

# Fetal Alcohol Spectrum Disorder: What it is and how to support students diagnosed with the condition

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# Outline

- Fetal Alcohol Spectrum Disorder: What is it?
- What are the signs and symptoms of an individual with this condition?
- How is it diagnosed?
- What functional impairments might we expect in the post-secondary setting?
- What accommodations, services, and supports might be most relevant?

# Fetal Alcohol Spectrum Disorder: What is it?

- **Fetal Alcohol Syndrome (FAS)** first used to describe a cluster of birth defects due to prenatal alcohol exposure (including growth restriction, craniofacial abnormalities, and intellectual disabilities).
- **Fetal Alcohol Spectrum Disorder (FASD)** later adopted to describe a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero.
- Prevalence estimate of **1 in 100 people** in Canada
- FASD is a **lifelong disorder** which, without appropriate support, leads to negative outcomes such as homelessness, mental health issues, substance use, unplanned parenthood, and justice system involvement (Barr et al., 2006; Streissguth et al., 2004; Streissguth & O'Malley, 2000)



**What are the signs and symptoms  
of an individual with this condition?**

- **Heterogeneous** condition
- However, commonly there are challenges with **daily living skills, communication, and socialization**, as well as **behavioural problems, limited education and vocational achievement**, and **substance misuse** that are not fully accounted for by overall intellectual functioning (Day et al., 2013; Famy et al., 1998; Fast et al., 1999; Rangmar et al., 2015; Temple et al., 2011).
- Those who were **less affected physically by PAE** (but had significant cognitive impacts) showed the greatest level of difficulty, and **men with PAE** were particularly at risk for difficulties in daily living and transition to adult roles. (Lynch et al., 2015).



# How is it diagnosed?

# Diagnosing FASD

- Requires a **multidisciplinary team** and involves a complex **physical and neurodevelopmental** assessment.
- The most up-to-date diagnostic criteria are the **Fetal Alcohol Spectrum Disorder (FASD): Canadian Guidelines for Diagnosis** (published in the Canadian Medical Association Journal)
- A referral for assessment should be initiated when there is **evidence of or suspected prenatal alcohol exposure** at levels associated with physical or developmental effects.

AND

- Evidence of **physical and/or neurodevelopmental challenges** that are often associated with prenatal alcohol exposure.

# Reliable Sources to Confirm Prenatal Alcohol Use

- Confirmation requires **documentation that the biological mother consumed alcohol during the pregnancy (>7 drinks a week and/or 2 or more episodes of binge drinking  $\geq 4$  drinks):**
  - Reliable clinical observations
  - Self-report
  - Reports by a reliable source
  - Medical records documenting positive blood alcohol concentrations
  - Alcohol treatment
  - Other social, legal, or medical problems related to drinking alcohol during the pregnancy

