

## Improving Outcomes for Children with Fetal Alcohol Spectrum Disorders

### Understanding Stigma and Adopting the Neurodevelopmental Lens

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1

How will understanding more about FASDs assist me in my work with families and young children?

How does stigma interfere with increasing FASD awareness, identifying, and supporting families and children with FASDs?

How would having an FASD-informed approach help me in supporting caregivers and children with FASD?

What resources and supports are there to help families and children with FASD improve their functioning?



2

## FASD Presentation Agenda

- Overview of Fetal Alcohol Spectrum Disorders
- Primary characteristics of children with FASD
- Adopting an FASD-informed approach to effectively support children with FASD
- Understanding how FASD Stigma impacts awareness, identification, and support
- Improving outcomes through increasing protective factors (early identification and stable, nurturing homes)
- Adopting the Neurodevelopmental Lens - Reframing attitudes and feelings towards children with FASD
- Supporting use of Positive Support Strategies and Accommodations to provide support to children in the school and home



3

## Alcohol = Teratogen

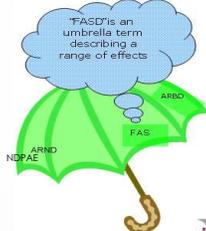
- A teratogen is a substance that is toxic to a developing baby and can interfere with healthy development causing brain damage and other birth defects.
- *"Of all the substances of abuse (including cocaine, heroin, and marijuana), alcohol produces by far the most serious neurobehavioral effects in the fetus resulting in life-long permanent disorders of memory, impulse control, and judgment."*  
Institute of Medicine Report to Congress, 1996
- No type of alcohol or illicit drugs consumed during pregnancy are completely without risk.



4

## FASD Terminology

- Fetal Alcohol Syndrome (FAS)
- Alcohol-Related Birth Defects (ARBD)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Fetal Alcohol Spectrum Disorders (FASD)
- **DSM V** – Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure (NDPAE)




5

## FASD Prevalence vs Other Disabilities

• Muscular Dystrophy	0.001%
• Spina Bifida	0.001%
• Down Syndrome	0.12%
• FAS	0.6 -0.9%
• Autism	1.8% (or 1 in 54) CDC (2020)
• FASD (Gen Pop.)	1.1% - 5% (using conservative approach) May et al., (2018) US data
• FAS and FASD (Foster Care)	4% and 16.9% Lange et al. (2013) Canadian data
• FASD in Special Populations (foster care, corrections, special ed, Aboriginal pop)	10 to 40 times higher than general population Popova et al. (2019)



6

### University of Washington 4-Digit Diagnostic Code

Astley (2011)

Growth Deficiency	<ul style="list-style-type: none"> <li>Rank 1 to 4</li> <li>Height, weight, head circumference</li> </ul>
Facial Features	<ul style="list-style-type: none"> <li>Rank 1 to 4</li> <li>Palpebral fissures, philtrum, upper lip</li> </ul>
CNS Damage	<ul style="list-style-type: none"> <li>Rank 4 Medical dx (seizures, microcephaly)</li> <li>Rank 2-3 Neurodevelopmental deficits</li> <li>Rank 1 No evidence</li> </ul>
Prenatal Alcohol History	<ul style="list-style-type: none"> <li>Rank 4-3 Positive alcohol exposure</li> <li>Rank 2 Unknown (most cases)</li> <li>Rank 1 No alcohol exposure</li> </ul>



7

### Example of a Child Diagnosed with FASD using the 4-digit code

4-Digit Diagnostic Code Grid

One Example of FAS

			3	4	4	4	
significant	significant	definite	4	X	X	X	high risk
moderate	moderate	probable	3	X			some risk
mild	mild	possible	2				unknown
none	none	unlikely	1				no risk
Growth Deficiency	FAS Facial Features	Brain Dysfunction	Growth	Face	Brain	Alcohol	Gestational Alcohol



8

### Facial Characteristics

- Short palpebral fissures (small eye width)
- Indistinct philtrum
- Thin upper lip
- Flat midface
- Minor ear anomalies
- Short, upturned nose
- Receding chin, underbite




9

### But remember. . . .

- Only a **small percentage** of children with Prenatal Alcohol Exposure (PAE) will present with facial features
- Most children with PAE have **no** classic facial features



10

### Alcohol and Pregnancy

- Any amount of alcohol, even the alcohol in one glass of wine, passes through the placenta from the mother to the growing baby.
- Developing babies lack the ability to process or metabolize alcohol through the liver or other organs. The embryo or fetus has the same blood alcohol concentration as the mother.
- It makes no difference if the alcoholic drink consumed is a beer, glass of wine or a distilled spirit or liquor such as vodka.




