

**NC Department of Health and Human Services** 

Division of Mental Health, Developmental Disabilities, and Substance Use Services

# Parents Speak: Lived Experience with Fetal Alcohol Spectrum Disorder

Ginger Yarbrough, MPA, CPHQ, NADD-DDS Director, IDD, TBI & Olmstead, DMH/DD/SUS

Kathy Hotelling, Ph.D., ABPP Co-Founder and Board Chair, NCFASD Informed, Inc.

**September 24, 2025** 

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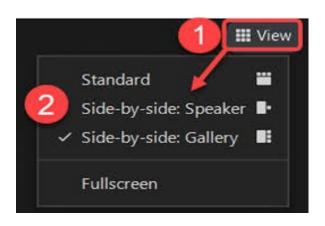
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### Housekeeping





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# Agenda

- 1. Welcome and Introductions
- 2. Overview of Fetal Alcohol Spectrum Disorder
- 3. Panel Discussion
- 4. Q&A Session

### **Speakers**

Ginger Yarbrough, MPA, CPHQ, NADD-DDS
Director, IDD, TBI & Olmstead, DMH/DD/SUS



- 24 years in IDD/TBI & dual diagnosis (DD & MH) field
- Experience as a Direct Support Professional, Care Manager, and Quality Management
- DMH/DD/SUS since March 2023

#### Kathy Hotelling, Ph.D., ABPP Co-Founder and Board Chair, NCFASD Informed, Inc.



- 18 years studying FASD and serving as Consulting Psychologist in FASD field
- Mother of 31-year-old daughter with FASD
- Retired Counseling Psychologist

# Parents Speak: Lived Experience with Fetal Alcohol Spectrum Disorder

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in partnership with the

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NCDHHS

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Mission: Create FASD informed communities to empower individuals impacted by prenatal exposure to alcohol.

<u>Vision</u>: A world where individuals with FASD can thrive.

## Umbrella Term



## Drinking during pregnancy

#1 CAUSE

of intellectual and developmental disabilities



# 1 in 20

Philip May (UNC) and Colleagues (Lancet, 2018)



Only 10% are diagnosed properly

90% have misdiagnosis or missing diagnosis

# WHOLE BODY DIAGNOSIS

# Failure to Diagnose = Failure to Treat

# Implications of No Diagnosis on Foster Care System

558 infants/children enter care each day in US:104 have FASD

42% of NC foster children had 2 or more placements

22% had over 4 placements

Problematic behaviors which foster parents feel ill equipped to handle

Diagnosis of FASD would indicate that <u>different</u> parenting tools are needed

# Recognizing FASD

What are the red flags?



Presence of facial dysmorphology (only 10%)

Confirmed prenatal exposure to alcohol

Confirmed maternal drug use

Possible maternal alcohol/drug use or dependency

Biological sibling with FASD diagnosis

- In foster care system
  - **❖558** enter system daily
  - ❖104 have FASD

(Casey Foundation, TAEC, 2022)

Domestically or internationally adopted

# Multiple co-occurring disorders LARGE red flag

Don't respond typically to interventions
 Medication
 Talk therapy

# Common Symptoms

#### **INFANTS**

- Low birth weight; failure to thrive; small size; small head circumference
- Disturbed sleep; unpredictable sleep patterns, irritability, restlessness
- Often trembling and difficult to sooth; may cry a lot
- Problems with bonding
- Weak sucking reflex; little interest in food; feeding difficulties
- Poor muscle tone, floppy or too rigid
- High susceptibility to illness
- High sensitivity to sights, sounds and touch
- Failure to develop routine patterns of behavior
- Motor delays
- Behavioral deficits (e.g., lack of social engagement; emotional withdrawal; difficulties with emotion regulation)

#### **PRESCHOOLERS**

- Slow to acquire skills
- Difficulties with emotional regulation (rages)
- Feeding and sleep problems
- Poor fine and gross motor control
- Short attention span
- Difficulty following directions or doing as instructed
- Hypersensitive to sounds, lights and being touched
- Hypersensitivity (irritability, stiffness, over-reaction to injury)
- Easily distracted or hyperactive
- Difficulty with changes and transitions; prefers routines
- Receptive and expressive language delays
- Lack of inhibition
- Conduct problems
- Insecure attachment

### **SCHOOL-AGED CHILDREN**

Sleep difficulties

Difficulty processing received information

Difficulty with comprehension (reading)

Ongoing expressive and receptive language delays

Poor attention span; low impulse control

Difficulty keeping up as school demands become increasingly abstract

Consistent repetition needed to learn a skill

Ongoing sensory difficulties which may lead to behavior changes or challenges

May need constant reminders

#### **Older Children/Teens**

Some of above symptoms may be minimized with interventions such as

- Physical therapy
- Occupational therapy
- Speech language therapy
- Social skills training

# As chronological age increases

and expectations to be independent also increase, symptoms often do not dissipate or may become worse

Developmental Age must be considered in setting expectations

# Executive Functions Across the Lifespan

- Planning
- Problem Solving
- Motivation
- Judgment
- Decision Making
- Impulse Control
- Social Behavior
- Memory

# Other notable Characteristics across the lifespan

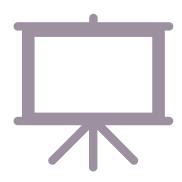
- Dysmaturity
- Literal
- Slow Processing Speed
- Impulse

# www.ncfasdinformed.org

# Panel Discussion

### **Question and Answer Session**





Questions and feedback are welcome at <a href="mailto:BHIDD.HelpCenter@dhhs.nc.gov">BHIDD.HelpCenter@dhhs.nc.gov</a>.

The presentation slides for this webinar will be posted to the <u>Community Engagement & Training</u> webpage.



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