The Prenatal Alcohol History – it is hard to get and it matters how we define it

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Conflicts of interest

no industry connections

Introduction

- Prenatal Alcohol Exposure **(PAE)** History
- NECESSARY
- DIFFICULT
- VAGUELY DEFINED - PREVIOUSLY

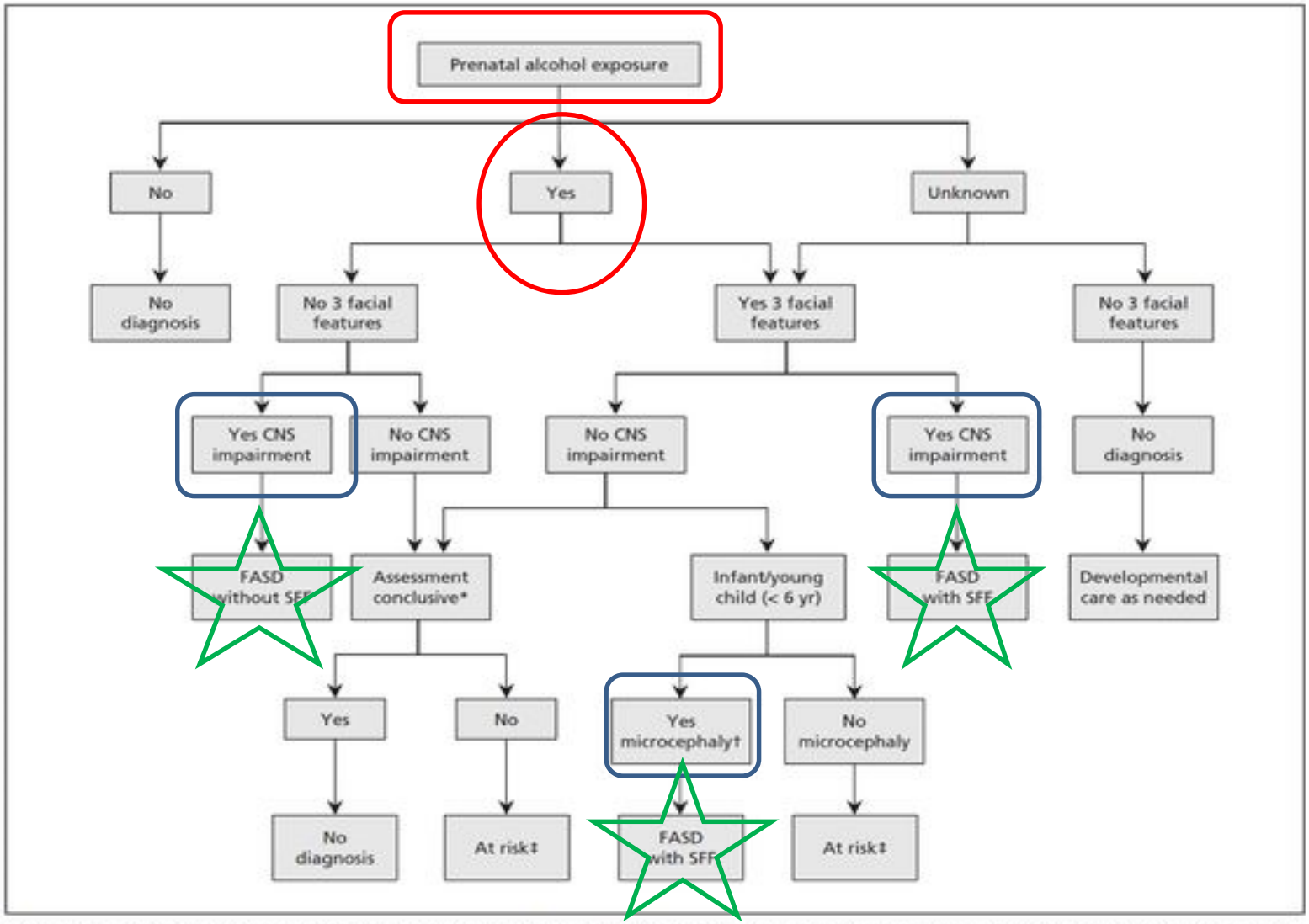

Figure 1: Diagnostic algorithm for fetal alcohol spectrum disorder (FASD). *Assessment conclusive = clinician conducting the neurodevelopmental assessment is satisfied that the session was a true representation of the person's ability and that any deficits reported were not due to extenuating circumstances. Assessments may be inconclusive for children under six years of age, because some domains cannot be assessed with confidence until the person is older or because of other confounding factors, such as temporary life stress or illness; see the text for more information. †Microcephaly is not the only pathway to diagnosis for infants and young children; these individuals may also receive other FASD diagnoses, as specified elsewhere in the algorithm, if they show three areas of substantial impairment on neurodevelopmental tests. ‡At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. An at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be the diagnosis. Clinical judgment is recommended. Note: CNS = central nervous system (yes/no impairment in ≥ 3 brain domains), SFF = sentinel facial features.

DPN DIAGNOSTIC MODEL-4 DIGIT CODE

GROWTH =

FACE =

BRAIN =

ALCOHOL =

Each of the above individually coded 1,2,3 or 4 according to severity

BRAIN =

Table 5: Criteria for CNS Ranks 1 through 4

4-Digit Diagnostic Rank*	Probability of CNS Damage	Confirmatory Findings
4	Definite **Structural and/or Neurological Abnormalities** *Static Encephalopathy*	• Microcephaly: OFC 2 or more SDs below the norm. *and / or* • Significant abnormalities in brain structure of presumed prenatal origin. *and / or* • Evidence of hard neurological findings likely to be of prenatal origin.
3	Probable **Significant Dysfunction** *Static Encephalopathy*	• Significant impairment in three or more domains of brain function such as, but not limited to: cognition, achievement, memory, executive function, motor, language, attention, activity level, neurological 'soft' signs.
2	Possible **Mild to Moderate Delay or Dysfunction** *Neurobehavioral Disorder*	• Evidence of delay or dysfunction that suggest the possibility of CNS damage, but data to this point do not permit a Rank 3 classification.
1	Unlikely	• No current evidence of delay or dysfunction likely to reflect CNS damage.

