



THE PATH TO SOCIAL CHANGE IN FASD

PETER W CHOATE

SOCIAL WORK

CHRISTINE A LOOCK

PEDIATRICS



ASSOCIATE PROFESSORS



“FAS is the tip of the iceberg.”

-Ann Streissguth



CHANGING OUR PERSPECTIVE

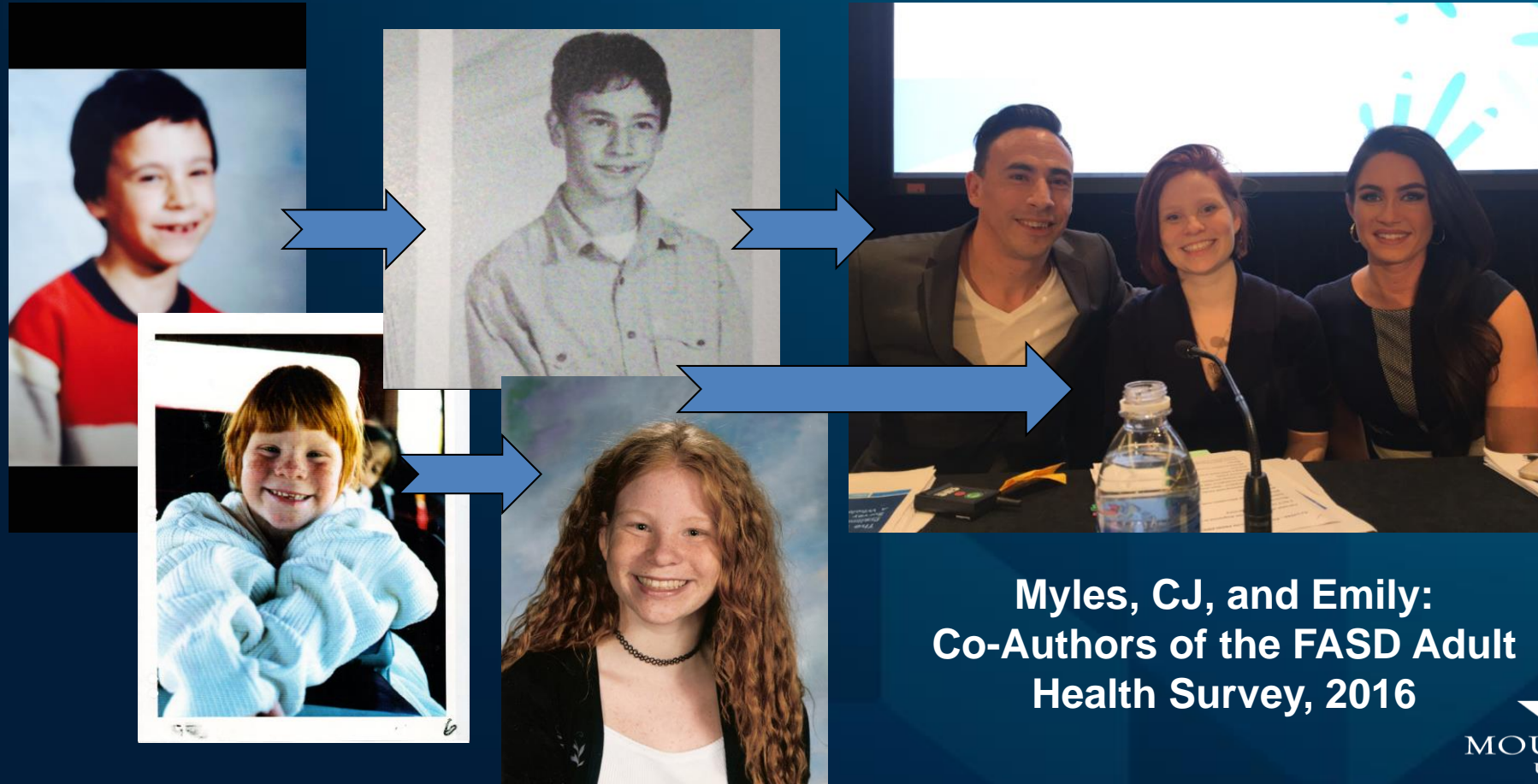


OVER the PAST 40 YEARS



**“FASD is a whole body lifelong condition. ...
We need support as adults too”.**

Pediatrics & Adolescents

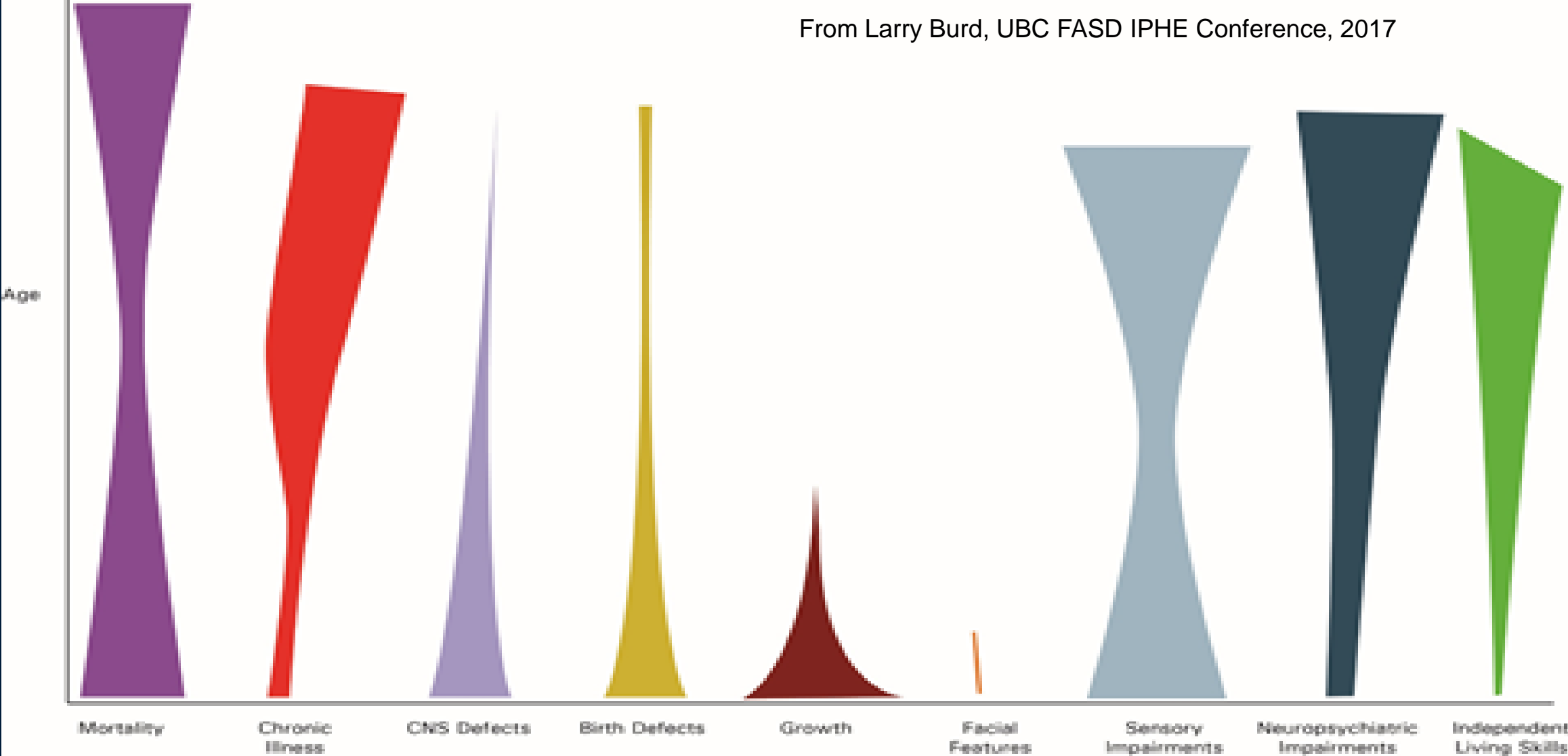