11

### How is the developing brain affected by prenatal alcohol exposure?



12

## Brain Structures Affected by Prenatal Alcohol Exposure

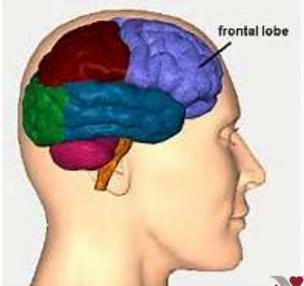



13

## Frontal Lobe

**Executive Functions**

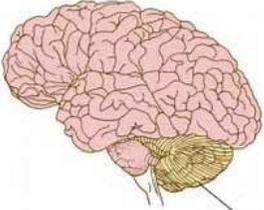
- Attention
- Memory
- Impulse control
- Judgment
- Planning
- Problem solving
- Self monitoring




14

## Cerebellum

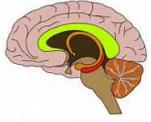
- Controls balance, coordination, movement
- Impacts learning and cognitive skills




15

## Corpus Callosum

- Passes information from left brain (rules, logic) to right brain (impulses, feelings) and vice versa
- Related to attention deficits
- Abstract reasoning
- Psychosocial functioning




16

## Brain Structures in the Limbic System

**Limbic System**

**Hypothalamus**

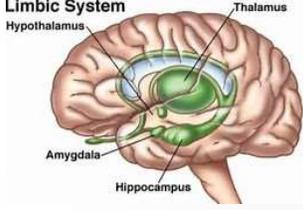
- Controls appetite, emotions, temperature, pain

**Amygdala**

- Central part of emotional circuitry
- Social behavior, aggression, emotional memory

**Hippocampus**

- Verbal memory affected
- Damage can cause stress, anxiety, depression




17

## How does brain damage from PAE relate to the behaviors/symptoms seen in children with FASD?



18

## Primary CNS Disabilities

<ul style="list-style-type: none"> <li>Developmental Delays (speech, fine &amp; gross motor)</li> <li>Sensory Processing Problems</li> </ul>	<ul style="list-style-type: none"> <li>Learning Disabilities</li> <li>Cognitive Delays</li> <li>Memory Impairments</li> </ul>
<ul style="list-style-type: none"> <li>Literal Thinking</li> <li>Social Skill Deficits</li> <li>Perseveration</li> <li>Can't Generalize</li> </ul>	<ul style="list-style-type: none"> <li>Impulsive</li> <li>Poor judgment</li> <li>Disorganized</li> <li>Poor Problem Solving</li> </ul>



19

## Secondary Disabilities

Streissguth (2004)

- School problems/failure
- Mental health problems
- Social problems/Negative peer group association
- Substance abuse
- Risky sexual behaviors
- Legal/criminal problems
- Difficulty w/employment
- Difficulty w/independent living




20

## Protective Factors

Streissguth (2004)

- Being diagnosed at early age (<6 years)
- Living in stable, nurturing home for 72% of life



21

## Stigma is a Major Barrier to the Goals of . . .

- Preventing prenatal alcohol exposure

AND

- Identifying and Helping individuals living with FASD




22

## FASD and Stigma

- Do people affected by FASD get treated differently (in a negative way) than other children and families??
- Do birth mothers of children with FASD get treated differently??




23

## Personal responsibility and blame towards biological mothers

Blame and shame have been shown to negatively impact the self-perception of pregnant women using alcohol or drugs.

The perception of negative judgment may dissuade women from disclosing this information or seeking help.

Women may fear they may lose their children to the child protection system.

Some states are criminalizing women who admit drug or alcohol use during pregnancy.

### Underlying Values/Beliefs

- "It's a form of child abuse."
- "She is a bad mother."
- "She puts her own needs, wants, and desires before her child's."
- "She is in denial, or just gives excuses."

Corigan et al (2018)



24

**What factors are not taken into account when we think about reasons why a woman may drink during pregnancy?**

- Drinking alcohol before pregnancy was recognized.
- Unaware of risks or received inaccurate information about risks of PAE
- Knew someone who drank during pregnancy
- Drinking alcohol is a socially acceptable norm
- Some women with past or current trauma may continue to drink during pregnancy



25

**Misconceptions or misinformation about alcohol use during pregnancy**

- Some types of alcohol pose less risk than others
- Drinking only causes problems early in pregnancy
- Women need to consume large amounts of alcohol to cause harm
- Sometimes physicians and other health care providers encourage women to participate in light drinking during pregnancy (as a way to relax, for example)



26

Though there are many factors that influence whether a woman drinks alcohol during pregnancy, a FASD-informed belief would be that . . .

