

# Researching the Prevalence and Characteristics of FASD in International Settings

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IHE Consensus Development Conference on

**Fetal Alcohol Spectrum Disorder  
(FASD) – Across the Lifespan**

October 7 to 9, 2009, The Westin Edmonton, Edmonton, Alberta



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## Simple View of Causation: QFT and the Severity of Damage

- An individual child's traits of FASD are completely influenced by:

**Q**uantity (amount) of alcohol consumed by mother during pregnancy.

**F**requency (how often) that she drinks.

**T**iming of the drinking during gestation of the fetus.



## Blood Alcohol Concentration: Threshold for FAS or PFAS?

- Cannot be extrapolated to humans from animal models.
- Is limited by human research methods (e.g. clinical trials with pregnant women are not ethical).
- Is affected by other maternal traits (co-factors of risk).
- Varies greatly with each, individual human.



# It's Not That Simple

- There are a number of **co-factors**, exclusive of alcohol, that increase, mediate, or mitigate risk for FASD in a particular:
  - Child
  - Mother
  - Pregnancy
  - Community



# Some Known Co-Factors of Maternal Risk and Fetal Damage

## ***Biological:***

- Nutrition, life long and during index pregnancy.
- Body mass (BMI) and weight of the mother.
- Genetic - Alcohol metabolism, liver genotype, and liver phenotype.
- Race and Ethnicity

## ***Demographic, Childbearing, and Socio-cultural:***

- Maternal age, gravidity, parity, and birth order.
- Socioeconomic status (SES): including maternal education, income, and home environment.
- Spirituality/religiosity.
- Familial issues, psychological distress, and other traits.



# Peak BAC Levels of South African Women: Estimated from Interviews

Drinking Mothers of Children who are:

|                                 | <u>FAS</u>  | <u>PFAS</u> | <u>Controls</u> |
|---------------------------------|-------------|-------------|-----------------|
| <b>1<sup>st</sup> trimester</b> |             |             |                 |
| D.D.D. **                       | 5.7         | 3.9         | 3.8             |
| BAC (SD) ***                    | 0.197 (.17) | 0.155 (.07) | 0.122* (.11)    |
| <b>2<sup>nd</sup> trimester</b> |             |             |                 |
| D.D.D.                          | 5.7         | 3.2         | 3.7 *           |
| BAC (SD)                        | 0.200 (.17) | 0.124 (.09) | 0.084* (.09)    |
| <b>3<sup>rd</sup> trimester</b> |             |             |                 |
| D.D.D.                          | 5.5         | 2.7         | 3.7             |
| BAC (SD)                        | 0.191 (.17) | 0.102 (.12) | 0.076* (.09)    |

\*p < .05    \*\*D.D.D. = drinks per drinking day    \*\*\* BAC = grams per deciliter, estimated by BACCuS (w/ sex, wgt., quantity, duration)    Source: May et al., 2008



# Height, Weight, and Body Mass Index of South African Women

Mothers of Children with:

|                 | <u>FAS</u> | <u>PFAS</u> | <u>Controls</u> |
|-----------------|------------|-------------|-----------------|
| Height (cm.)    | 154.7      | 155.2       | 157.6*          |
| Weight (kg.)    | 53.9       | 56.7        | 68.3 *          |
| Head Cir. (cm.) | 54.8       | 54.9        | 54.9            |
| BMI             | 22.5       | 23.5        | 27.4*           |

Source: May et al., 2008

\*p <.001





South African Clinical Team, May, 2008

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**South African Clinical Research Team  
BRAM: March, 2009**

Core Prevention Research Field Team,  
South Africa, 2008



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# Three Major Methods for Studying the Prevalence of FAS and FASD

- Surveillance and Record Collection Systems:
  - Birth certificates, registries, & capture studies.
- Clinic-based studies:
  - Antenatal alcohol screens & dx. of newborns.
- Active Case Ascertainment studies:
  - Specialty referral clinics with active outreach.
  - In-school studies.