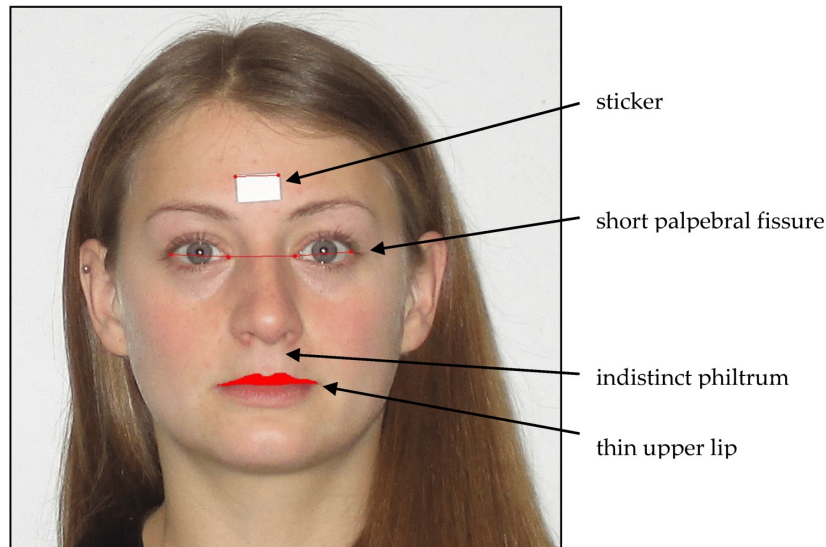
OR

- The presence of all **three facial features**



# Sentinel Facial Features

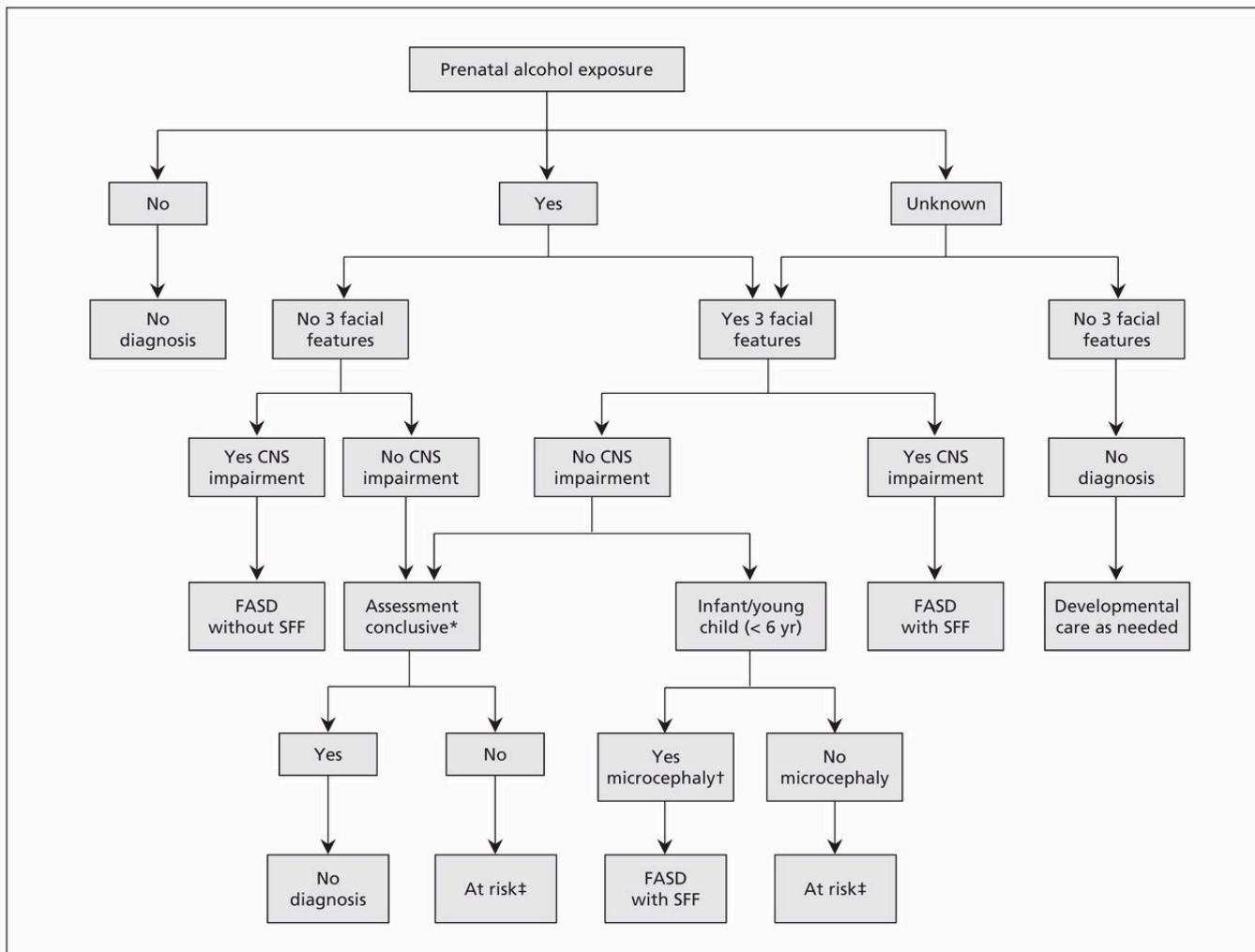
- Palpebral fissure length  $\geq 2$  SDs below the mean ( $< 3^{\text{rd}}$  percentile)
- Philtrum rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide
- Upper lip rated 4 or 5 on 5-point scale of the University of Washington Lip-Philtrum Guide