*no woman drinks because she wants to hurt her baby.*



27

**Important to examine our own biases and beliefs and how they might contribute to ongoing Stigma**

- What are your beliefs about alcohol and pregnancy?
- Do you have family/friends who drank during pregnancy?
- Do these beliefs affect how you think about children who have been exposed prenatally to substances/alcohol?
- Are they labeled as 'bad children' or a 'lost cause'?




28

**Protective Factor #1  
Early Identification**

**Characteristics of  
Children with FASD**

29

**Infant and Toddler  
Primary Disabilities**

Feeding Issues	Sleeping Problems	Negative Affectivity
Greater Stress Reactivity	Sensory Regulation Problems	Developmental Delays



30

## Preschool Primary Disabilities

Adaptive Behavior Deficits	Sleep Problems	Short Attention
Behavior Dysregulation/Tantrums	Atypical Sensory Responses	Fine/Gross Motor Delays
Social Skill Deficits	Negative Affectivity	Poor coordination



31

## FASD Medical Referral




32

## Asking the Difficult Questions

- Establish rapport with biological mother or family
- Convey empathy and non-judgment.
- State that you are trying to get information that will help the child and family.
- Ask about the drinking habits of other family members first.
- Ask **how much** someone drinks, **not if** they drink.
- Ask how far along was pregnancy when mother found out.
- Break down the consumption questions into three time periods: 1) before the mother was pregnant (with statements like "many people drink while they are pregnant because they don't know they are pregnant"); 2) before the mother learned she was pregnant; and 3) after the mother learned she was pregnant.
- Get the interviewee's definition of what a "drink" is, including what type of drink is consumed and how large she considers an average drink to be.
- Try not to ask yes/no questions.



33

## Identifying and referring a child for a FASD medical assessment

**Caregivers/Parents**

- Speak to pediatrician to discuss referral to FASD medical clinic
- For open DCFS cases, speak to DCFS CSW to submit a referral to FASD medical clinic

**Diagnostic Clinics**

Stramski Center - 562-728-5034  
LAC+USC FASD Clinic - 323-409-5086  
Cedars Sinai Medical Genetics - 310-423-9914

**Providers can Assist with:**

- Gathering prenatal history
- Obtain Regional Center assessments, psycho-educational assessments, psychological assessments
- Encourage and refer parents/caregivers to obtain FASD medical assessment for their child which will increase understanding of their child
- Assist in linking to appropriate support services for child/teen and caregivers



34

## Protective Factor #2 Stable and Nurturing Home Environment

### Helpful interventions and building positive relationships



35

## Importance of Caregiver and Provider (School, Mental Health, etc.) Support

- Caregivers/teachers/therapists need **Education** and increased understanding of how PAE affects the brain
- Caregivers/teachers/therapists need to learn to **Reframe** how they view the child/teen's challenges and behaviors
- Through reframing, caregivers/teachers/therapists will increase their **positive thoughts, feelings, and attitudes** towards the child/teen
- Reframing helps caregivers/teachers/therapists increase **empathy, attunement, and positive relationship** with child/teen
- Which helps the caregivers/teachers/therapists utilize **more positive behavior support strategies** and increase the use of **Accommodations** (antecedent-based strategies) to improve the child/teen's functioning



36

# FASD Informed Approach: Adopting the Neurodevelopmental Lens

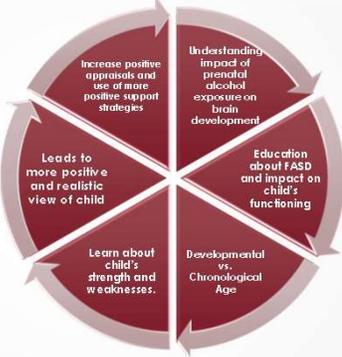
## “Reframing”



37

## Reframing

Changing “Won’t to Can’t”  
(Malbin, 2002)




38

## Adjusting Expectations

### What is child's “acts like” age?

Chronological Age	Functional/Developmental Age
<ul style="list-style-type: none"> <li>Age 5 years                             <ul style="list-style-type: none"> <li>Follow 3 instructions</li> <li>Sit still for 20 minutes</li> <li>Take turns</li> </ul> </li> <li>Age 10 years                             <ul style="list-style-type: none"> <li>Answer abstract questions</li> <li>Get along and solve problems</li> <li>Learn from worksheets</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Age 5 years going on 2 years                             <ul style="list-style-type: none"> <li>Follow 1 instruction</li> <li>Sit still for 5-10 minutes</li> <li>“My way or no way”</li> </ul> </li> <li>Age 10 years going on 6 years                             <ul style="list-style-type: none"> <li>Mirror and echo words and bxs</li> <li>Learn thru modeled problem solving</li> <li>Learn thru physical experiences</li> </ul> </li> </ul>



39

## REFRAME THE BEHAVIOUR

“KIDS DO WELL IF THEY CAN!”