## Prevalence of **FAS** Produced by Various Methods (avg. per 1,000 children)

| Method  | n   | Mean | Median |
|---|-----|------|--------|
| Surveillance  | 15  | 0.85 | 0.27   |
| Clinic Based  | >50 | 1.8  | 1.9    |
| Active Case Ascertainment<br>(does not include in-school studies) | 8   | 15.6 | 8.5    |





## Prevalence of **FASD** Produced by Various Methods (avg. per 1,000 children)

| Method   | n | Mean           | Median         |
|--|---|----------------|----------------|
| Surveillance   | 0 | ---            | ---            |
| Clinic Based   | 3 | 6.2<br>(0.6%)  | 4.8<br>(0.5%)  |
| Active Case Ascertainment<br>(excluding in-school studies) | 8 | 38.2<br>(3.8%) | 19.0<br>(1.9%) |



## Most Quoted **Current** Estimates of FAS and FASD

| Diagnosis   | Per 1,000 | Per Cent    | Source  |
|-------------|-----------|-------------|---|
| <b>FAS</b>  | 0.5 – 2.0 | 0.05 - 0.2% | May & Gossage, 2001<br>(Literature review)    |
| <b>FAS</b>  | 0.5 – 3.0 | 0.05 - 0.3% | Stratton, et al., 1996<br>(avg. –IOM Report)  |
| <b>FASD</b> | 9.1       | 1%          | Sampson, et al., 1997<br>(clinic-based study) |



## In-School Prevalence Studies

- Provide access for a team of specialists to a general population of children.
- Children in first grade are at an optimal stage of life (6-7 years) for an accurate diagnosis within the realm of FASD.
  - Dysmorphology and growth are well known and documented.
  - Solid neurobehavioral tests apply.
  - Retrospective maternal interviews are less stressful and are more accurate (TLFB methods).
  - Early identification makes early intervention possible
- Active consent from parents can be an obstacle.





Italy, 2005

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**FASER – Italia, 2005**







Italy, 2006

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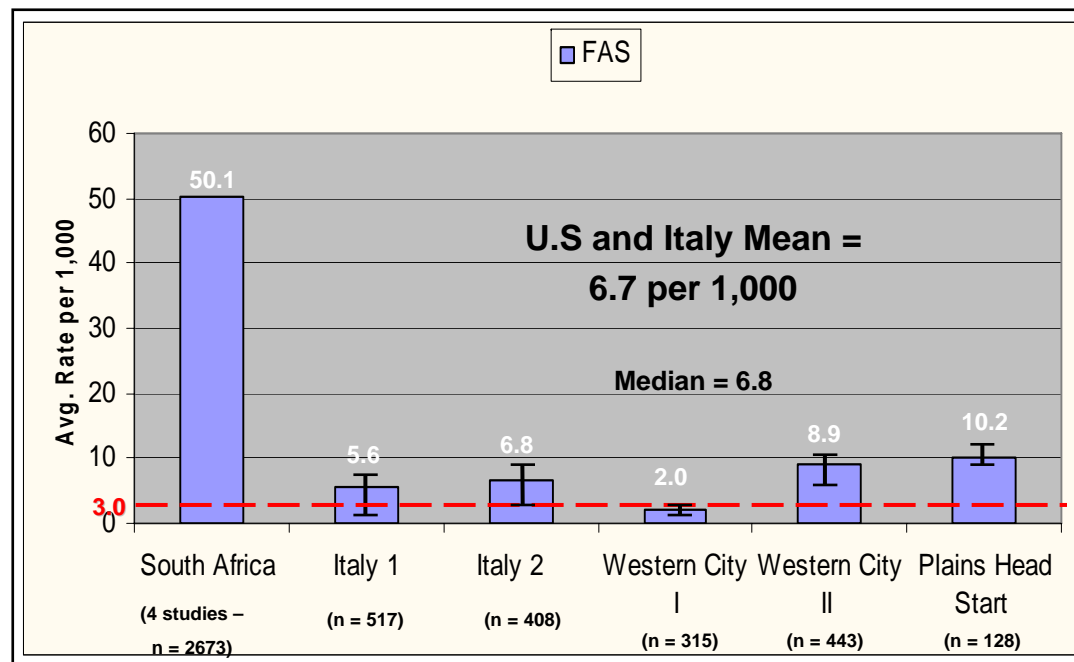