**Myles, CJ, and Emily:
Co-Authors of the FASD Adult
Health Survey, 2016**






FASD Phenotype

From Larry Burd, UBC FASD IPHE Conference, 2017



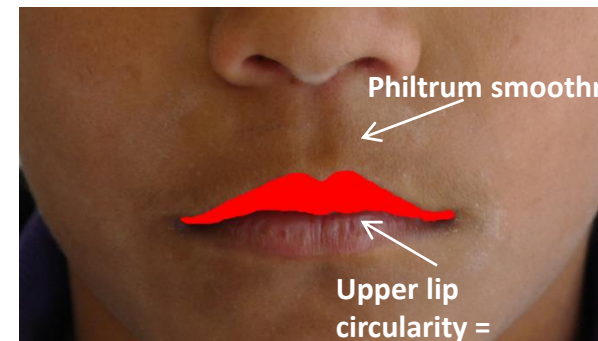
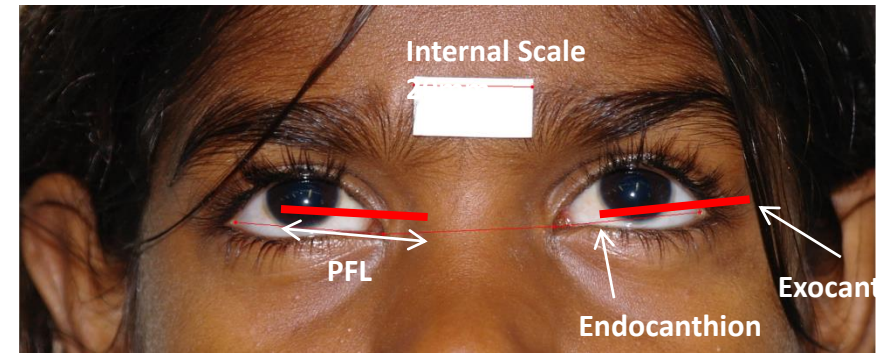
“Harmonizing” how we describe FAS & FASD

Common Diagnostic Algorithms

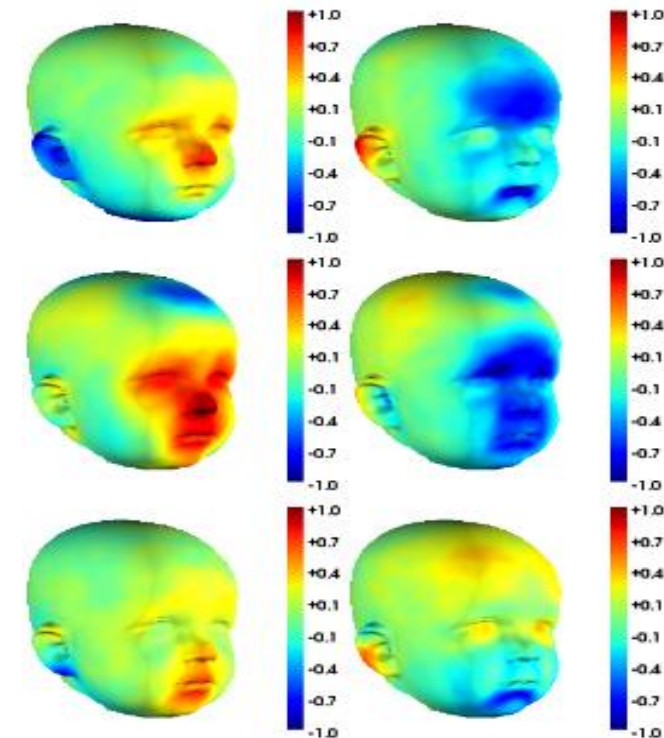
- FAS  (FASD with 3FF)
- Partial FAS 
- ARND  (FASD with <3 FF)
- ARBD