* Transfer the resulting 4-Digit Diagnostic Rank for CNS to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

ALCOHOL =

Table 6: Criteria for Prenatal Alcohol Exposure Ranks 1 through 4

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2	Unknown Risk	• Alcohol use during pregnancy is UNKNOWN.
1	No Risk	• Alcohol use during pregnancy is CONFIRMED to be completely ABSENT from conception to birth.

Transfer the resulting 4-Digit Diagnostic Rank for Alcohol Exposure to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

Previous PAE definitions

- Canadian Guidelines **2005** (IOM)

The possible FASD diagnoses:

FAS, Partial FAS, ARND**…… **with confirmed maternal alcohol exposure***

* **A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking.** Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behaviour while drinking or alcohol-related medical problems such as hepatic disease. Confirmation may be from maternal interview or reliable collateral sources.

†As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND**, these patterns of alcohol use should be incorporated into the diagnostic criteria.

**ARND = alcohol related neurodevelopmental disorder

Canadian Guidelines **2015**

Early release, published at www.cmaj.ca on December 14, 2015. Subject to revision.

CMAJ GUIDELINES CME

Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan

Jocelynn L. Cook PhD, Courtney R. Green PhD, Christine M. Lilley PhD, Sally M. Anderson PhD, Mary Ellen Baldwin, Albert E. Chudley MD, Julianne L. Conry PhD, Nicole LeBlanc MD, Christine A. Loock MD, Jan Lutke, Bernadene F. Mallon MSW, Audrey A. McFarlane MBA, Valerie K. Temple PhD, Ted Rosales MD; for the Canada Fetal Alcohol Spectrum Disorder Research Network

CMAJ podcasts: author interview at https://soundcloud.com/cmajpodcasts/141593-guide

The consequences of prenatal alcohol exposure were first described more than 40 years ago.[1,2] The term "fetal alcohol syndrome" (FAS) was first used to describe the cluster of birth defects due to prenatal alcohol exposure (including growth restriction, craniofacial abnormalities and intellectual disabilities) with lifetime consequences.[2] The term "fetal alcohol spectrum disorder" (FASD) has since been adopted to describe a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero. The prevalence has been estimated at 1 in 100 people, which translates to more than 330 000 affected individuals in Canada.[3]

The development of clinical capacity for FASD diagnosis remains difficult,[4] because the diagnosis requires a medical evaluation and neurodevelopmental assessment conducted by a multidisciplinary team. In 2005, an international, collaborative, evidence-based guideline for diagnoses related to prenatal alcohol exposure was published.[5] Since then, the field has evolved, and additional evidence, expertise and experience have emerged to suggest that a revision was required to improve both diagnoses and outcomes. The literature has also shown that impairments in behaviour and function associated with FASD have been detected from exposure to binge drinking, even infrequently or early in pregnancy, which underscores the importance of pre-pregnancy counselling. Specific research involving infants, young children and adults with FASD, as well as further insight into the neurodevelopmental dysfunction and nomenclature, prompted the update and revision process. A literature review and broad consultation process was undertaken to revise the 2005 guideline for diagnosing FASD.[5]

Scope

Recommendations are focused on the diagnostic process and are geared toward members of multidisciplinary diagnostic teams in Canada, who have received the required expertise and experience through specialized training. Although primary health care providers, who provide antenatal care and counsel individuals considering pregnancy, may also benefit from these recommendations, the diagnostic process should not be performed in isolation; multidisciplinary input is required.

Methods

Guideline steering committee

A 14-member steering committee was formed in September 2012. Members were selected by the Canada Fetal Alcohol Spectrum Disorder Research Network based on previous involvement with the 2005 diagnostic guideline, expertise in FASD and expertise in areas requiring specific attention (e.g., diagnostic guidelines for infants and young children, and adults; nomenclature; and the neurodevelopmental assessment criteria). The committee consisted of four psychologists, three researchers, three pediatricians, one social worker, one clinical geneticist, one FASD clinic coordinator and one parent of individuals living with FASD.

Competing interests: None declared.

This article has been peer reviewed.

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KEY POINTS

- Fetal alcohol spectrum disorder (FASD) is a diagnostic term describing the constellation of effects that result from prenatal alcohol exposure.
- Making a diagnosis of FASD requires a multidisciplinary team and involves a complex physical and neurodevelopmental assessment.
- Diagnosis of FASD is critical to improve outcomes for affected individuals and families, and to inform pre-pregnancy counselling to prevent future cases.