40

# FASD INFORMED LENS

The FASD-informed Lens focuses an educators FASD-informed Practice.




41

# Accommodations

## Caregiver/Provider response changes and Environmental Changes



42



43

### Types of Environmental Accommodations

- Visual schedules
- Labels for drawers
- Decreasing clutter
- White noise
- Blackout curtains
- Quiet workspace

44

### Referrals for children with FASD

**Identification**

- Assist in gathering prenatal information from mother, family members or other sources via interview or from records

**Referrals**

- FASD Medical Screening
- Mental health/Support services for child
- Parenting/collateral support services

**Advocate and help link to support resources**

- Regional Center
- School District – Referral for IEP or ensure that current IEP is providing enough support for child
- Refer to Legal Aid to assist

45

### Mental health/Support services for young children with FASD

- Dyadic Therapy** with FASD-informed therapist (CPP, PCIT)
- Group therapy** (social skills, self-regulation)
- Individual rehab** – Additional skills-building support
- Occupational Therapy** – Addressing sensory issues and fine/gross motor delays to increase regulation and improve functioning

**Medi-Cal clinics**

- Miller's Children Hospital – 562-933-8832
- CHLA - 323-361-2118 (need to be client at CHLA)
- Glendale Adventist – 323-255-1134
- VIP CMHC 323-221-4234 (need to be client at VIP)

**Clinics that accept insurance/private pay**

- Pediatric Therapy Network – 310-328-0276
- Center for Developing Kids – 626-564-2700

- Psychotropic Medication** – Ideally with child-adolescent psychiatrist familiar with FASD or willing to learn

Psychotropic medication algorithm <https://canfasd.ca/algorithm/>

46

### Parent/Collateral Services and Supports

- Parenting classes**
  - FASCETS online classes (fee-based)
  - Triumph Today videos (fee-based)
  - VIP CMHC Triumph classes (Medi-Cal and some Pro Bono)
- Parenting-Focused Programs**
  - Families Moving Forward Program
  - Triple P
  - Dyadic Therapy – CPP or PCIT
- Parent support groups**
  - FASD Network of Southern California Parent Support Groups online
  - Double Arc Parent Support Groups online
  - VIP CMHC FASD Parent Support Groups online

47

### Triumph Through the Challenges of Fetal Alcohol Spectrum Disorders

- A six-week psychoeducational collateral group that addresses:
  - Diagnosis
  - Characteristics of FASD
  - Strategies to address inappropriate behaviors
  - Advocacy
  - Coping strategies for caregivers

48

### Families Moving Forward (FMF) Program Caregiver-focused intervention

Bertrand et al (2009)



- Research-Validated Intervention – Children 4-12 yrs
- Caregiver-focused educative and facilitative model
- Low-intensity, sustained weekly or biweekly intervention – 16 sessions
- Effective with different ethnic groups and family structures
- Core components along with individualized sessions



49

### What can Providers do to Improve Outcomes for the children they advocate for?

- Become curious and **increase your own FASD knowledge**
- **Identify children** who may have PAE and refer for FASD medical assessment
- **Utilize the neurodevelopmental lens** and FASD-informed approach to support children with FASD
- **Provide support and refer to services** (Mental Health Services, Special Education, Regional Center)
- **Increase resiliency and hope** for child and family



50

### Building resiliency through supporting caregivers and fostering interdependence

Clinical observations have revealed that caregivers and families are the primary advocates for individuals with FASDs throughout their lifetime (Olson, Oti, Gelo, & Beck, 2009). Therefore, in order to increase the likelihood that individuals with FASDs experience resilience despite significant adversity, it is vital that high quality caregiving and supportive and stable home environments are the focus for interventions. Caregivers who are clean, sober, and have the ability to advocate on the behalf of individuals with FASDs, will have the strongest positive impact on these individuals.




51

### Helpful FASD Websites

- <http://www.cdc.gov/ncbddd/fasd/>
- <http://www.nofas.org/treatments-support/>
- <http://www.mofas.org/>
- <https://www.uvm.edu/cess/cdci/educators-fasd>
- <https://www.fasdhub.org.au/fasd-information/managing-fasd/what-can-teachers-do/>
- <https://sites.duke.edu/fasd/chapter-4-the-fasd-student-and-the-classroom/effective-teaching-strategies/>
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- [http://podcast.casaforchildren.org/fetal\\_alcohol\\_spectrum\\_disorder](http://podcast.casaforchildren.org/fetal_alcohol_spectrum_disorder)
- <https://fasdcenter.org/>



52

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53

### Thank you!

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54