DSM-5 315.8 Neurodevelopmental disorder associated with prenatal alcohol exposure

ICD-11 (ICD-10-CM Q86.0 Fetal alcohol syndrome (dysmorphic))



Astley facial Dx software



Muggli JAMA Pediatrics

Harmonizing our global approach to classification

Reframing FASD:

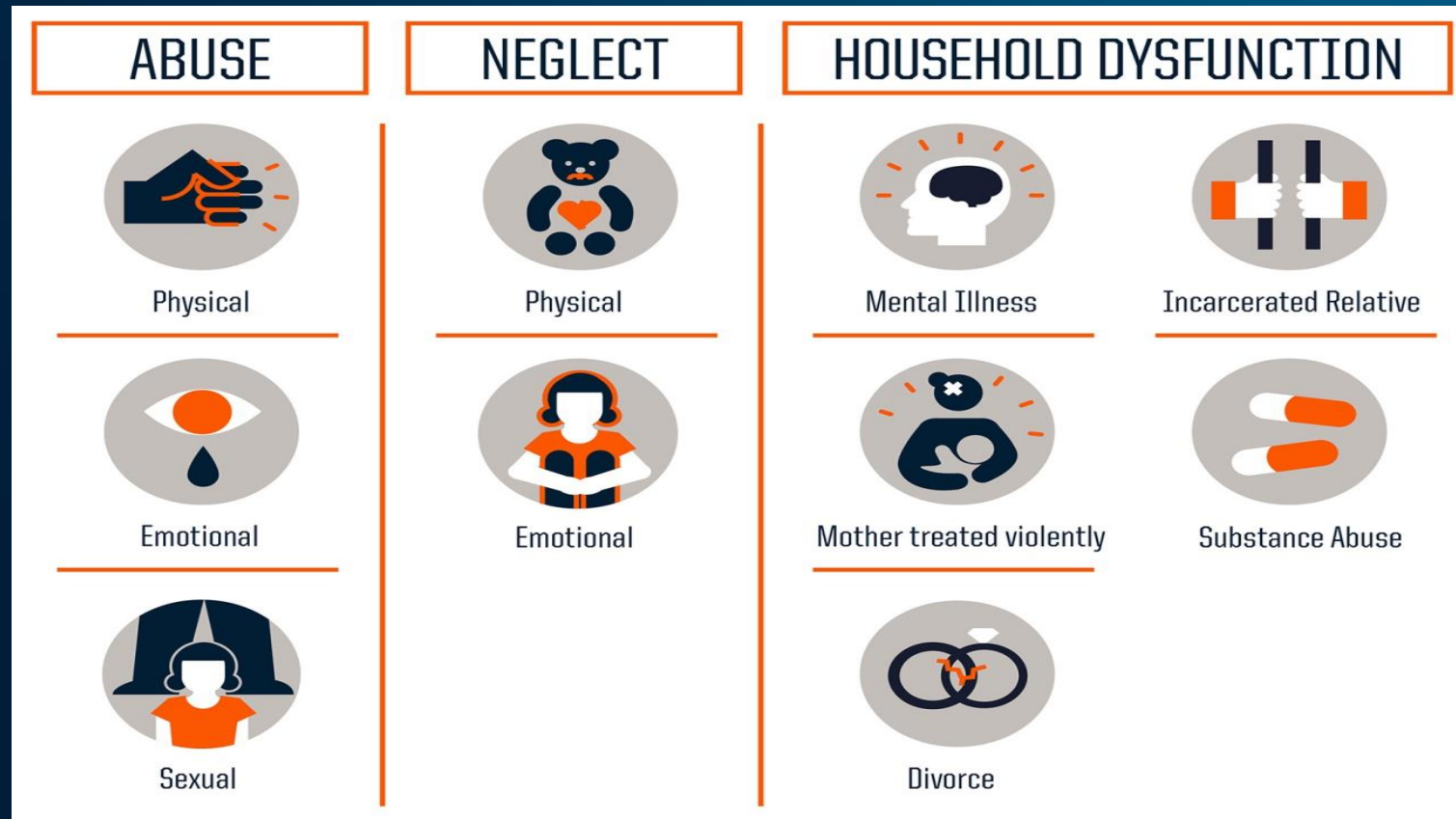
*“Fetal alcohol spectrum disorder (FASD) can result from exposure to alcohol during pregnancy. Whether or not alcohol exposure leads to FASD depends on a **complex set of biological and social factors that interact in different ways for each person.** Biological factors can include a woman’s sensitivity to alcohol, metabolism, and size. **Social factors like chronic stress, violence, trauma, or poverty can increase the chances that a baby might be born with FASD.**”*



From Fond, M., Kendall-Taylor, N., Volmert, A., Gerstein Pineau, M., & L’Hôte, E. (2017). Seeing the spectrum: Mapping the gaps between expert and public understandings of fetal alcohol spectrum disorder in Manitoba. Washington, DC: FrameWorks Institute.