2.0 Medical assessment‡		
2.1 The diagnostic process should include compiling a social and medical history and complete physical examination.	Strong	High
2.2 Confirmation of prenatal alcohol exposure requires documentation that the biological mother consumed alcohol during the index pregnancy based on: reliable clinical observation; self-report; reports by a reliable source; medical records documenting positive blood alcohol concentrations; alcohol treatment; or other social, legal or medical problems related to drinking during the pregnancy. The presence of all three facial features has such high specificity to alcohol exposure and FASD that confirmation of alcohol exposure is not required.[11] The presence of fewer than three facial features does not have the same degree of specificity and therefore requires other confirmation.	Strong	Moderate
3.0 Sentinel facial features		
3.1 The following three sentinel facial features must be present because of their specificity to prenatal alcohol exposure: • Palpebral fissure length ≥ 2 SDs below the mean (< third percentile). • Philtrum rated 4 or 5 on 5-point scale of the University of Washington Lip–Philtrum Guide.[12] • Upper lip rated 4 or 5 on 5-point scale of the University of Washington Lip–Philtrum Guide.[12]	Strong	High
4.0 Neurodevelopmental assessment		
4.1 A diagnosis of FASD is made only when there is evidence of pervasive brain dysfunction, which is defined by severe impairment in three of more of the following neurodevelopmental domains: motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication.	Strong	High
4.2 Severe impairment is defined as a global score or a major subdomain score on a standardized neurodevelopmental measure that is ≥ 2 SDs below the mean, with appropriate allowance for test error. In some domains, large discrepancies among subdomain scores may be considered when a difference of this size occurs with a very low base rate in the population (≤ 3% of the population). Clinical assessment with converging evidence from multiple sources and DSM-V diagnostic criteria[13] for certain disorders may also be considered in specific domains that are not easily assessed by standardized tests. For example, in the affect regulation domain, the following diagnoses may be taken as an indication of severe impairment: major depressive disorder (with recurrent episodes), persistent depressive disorder, disruptive mood dysregulation disorder, separation anxiety disorder, selective mutism, social anxiety disorder, panic disorder, agoraphobia or generalized anxiety disorder). A domain-by-domain discussion of how these criteria are operationalized is outlined in Appendix 1 (available at www.cmaj.ca/lookup/suppl/doi:10.1503/cmaj.141593/-/DC1).	Strong	Moderate
5.0 Nomenclature and diagnostic criteria		
5.1 A diagnosis of FASD may be made if an individual meets either of the two sets of criteria below: 5.1.1 FASD with sentinel facial features • Simultaneous presentation of the three sentinel facial features (see section 3.0); AND • Prenatal alcohol exposure confirmed or unknown; AND • Evidence of impairment in three or more of the identified neurodevelopmental domains (see section 4.0) or, in infants and young children, evidence of microcephaly. OR 5.1.2 FASD without sentinel facial features • Evidence of impairment in three or more of the identified neurodevelopmental domains (see section 4.0); AND • Confirmation of prenatal alcohol exposure, with the estimated dose at a level known to be associated with neurodevelopmental effects.	Strong	High

Canadian Guidelines **2015** for PAE

More clarity……

"Confirmation of PAE with an estimated dose at a level known to be associated with neurodevelopmental effects"

APPENDIX:

"At this time the threshold of PAE known to be associated with adverse neurodevelopmental effects is **7 or more standard drinks per week ….{or 2 binges of 4 drinks / occasion}**

"These recommendations are tentative and may become outdated as more information becomes available……"

weight [53]. As well, 7 standard drinks/week has been (cautiously) suggested as a possible threshold by several researchers in the field [54, 55], and data to corroborate that 7 drinks/week can lead to structure and/or functional abnormalities has also been made [22, 54, 56-58]. As reviewed by Jacobson & Jacobson (1994), most measures of adverse outcomes correlated with a range of 7-28 standard drinks/week [59]. However, because few pregnant women drink every day, 7 standard drinks/week typically represents relatively heavy doses of alcohol on drinking days [60]. Most adverse neurodevelopmental effects have not yet been shown to occur with exposure below 7 standard drinks/week [59]. However, adverse neurodevelopmental effects have been shown to be related to episodes of binge drinking equivalent to 4-5 standard drinks/occasion [22, 50, 63-69] and there is evidence that even a single episode of binge drinking may have measurable neurodevelopmental effects in humans [69] and animals [61].

There is also evidence that exposure to alcohol early in pregnancy, before some women may know that they are pregnant, can affect physical and neurodevelopmental development [62-64]. For this reason, it is important to assess and consider alcohol exposure that occurred prior to pregnancy recognition. At this time, the threshold of alcohol exposure known to be associated with adverse neurodevelopmental effects is 7 or more standard drinks per week, or any episode of drinking 4 or more drinks on the same occasion [65]. Because the effect sizes seen with a single binge episode are relatively small, a threshold of 2 binge episodes is recommended as a minimum for

Appendix to: Cook JL, Green CR, Lilley CM, et al.; Canada Fetal Alcohol Spectrum Disorder Research Network. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2015. DOI:10.1503/cmaj.141593.

ALCOHOL =

Table 6: Criteria for Prenatal Alcohol Exposure Ranks 1 through 4

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BUT WAIT...
what is the best we can get most of the time?

often the best we can get is……

- “confirmed, but in unknown exact quantity”

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So what would happen if I were to retrospectively applied this guideline to those we have diagnosed with FASD in the last 5 years?

This study - Objectives

Mixed methodology- qualitative & quantitative

1) Ask those who work in the field interviewed experienced professionals about the difficulties they face in gathering the PAE history and what methods work best for them

2) Diagnostic comparison of old vs new guidelines we calculated the percentage of our past assessments where the minimal threshold of PAE as outlined in Guidelines was available.

Methods - Qualitative

Individual interviews

- FASD diagnostic team (N=6)
- Sample of community social workers (N=10).

We qualitatively analysed

- the challenges faced in gathering the PAE history
- identified strategies used

Results - Qualitative

- Few of the social workers were aware of the level of detail for PAE mentioned in the new 2015 guidelines

- It would be impractical if not impossible, to obtain a detailed PAE history as suggested in the Guidelines in most cases

Results - Qualitative

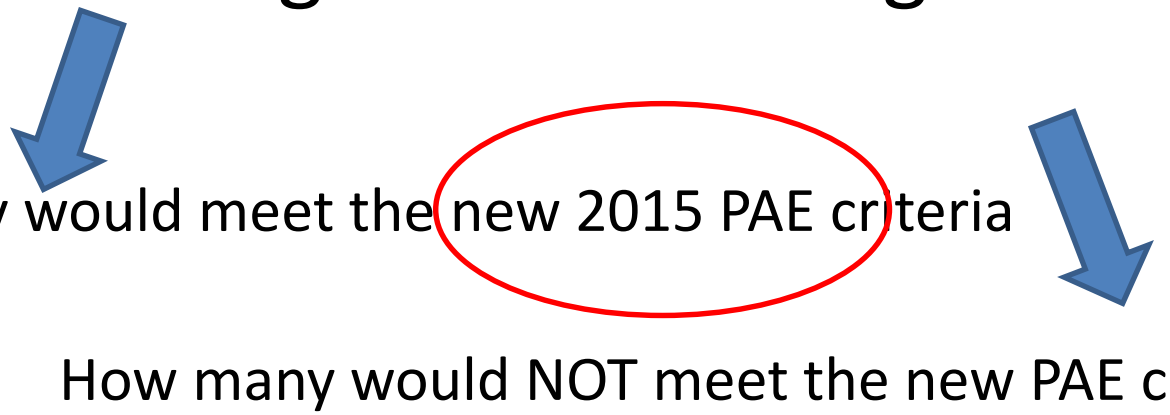
- Challenges to get the level of detail suggested in the Guidelines
  - absence of birth mother
  - mother's reluctance to speak about PAE due to stigma or the fear of losing her children.
  - credibility of sources is difficult to assess.