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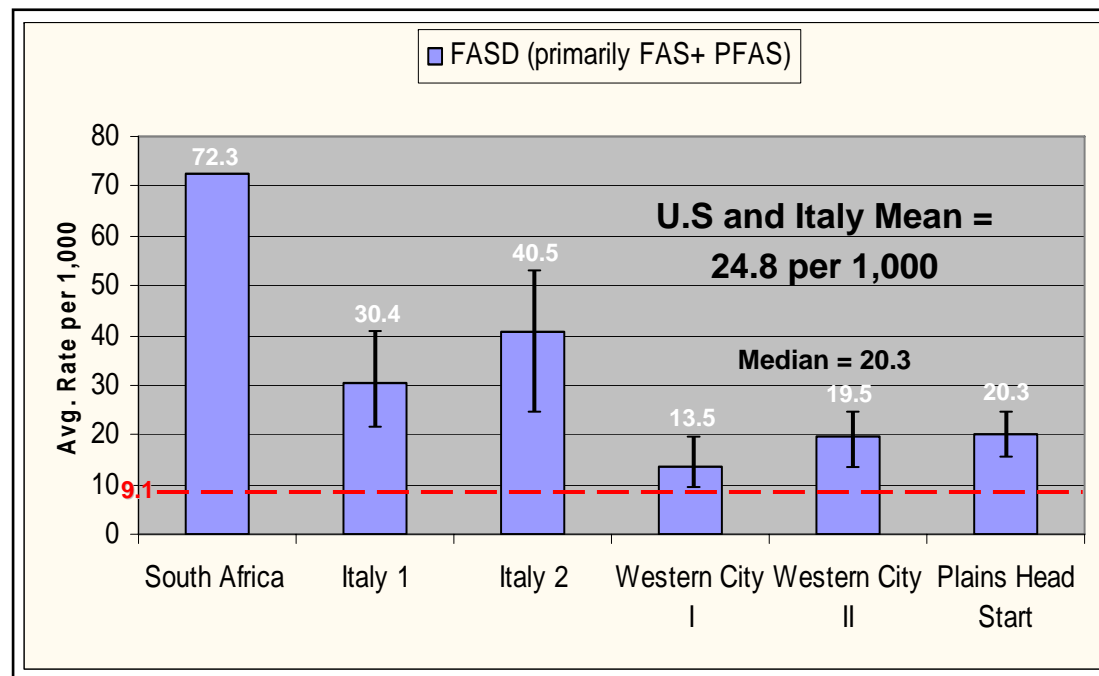
## Prevalence of FAS from In-School Studies



Source: May et al., DDRR, 2009.



## Prevalence of FASD from In-School Studies



Source: May et al., DDRR, 2009.



# New General Population Prevalence Estimates of FASD: In-School Studies

Estimates per 1,000:

|             | <u>Current</u> | <u>In-school</u> |
|-------------|----------------|------------------|
| <b>FAS</b>  | 0.5 – 3.0      | 2.0 – 7.0        |
| <b>FASD</b> | 9.1 (1%)       | 20 – 50 (2-5%)   |

Source: May et al., DDDR, 2009.



# Is This a Substantial Public Health Problem? Background

- I was a skeptic of high rates of FASD in the first part of my career.
- Even with active case ascertainment studies using referral to special clinics, many cases of FASD are missed, especially those not meeting growth criteria.
- In-school studies take specialists to the general population look for cases of FASD.
- **Yes**, it is a larger problem than many of us expected.



# Why Are We Not Doing More Research in Human Populations?

- Public health is often lost in the zeal for specific FASD research and solutions that are reductionist in nature (“magic bullets”).
- The search for etiology often overpowers practical, basic considerations like the prevalence and characteristics of FASD.
- Most people don’t want to look for the problem.
- Stigma makes everyone ultra sensitive and uncomfortable.





USA Team with Three Italian Colleagues, 2007



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# Conclusions

- If we don't actively seek FASD cases, we won't find the majority of them, especially the less severe cases.
- FASD is the leading cause of mental deficiency in many modern societies.





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