Adverse Childhood Experiences: ACEs



WHAT IMPACT DO ACEs HAVE?

As the number of ACEs increases, so does the risk for negative health outcomes



Possible Risk Outcomes:

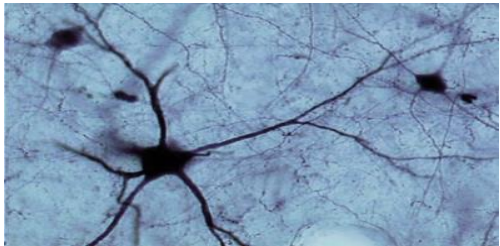
BEHAVIOR				
 Lack of physical activity	 Smoking	 Alcoholism	 Drug use	 Missed work
PHYSICAL & MENTAL HEALTH				
 Severe obesity	 Diabetes	 Depression	 Suicide attempts	 STDs
 Heart disease	 Cancer	 Stroke	 COPD	 Broken bones

Developmental Origins of Health and Disease

Exposure to adverse early pre-/postnatal environment can have lasting effects on physiology and risk for disease



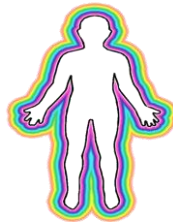
Genotype



Developmental Plasticity/trajectory



Adult Phenotype



Intrauterine environment:

- Alcohol
- Stress
- Chemicals
- Under nutrition
- Glucocorticoid exposure



Chronic diseases:

- Cardiovascular disease
- Type 2 diabetes
- Hypertension
- Mental health disorders
- Immune-related disorders



Applying ACE Scores to the Experiences of Youth with FASD

Comparison with Kaiser ACE Study Participants (Julie Conry et al)

Majority of youth with FASD had 4 or more ACES (4.8). Only 1 had no score. The coding did not capture the extent of trauma or intergenerational trauma experienced by many of these youth and their families of origin.

ACE Item	ACE Study %	FASD %
Physical abuse	26	54
Emotional abuse	10	48.6
Sexual abuse	21	48.6
Alcohol/drug abuse in household	28	78.4
Incarcerated family member	6	13.5
Family member with mental illness	20	37.8
Mother treated violently	13	40.5
Only one, or no parents	24	94.6
Emotional or physical neglect	10-15	56.8

Changing the Social Determinants & Health Equity

Healthy Public Policy:

- (1) Best start (0-6 years)
- (2) Maximize potential (youth)
- (3) Strengthen public health- obesity, smoking, alcohol
- (4) Good work for all
- (5) Healthy standard of living
- (6) Sustainable communities



“Enable all children, young people and adults to maximize their capabilities and have control over their lives.”

— Michael Marmot



Resiliency = Social Capital

**Trust
Relationships
Continuity of Care**



“Every child needs to be good at something.” – Edith Wilcock Look, RN

“Get a good education, marry well, stay interested.” – Carl J. Look with Jesse Owens





CHANGING THE WAYS WE WORK:

OUR SOCIAL PEDIATRICS RICHER MODEL & REALIST SYNTHESIS

“Linking In & Linking Across”

Loock, Lynam, Tyler et al 2018, in progress

1. Shared vision & values
2. Horizontal Relationships: Shared status & power
3. Knowledge Support: Inter-professional practice & training
4. Bridging Trust: Engagement, relationships & responsiveness
5. Empowerment of families & community
6. Accountability & evidence

HAS CHANGE BEEN SUCCESSFUL?

- **PREVELANCE RATES SAY NO!**
- **Conclusions and Relevance** Estimated prevalence of fetal alcohol spectrum disorders among first-graders in 4 US communities ranged from 1.1% to 5.0% using a conservative approach. These findings may represent more accurate US prevalence estimates than previous studies but may not be generalizable to all communities.
 - [May et al., 2018](#)