- Strategies
  - third party sources such as police record of arrests, emergency hospital visits, visits to detox centers during pregnancy, records in birth files have been used to obtain PAE histories.

Methods - Quantitative

5 year retrospective review of referrals for FASD assessment

Of those who got an FASD diagnosis



Methods -Quantitative

Of those who meet Brain/CNS criteria for FASD

Table 5: Criteria for CNS Ranks 1 through 4

4-Digit Diagnostic Rank*	Probability of CNS Damage	Confirmatory Findings
4	Definite **Structural and/or Neurological Abnormalities** *Static Encephalopathy*	• Microcephaly: OFC 2 or more SDs below the norm. *and / or* • Significant abnormalities in brain structure of presumed prenatal origin. *and / or* • Evidence of hard neurological findings likely to be of prenatal origin.
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1	Unlikely	• No current evidence of delay or dysfunction likely to reflect CNS damage.

* Transfer the resulting 4-Digit Diagnostic Rank for CNS to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

Methods - Quantitative

Of those who met Brain/CNS criteria for FASD

Probable CNS damage **(= Rank 3)**

is assigned when this testing evidence documents "significant" impairment in **three or more domains** of brain function. "Significant" impairment is generally defined as performance **2 or more standard deviations below the mean** (or its equivalent) on a standardized test.

Definite CNS damage **(= Rank 4)**

At least one "significant" structural or neurological finding is required for a classification of CNS Rank 4.

Methods - Quantitative

How many of those with an FASD diagnosis had high risk Alcohol = 4

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Results -Quantitative

- Patients referred between Jan 2011 - Nov 2016

- Referrals n=146

  female = 48 (32.88 %)

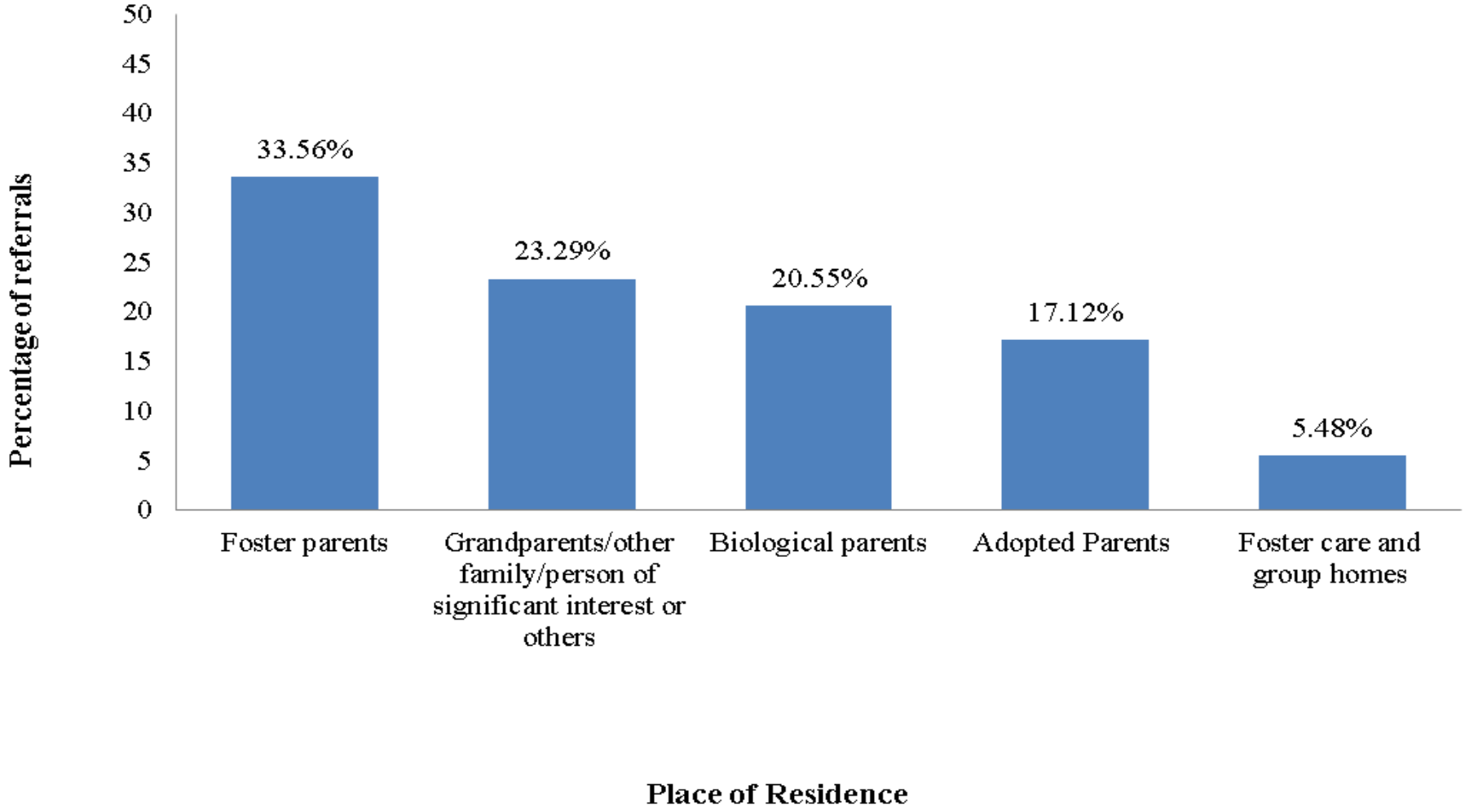
  male = 97 (66%)

- Age mean years (SD)

