪ Referral guidelines include: - known substantial prenatal alcohol exposure (maternal intake ≥7 drinks per week or ≥3 drinks on multiple occasions), or if there is - unknown prenatal alcohol exposure, but - caregiver or parental concern, or - three facial features (as above), or - ≥1 facial feature plus height or weight deficit, or - ≥1facial feature plus central nervous system abnormalities[8,9] ☐ Consider the use of screening tools, such as the "Neurobehavioural Screening Tool" and "Maternal Drinking Guide: Factsheet and Tool"[10]. (Be aware of the lack of demonstrated validity and reliability of existing FASD screening tools and the potential adverse effects of screening in the absence of, or long delays in, access to facilities able to provide diagnostic evaluation.)[7] ☐ Consider consultation with a medical geneticist to rule out other conditions of environmental or genetic etiology.[1,6]

Final thoughts…

- **Scattered Profiles** make it harder to predict skills and develop expectations. Often disability is mistaken for bad behaviour.
- **Executive functioning and impulsivity** can make service provision challenging.
- **Support, supervision, interdependence**. Even for those who appear to be “high functioning”

SURREY PLACE

Specialized Clinical Services for People with Developmental Disabilities and Autism Spectrum Disorder