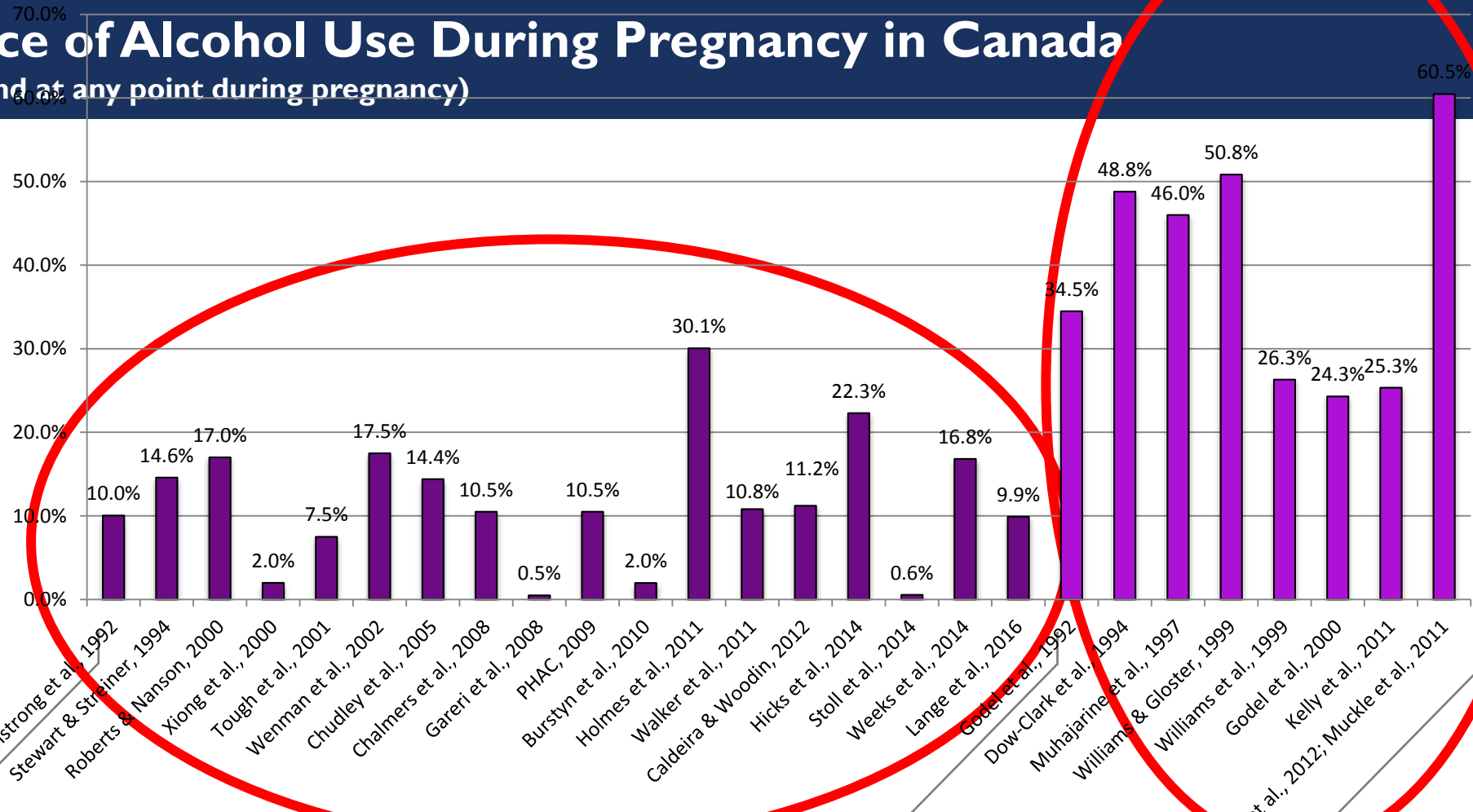
- This study provides the first population-based estimate of the prevalence of FASD among elementary school students (aged 7 to 9 years) in Canada. The estimate is approximately double or possibly even triple previous crude estimates
 - Popova et al., 2018



Prevalence of Alcohol Use During Pregnancy in Canada

(any amount, and at any point during pregnancy)

UBC, T-ACE
Screen
Population
Data, British
Columbia



From S. Popova, 2017

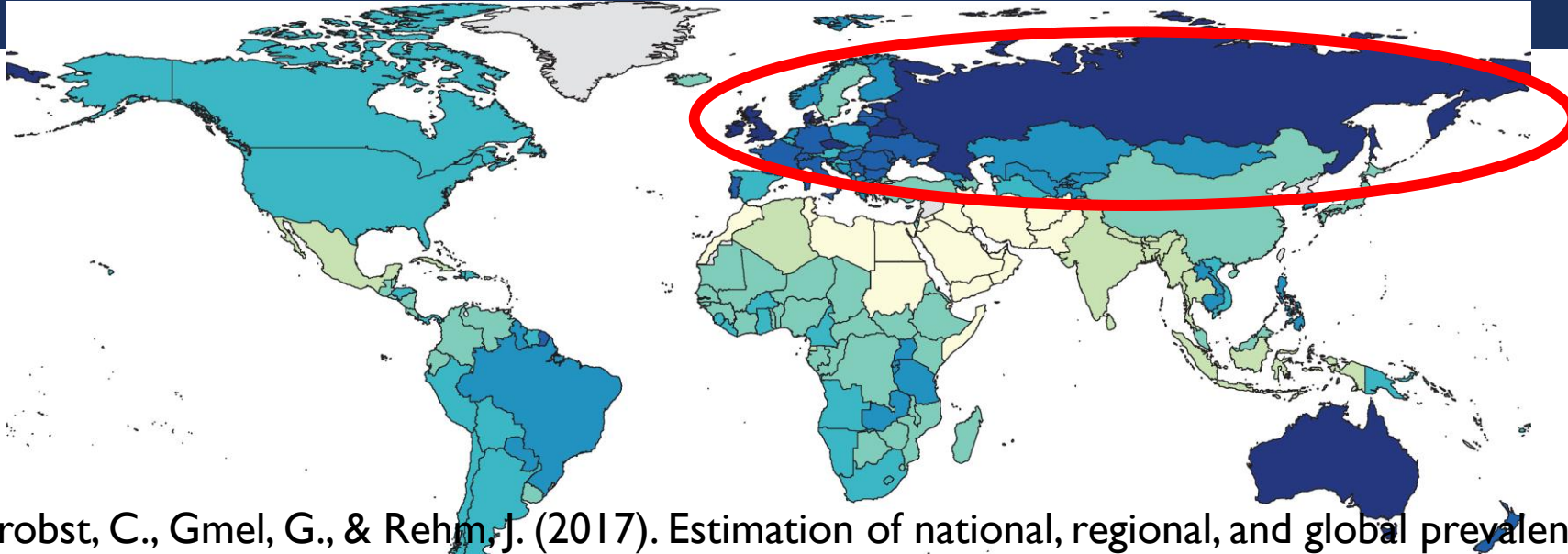
General Population
(Range: 0.5% to 30.1%)

Northern Communities
(Range: 24.3% to 60.5%)