  Female = 9.99 (2.69)

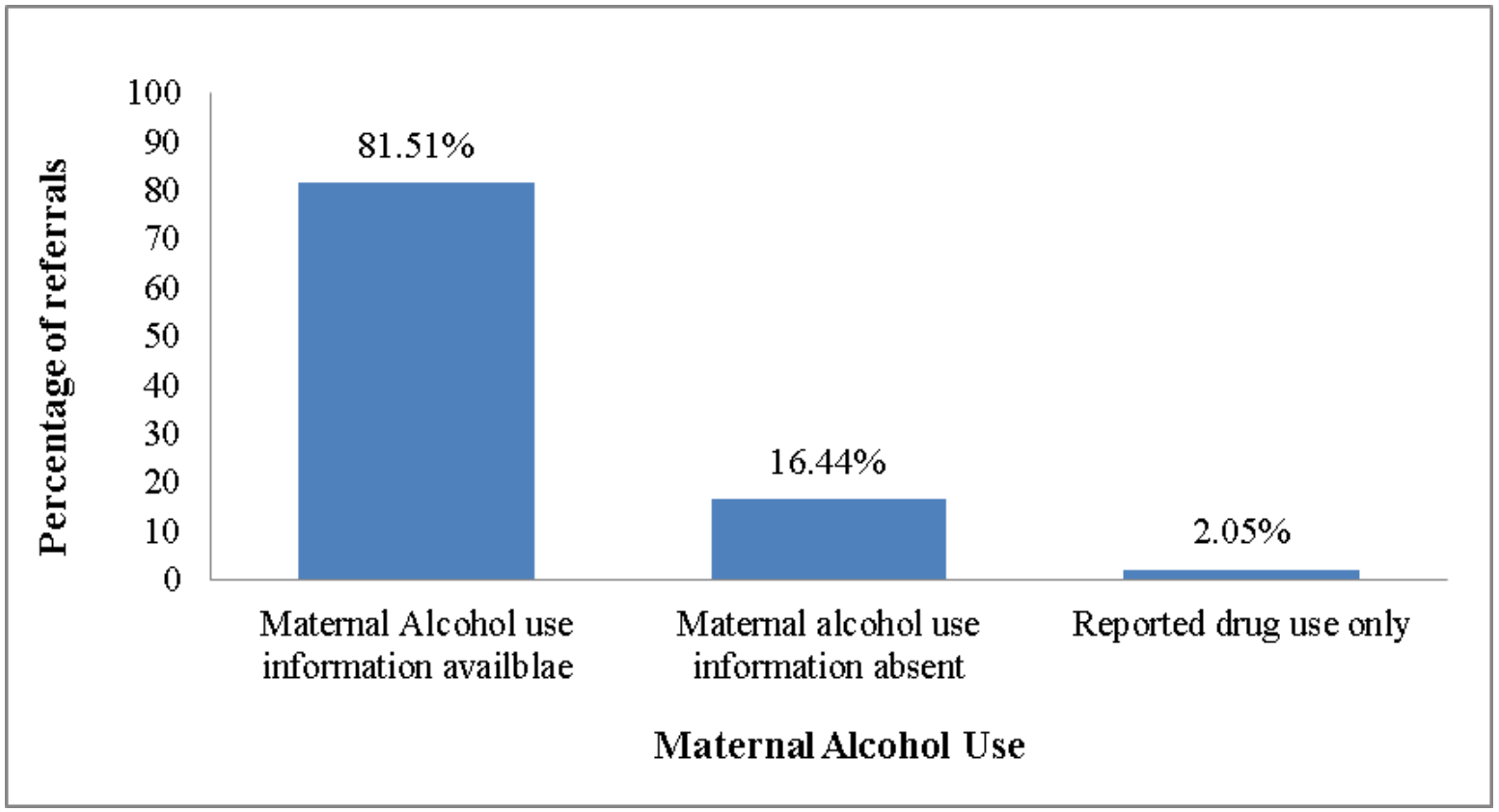
  Male = 9.08 (2.12)

Place of residence….



Information on PAE

- Present in **119 referrals** (81.51%)
- Absent in 24 (16.44%)
- Drug use only in 3 (2.05%)



Of the 119 in which PAE was present

30 (25.21%) had DPN = 4

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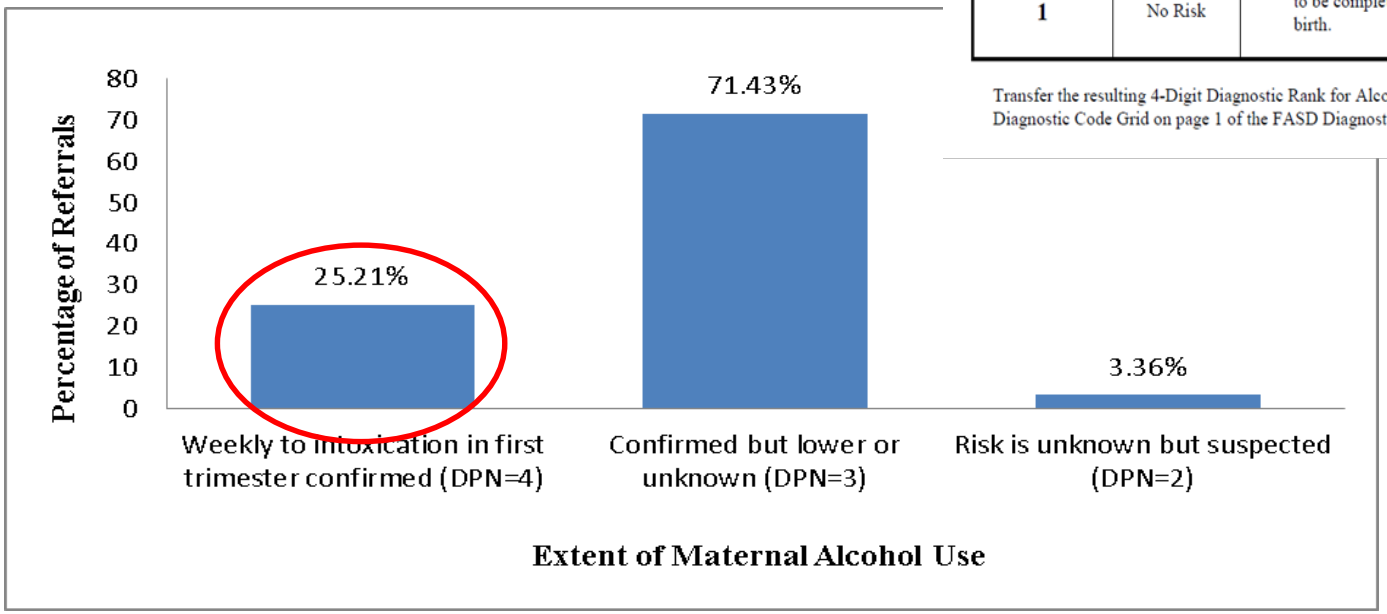