# Physical & Neurodevelopmental Assessment

- FASD requires **evidence of pervasive brain dysfunction**, defined by severe impairment ( $\geq 2$  SDs below the mean) in three or more of the following neurodevelopmental domains:
  - Neuroanatomy/neurophysiology (Physician)
  - Motor skills (OT)
  - Cognition (Psychology)
  - Language (SLP)
  - Academic achievement (Psychology)
  - Memory (Psychology)
  - Attention (Psychology)
  - Executive Function (Psychology)
  - Affect Regulation (Psychology)
  - Adaptive Behaviour, Social Skills, and/or Social Communication (Psychology)

## Diagnostic algorithm for fetal alcohol spectrum disorder (FASD).



Jocelynn L. Cook et al. CMAJ 2016;188:191-197

# Etiology versus Comorbidity

- It is appropriate to make additional relevant DSM-5 diagnoses, such as ADHD, ID, and/or LD when individuals meet those criteria as well as the criteria for FASD.
- These terms provide different levels of explanation:
  - FASD describes overall severe and pervasive neurodevelopmental dysfunction associated with prenatal alcohol exposure (primary disability).
  - Other diagnoses described particular patterns of symptoms that help to predict prognosis and treatment response (secondary disability).

# Why is Diagnosis Important?

- Can help the individual, their family, and service providers to understand the challenges associated with a life-long disability that requires accommodations and supports.
- An FASD diagnosis may help them access interventions and supports that address their bio-psycho-social needs with recommendations for basic supports, general, physical, and mental health.
- Client- and family-centred approaches that are based on strengths, and sufficiently flexible to account for individual barriers should be best practices for supporting individuals with FASD.

**What functional impairments might we expect in the post-secondary setting?**

## ... depends

- **No single neuropsychological profile** specific to all individuals with FASD.
- Presumed that differences in the dose and timing of exposure, as well as interacting genetic and environmental influences on brain development account for variability in presentations.
- Most common neurodevelopmental challenges include **attention, executive function, spatial working memory, mathematics, communication, and adaptive behaviour.**
- In all domains, the “**clinical cut-off**” is defined as **2 or more standard deviations below the mean.**

# FASD in the Post-Secondary Environment

- There is a dearth of literature on post-secondary experiences of adults with FASD. In a study conducted in Canada and the United States, six of 17 individuals with FASD completed their college programs.
  - Persistence was attributed to:
    - institutional factors (the fit between the program and the individual characteristics, availability of accommodations, grades, and the potential for positive social integration),
    - personal attributes (high school academic preparation, goal-directedness, and symptoms of the primary and secondary disabilities), and
    - family support (advocacy or assistance with self-advocacy, tutoring) (Duquette & Orders 2013).
  - Reasons for dropping out of college included cognitive symptoms of FASD (e.g., deficiencies in memory and attention, inability to work independently, and the need for slower-paced instruction) and substance abuse (Duquette and Orders 2013).





**What accommodations,  
services, and supports might  
be most relevant?**



# Linking Accommodations to Functional Impairments

Area of Functional Impairment	Possible Accommodations
Inattention	Stop-the-clock breaks; note-taking support
Executive Functions	Learning Strategies support
Motor Skills: Fine-motor	Typing written work
Affect Regulation	Counselling
Academic: Reading	Text-to-Speech software
Academic: Writing	Type written work to access spell check
Academic: Mathematics	Calculator; Referral to peer tutoring program
Adaptive Functioning	FASD Worker; Transition support



# But... Remember that FASD is Present

- Often best to be considered as a brain injury experienced in-utero.
- While skill development is important, environmental supports are also key.
- Support generally developing adaptive routines and schedules is important with regular check-ins with a trusted individual.
- Is important to frame behaviours and treatment plans, as certain protocols have been developed (such as for ADHD) and their condition may impact on treatment compliance



# Prevention

- All pregnant and postpartum women should be screened for alcohol use with validated measurement tools by service providers.
- Women at risk for heavy alcohol use should receive brief interventions (i.e., counselling and/or other services).
- Abstinence from alcohol should be recommended to all women during pregnancy to ensure the safest outcome for the fetus, and appropriate support should be provided, as indicated.

# Questions?



# Thank You!

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