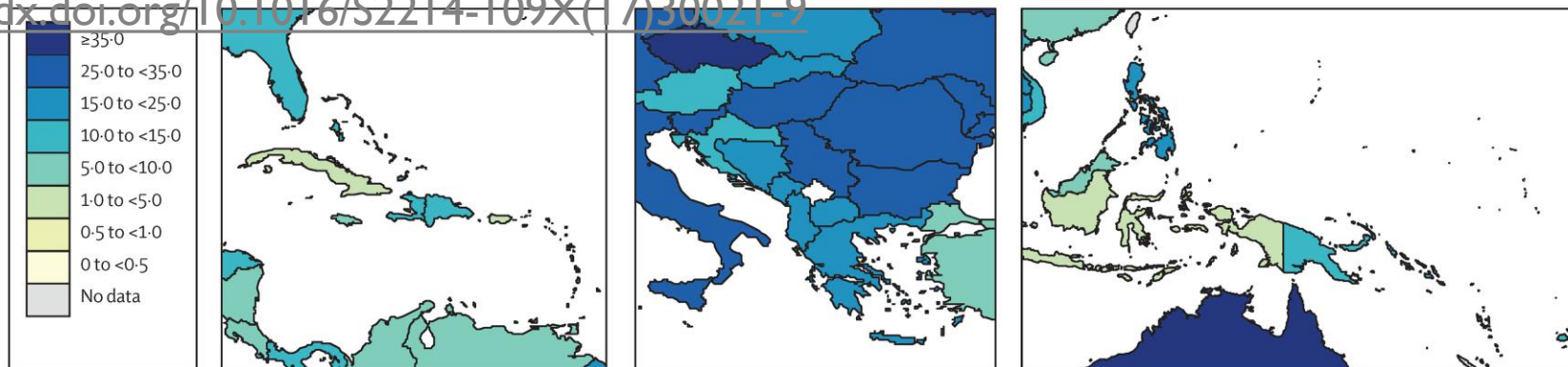
Centre
for Addiction and
Mental Health
Centre de
toxicomanie et
de santé mentale

POPOVA, ET AL (2017) GLOBAL PREVALENCE (%) OF ALCOHOL USE (ANY AMOUNT) DURING PREGNANCY AMONG THE GENERAL POPULATION IN 2012

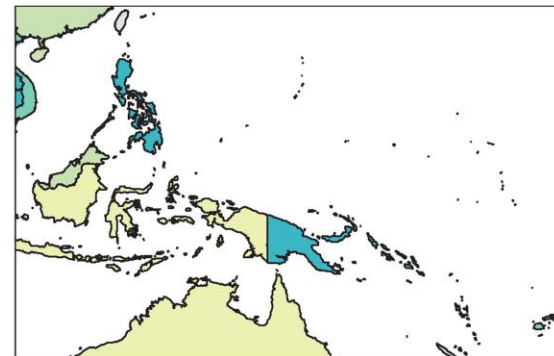
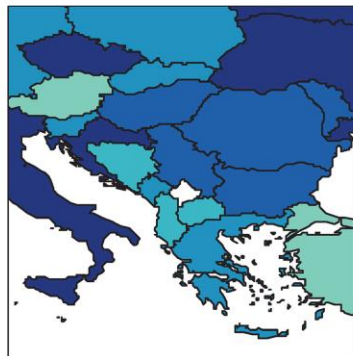
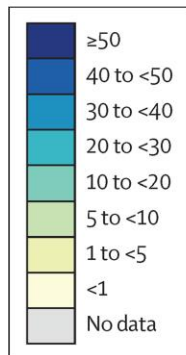
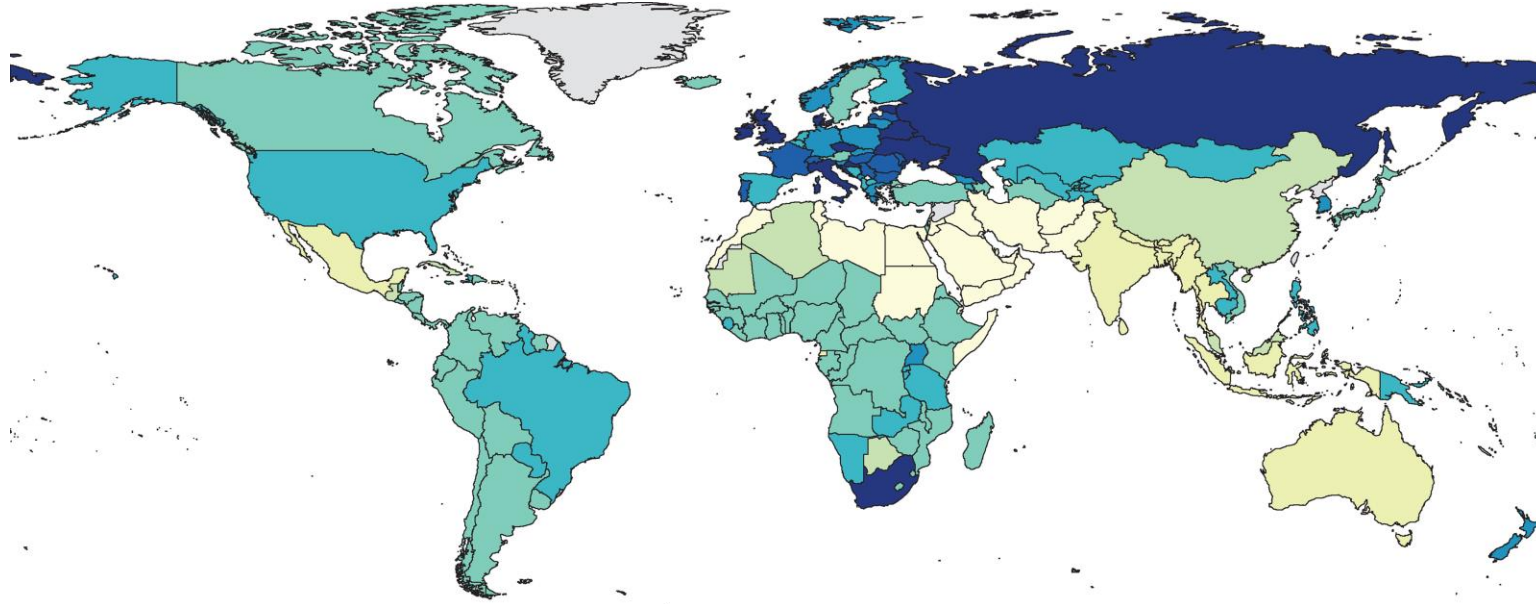