Of the 119 in which PAE was present

85 (71.43%) had DPN = 3

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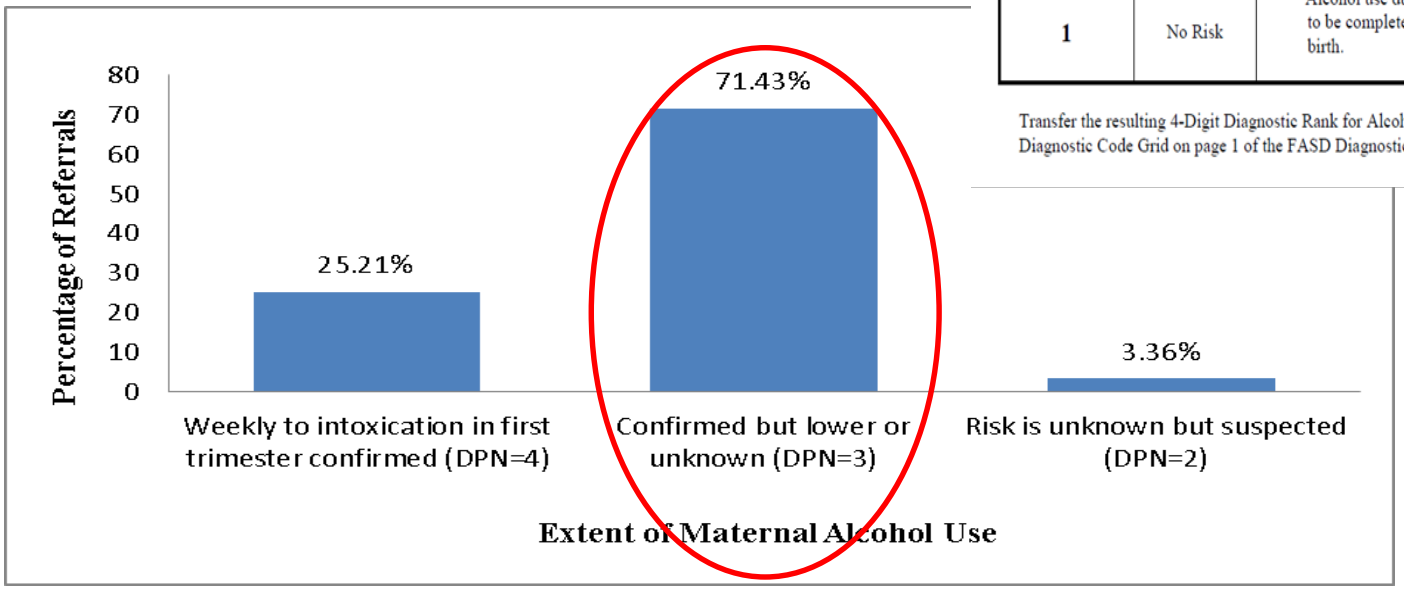

Brain criteria for FASD met in **77** clients of the 146 referrals

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2	Possible **Mild to Moderate Delay or Dysfunction** *Neurobehavioral Disorder*	• Evidence of delay or dysfunction that suggest the possibility of CNS damage, but data to this point do not permit a Rank 3 classification.
1	Unlikely	• No current evidence of delay or dysfunction likely to reflect CNS damage.

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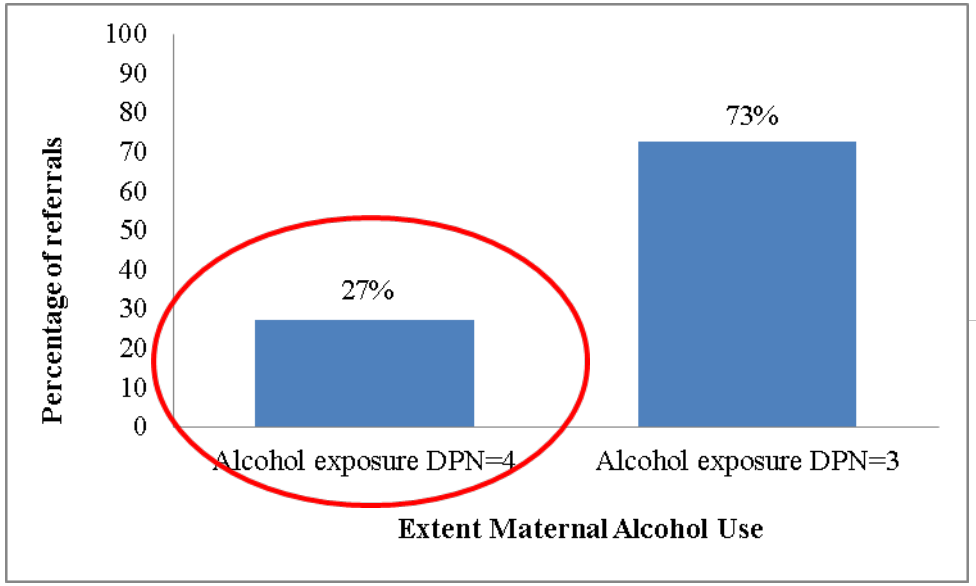
Only 21 (27%) would have met the Guidelines 2015 PAE criteria

