THE PATH TO SOCIAL CHANGE IN FASD

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“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”.

Myles, CJ, and Emily: Co-Authors of the FASD Adult Health Survey, 2016
Taking a Lifespan Perspective

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))

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.”

Adverse Childhood Experiences: ACEs

**ABUSE**
- Physical
- Emotional
- Sexual

**NEGLECT**
- Physical
- Emotional

**HOUSEHOLD DYSFUNCTION**
- Mental Illness
- Incarcerated Relative
- Mother treated violently
- Substance Abuse
- Divorce
WHAT IMPACT DO ACEs HAVE?

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

Risk:

- 0 ACEs
- 1 ACE
- 2 ACEs
- 3 ACEs
- 4+ ACEs

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

Slide adapted from Dr. Ni Lan and Dr. Joanne Weinberg
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.

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

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 Loock, RN

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

CHANGING THE WAYS WE WORK:
OUR SOCIAL PEDIATRICS RICHER MODEL & REALIST SYNTHESIS
“Linking In & Linking Across”

Loock, Lynam, Tyler et al 2018, in progress
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)

General Population
(Range: 0.5% to 30.1%)

Northern Communities
(Range: 24.3% to 60.5%)

From S. Popova, 2017
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?

TRAUMATIZED

UNINTENTIONAL – CONFUSED INFO

WITH MEDICAL DIRECTION

KNOWINGLY

ACCIDENTAL
PRECURSOR TRAUMA

ACES BEFORE IN AND AFTER PREGNANCY

INTERGENERATIONAL 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

CONNECTIONS THAT LAST

SUPPORT THE MOTHER

MANAGE THE TRAUMA

WHY THE TRAUMA
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