Popova, S., Lange, S., Probst, C., Gmel, G., & Rehm, J. (2017). Estimation of national, regional, and global prevalence of alcohol use during pregnancy and fetal alcohol syndrome: a systematic review and meta-analysis. *The Lancet Global Health*, 5(3), e290–e299.

Available from: [http://dx.doi.org/10.1016/S2214-109X\(17\)30021-9](http://dx.doi.org/10.1016/S2214-109X(17)30021-9)



POPOVA, ET AL, 2017, GLOBAL PREVALENCE OF FAS AMONG THE GENERAL POPULATION IN 2012

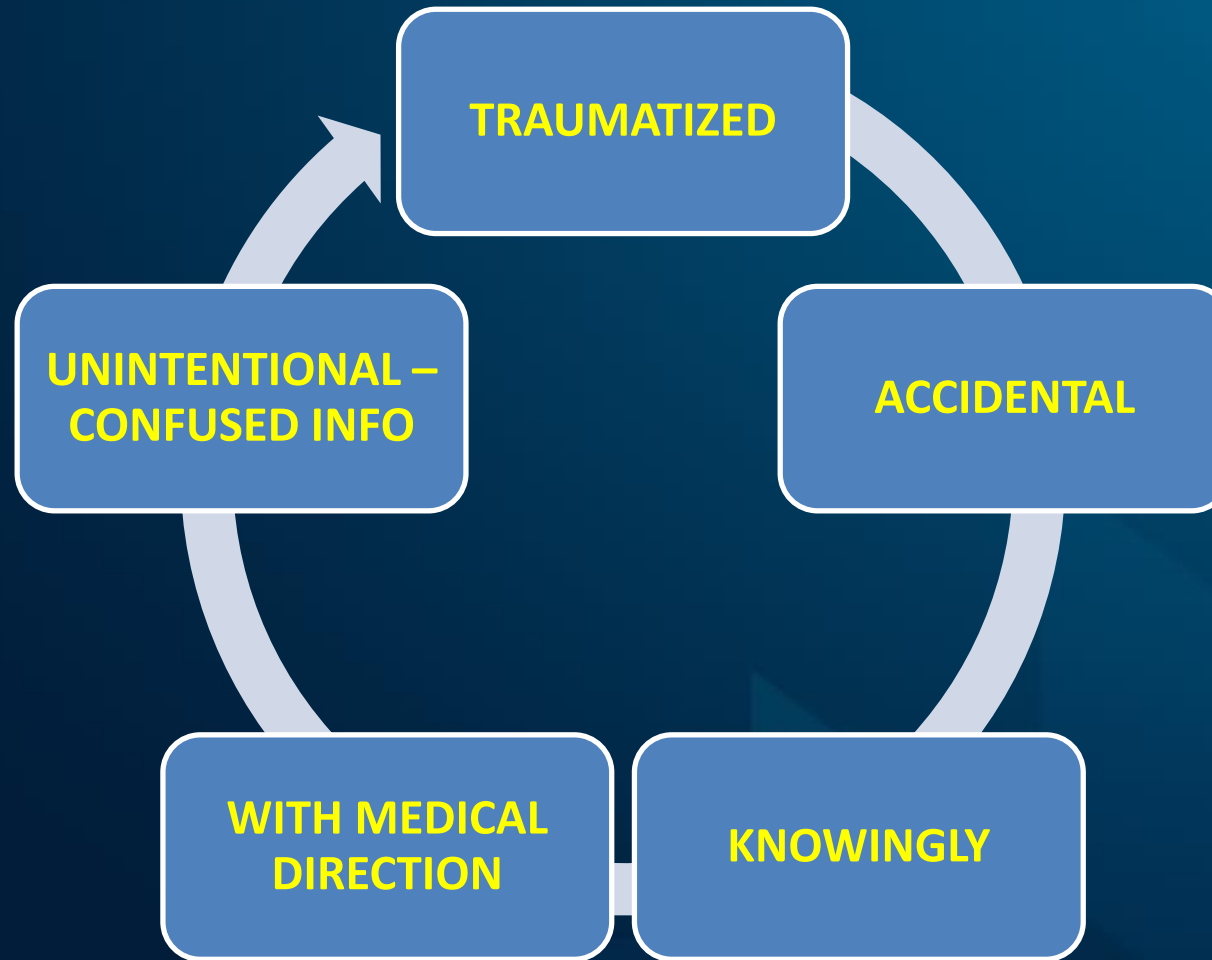


WHY?