(i.e. DPN Alcohol 4)



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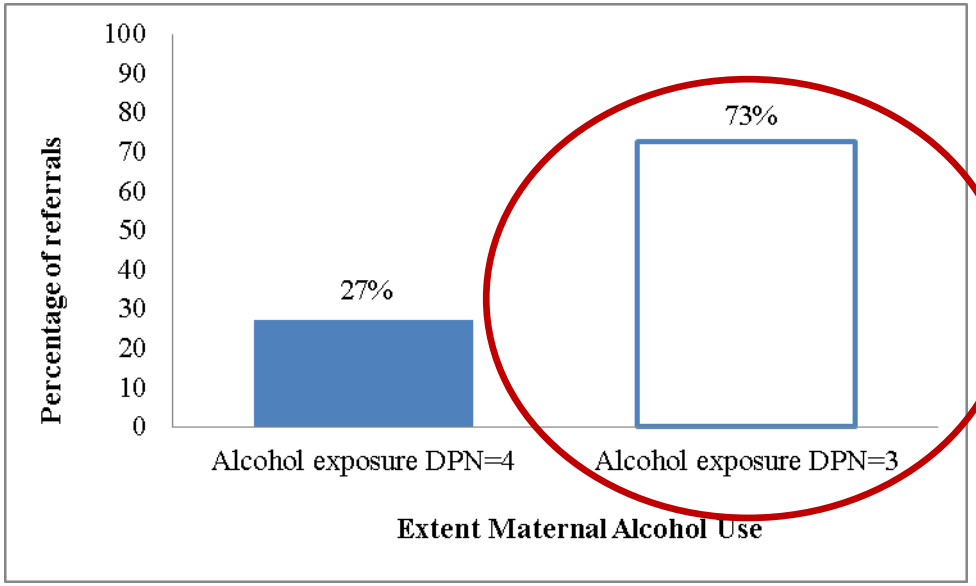
Conversely 56 (73%) did NOT meet Guidelines PAE criteria
(i.e. DPN Alcohol = 3)



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Transfer the resulting 4-Digit Diagnostic Rank for Alcohol Exposure to the 4-Digit Diagnostic Code Grid on page 1 of the FASD Diagnostic Form.