- BUILDING THE WRONG BRIDGES
- SEEING THE PROBLEM IN ONE WAY
- SEEKING SOLUTIONS THAT DON'T SPEAK TO THE RIGHT PEOPLE



WHO HAS CHILDREN WITH FASD?



**PRECURSOR
TRAUMA**

**ACES BEFORE IN
AND AFTER
PREGNANCY**

**INTER
GENERATIONAL
TRANSMISSION**



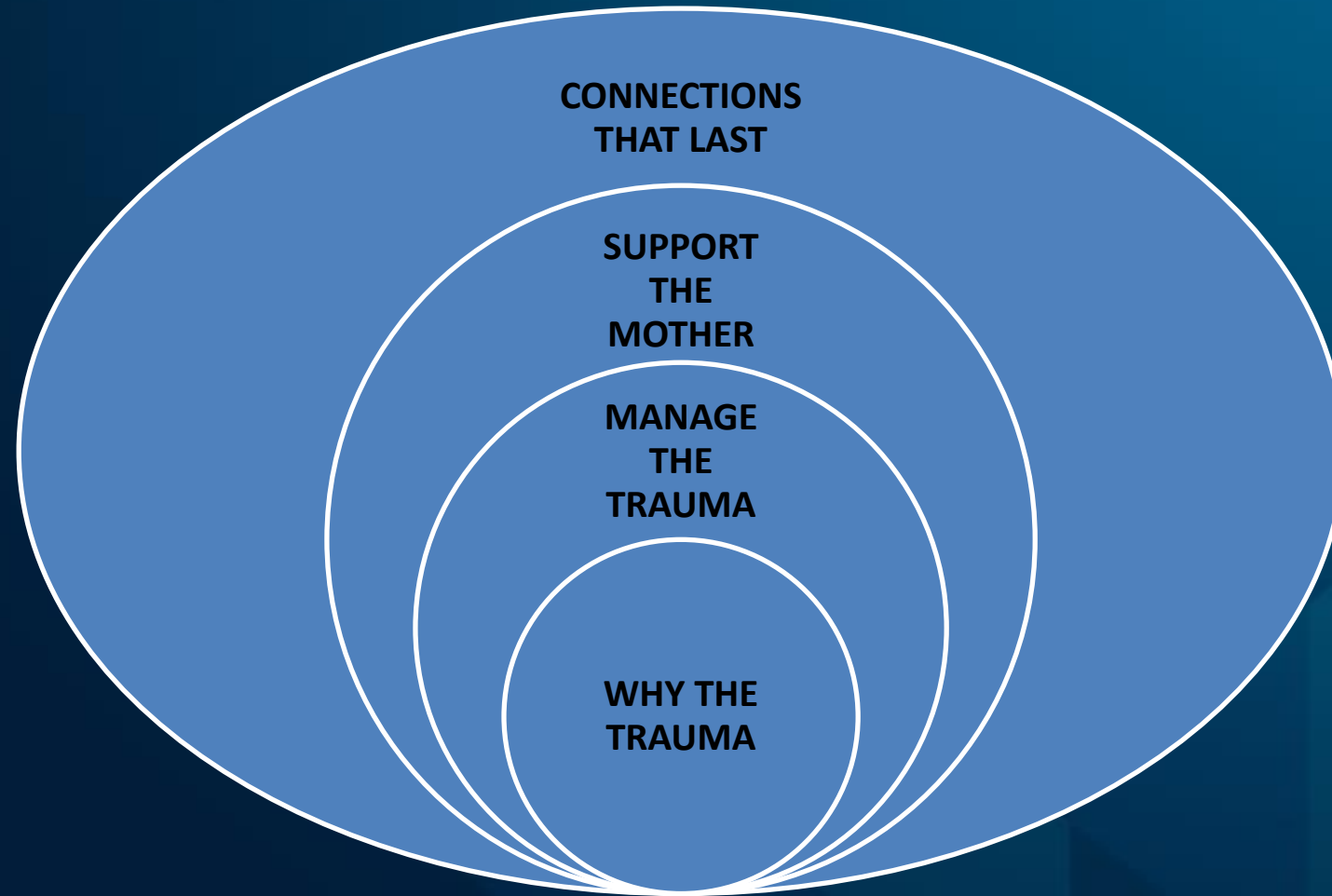
FASD AS A RESPONSE



- **THINK OF FASD AS AN OUTCOME NOT A PRIMARY RESPONSE**
- **WHAT UNDERLIES – TRAUMA**
 - PERSONAL
 - INTER-PERSONAL
 - INTRA-PERSONAL
 - INTER-GENERATIONAL



PREVENTION



DIALOGUE SHIFT

- **WHAT HAS THE SCIENCE SHOWN US TODAY?**
- **CAN WE STEP AWAY FROM 'JUST SAY NO'?**
- **CAN WE STEP INTO THE LIVED EXPERIENCES OF *PEOPLE EXPERIENCING FASD AND LIVING?***
- **CAN WE WORK WITH HARM REDUCTION?**
- **CAN WE ACCEPT A PERSON WITH FASD AS A WHOLE PERSON?**



- **CAN WE STOP BEING THE EXPERTS AND START LISTENING TO THOSE WHO ARE THE EXPERTS IN THE SOCIAL EXPERIENCE?**
- **CAPACITY VIEW IS NOT REDUCING THE PERSON TO THE UNIDIMENSIONAL VIEW OF FASD FROM WHICH ALL THINGS FLOW**





**IF WE ARE NOT
THE CHANGE
AGENTS, THEN
WE NEED TO
GET OUT OF THE
WAY FOR THOSE
WHO ARE**



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