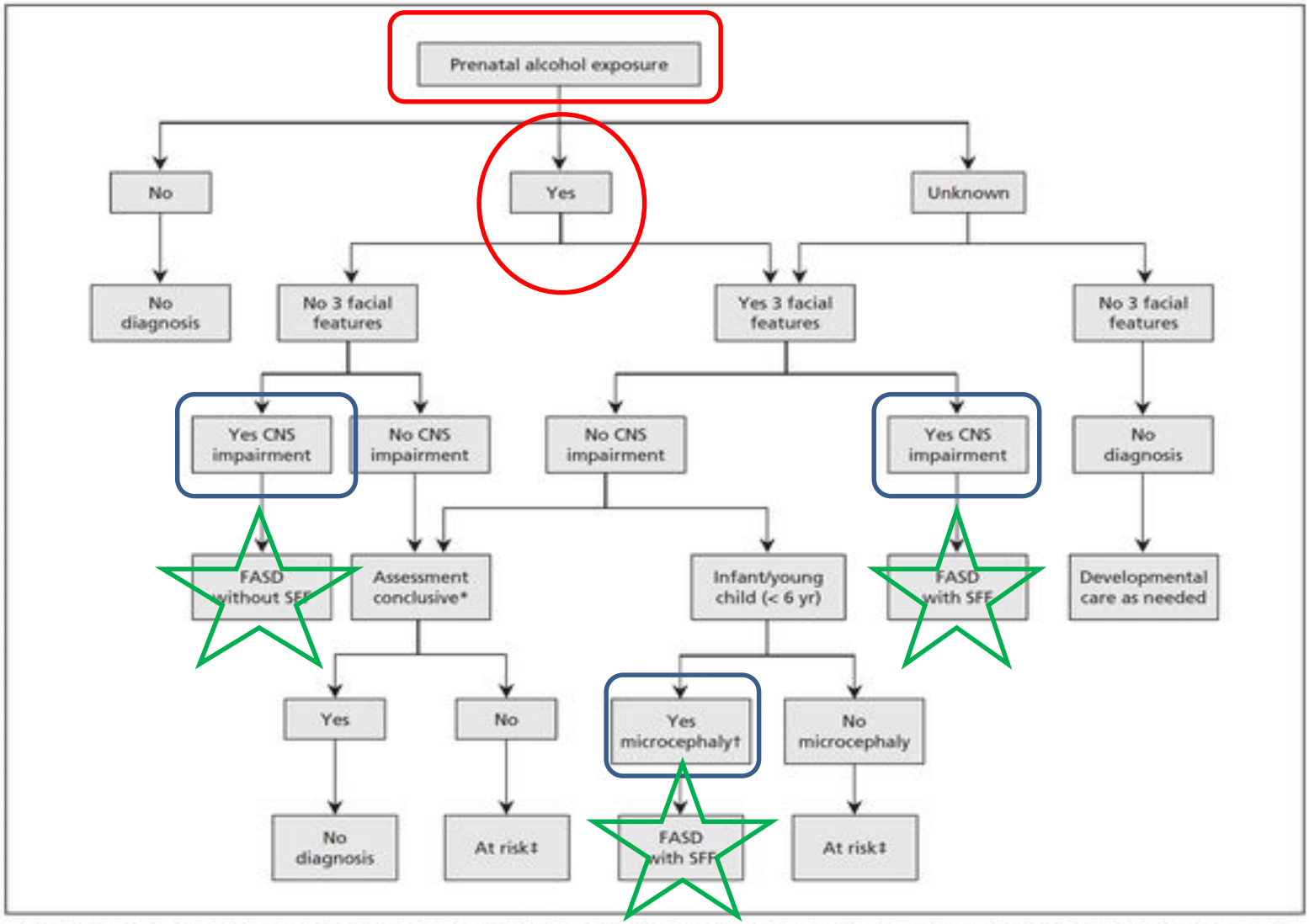

Figure 1: Diagnostic algorithm for fetal alcohol spectrum disorder (FASD). *Assessment conclusive = clinician conducting the neurodevelopmental assessment is satisfied that the session was a true representation of the person's ability and that any deficits reported were not due to extenuating circumstances. Assessments may be inconclusive for children under six years of age, because some domains cannot be assessed with confidence until the person is older or because of other confounding factors, such as temporary life stress or illness; see the text for more information. †Microcephaly is not the only pathway to diagnosis for infants and young children; these individuals may also receive other FASD diagnoses, as specified elsewhere in the algorithm, if they show three areas of substantial impairment on neurodevelopmental tests. ‡At risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure. An at-risk designation includes situations where a full neurodevelopmental assessment is not conclusive because of age or situational factors; therefore, FASD may not be the diagnosis. Clinical judgment is recommended. Note: CNS = central nervous system (yes/no impairment in ≥ 3 brain domains), SFF = sentinel facial features.

Conclusions…

- If the minimal PAE threshold were to be strictly applied to patients we diagnosed with FASD in the past 5 years there could potentially be a 73% drop in the FASD diagnoses we made

- We anticipate that our findings would be replicated in most other Canadian FASD diagnostic clinics.

- If clinicians (novice or experienced) were to diligently adhere to the minimal PAE threshold as suggested in the Guidelines, the incidence of new FASD diagnoses could drop dramatically.

Conclusions

- The Guidelines may need an addendum of caution and clarification
- We need the most clinically practical definition of PAE so as to not deny patients an appropriate diagnosis and needed services and supports.
- We need to develop more sensitive tools to obtain an accurate and detailed PAE history
- Until we have more sensitive tools to obtain an accurate and detailed PAE history or biomarkers for PAE…….

Conclusions…

How we define the threshold for PAE will have major implications for FASD diagnosis, epidemiology and ultimately patient care

Acknowledgements

- MSS Social workers

- Administrative staff at Child and Youth Services

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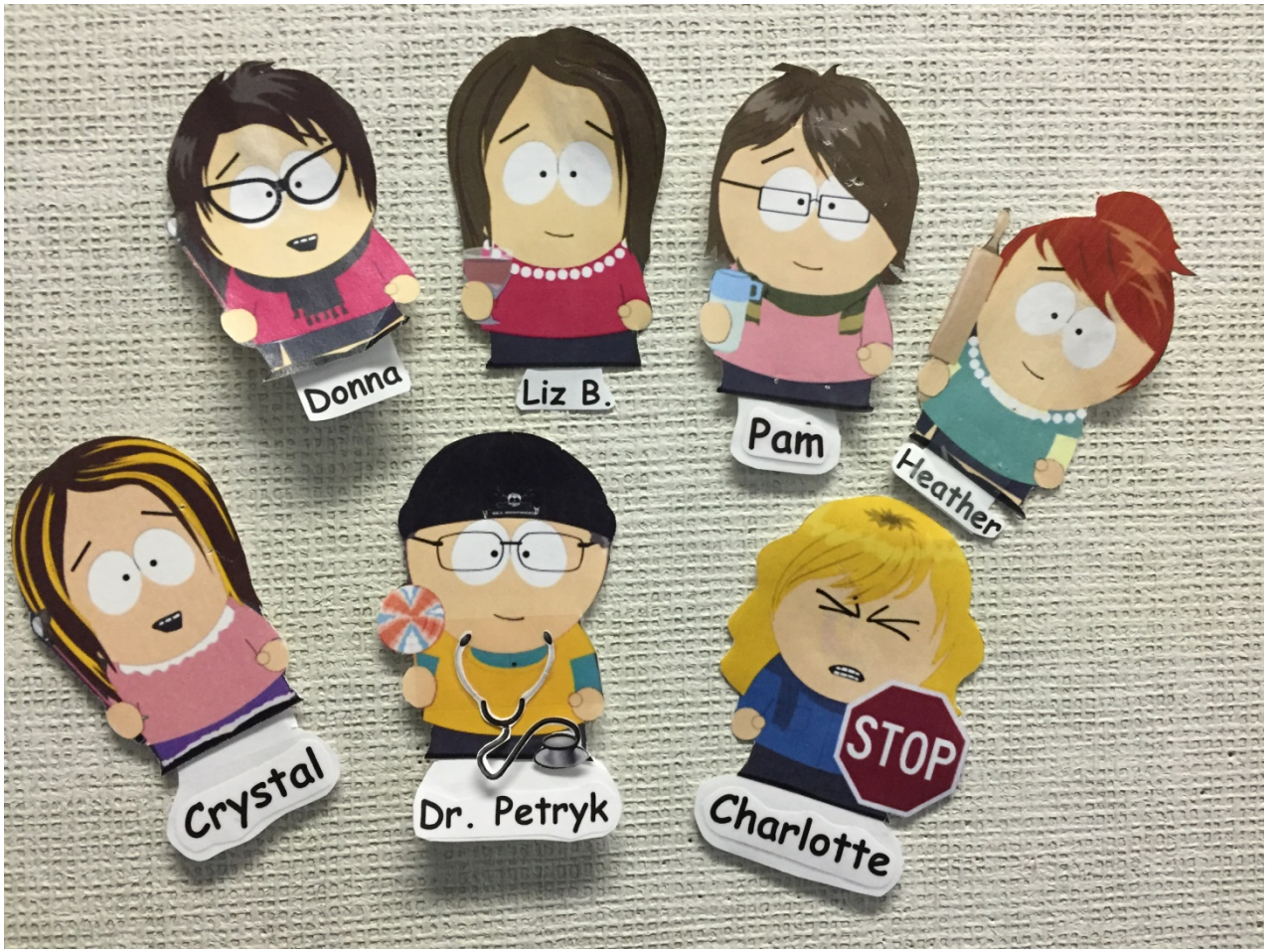
My diagnostic team

Complex Diagnosis Assessment Team (CDAT)



Questions?