

# Welcome!

We are so glad you are here!

We will get started shortly.  
In the meantime, we invite you to intentionally enter this space.



Silence your cell phone



Stretch



Close the door



Take a few deep breaths



Close browser windows



Emotionally release your to-do list



Check your audio and video



Take a bio break

# Prenatal Alcohol Exposure and Preventing FASD Webinar Series

## Meeting 3

TUESDAY, MAY 17, 2022

2 PM TO 3:30 PM ET

*THE HEALTHY START TA & SUPPORT CENTER IS OPERATED BY THE NATIONAL INSTITUTE FOR CHILDREN'S HEALTH QUALITY (NICHQ). THIS PROJECT IS SUPPORTED BY THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) OF THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) UNDER GRANT NUMBER 1 UF5MC327500100 TITLED SUPPORTING HEALTHY START PERFORMANCE PROJECT.*

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY**  
**start**  
TA & SUPPORT CENTER



# Agenda

**Housekeeping**

**Danisha Charles**  
HEALTHY START TA &  
SUPPORT CENTER (TASC)

**Fetal Alcohol Spectrum  
Disorders (FASD)  
through the Lifespan:  
Behaviors & Strategies**

**Kathy Mitchell**  
NOFAS

**Q&A**

**All**

**Closing & Evaluation**

**Danisha Charles**





THIS SESSION IS BEING RECORDED.



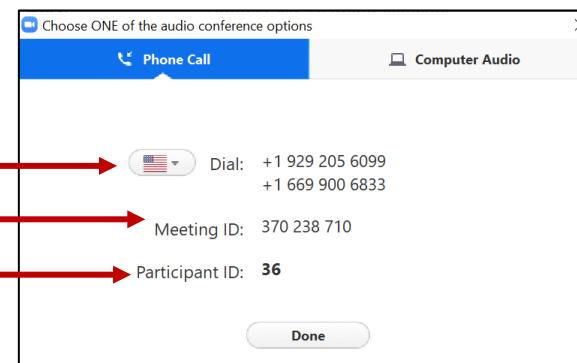
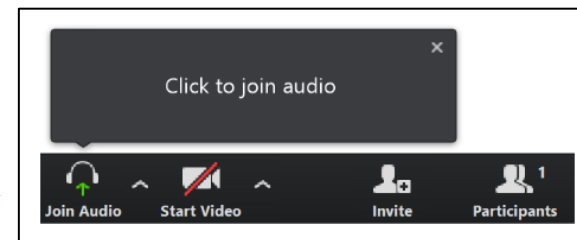
ALL PARTICIPANTS ARE MUTED UPON ENTRY. WE ASK THAT YOU REMAIN MUTED TO LIMIT BACKGROUND NOISE.



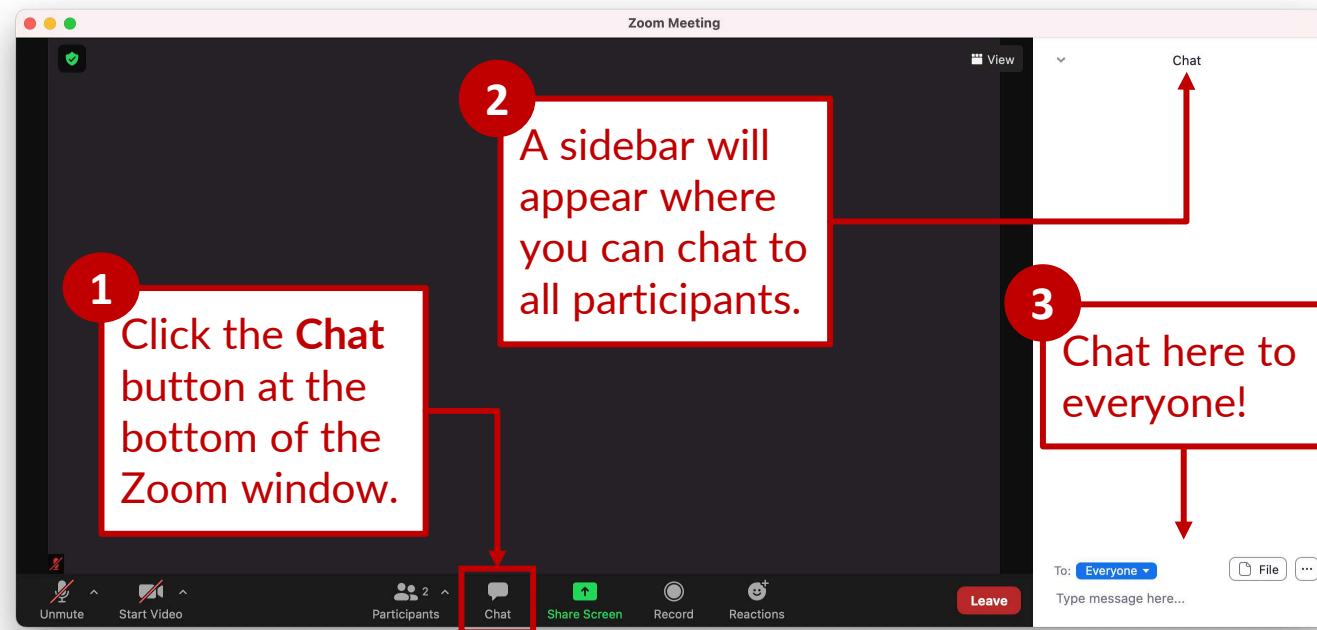
PARTICIPANTS ARE ENCOURAGED TO SHARE COMMENTS AND ASK QUESTIONS USING THE CHAT BOX.

# Audio

- AFTER YOU JOIN THE ZOOM SESSION, AN AUDIO CONFERENCE BOX MAY APPEAR
  - IF YOU DO NOT SEE THE BOX, CLICK **'Join Audio'**
- FROM THE AUDIO CONFERENCE BOX, SELECT **'Phone Call'** OR **'Computer Audio'**
  - IF ACCESSING THE SESSION AUDIO VIA PHONE:
    - DIAL ONE OF THE GIVEN NUMBERS NEXT TO **'Dial'**
    - YOU WILL BE PROMPTED TO ENTER THE **Meeting ID**
    - THEN YOU WILL BE PROMPTED TO ENTER THE **Participant ID**



# Chat





# Welcome

**Danisha Charles**

HEALTHY START TA & SUPPORT CENTER

*PRENATAL ALCOHOL EXPOSURE & PREVENTING FASD SERIES  
HOSTED BY THE HEALTHY START TA & SUPPORT CENTER AT NICHQ*

**NICHQ**  
National Institute for  
Children's Health Quality

**HEALTHY**  
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TA & SUPPORT CENTER

Prenatal Alcohol Exposure & Preventing FASD Series

# Schedule

Meeting 1

September 16, 2021

2 PM TO 3:30PM ET

Meeting 2

February 1, 2022

2 PM TO 3:30PM ET

Meeting 3

May 17, 2022

2 PM TO 3:30PM ET

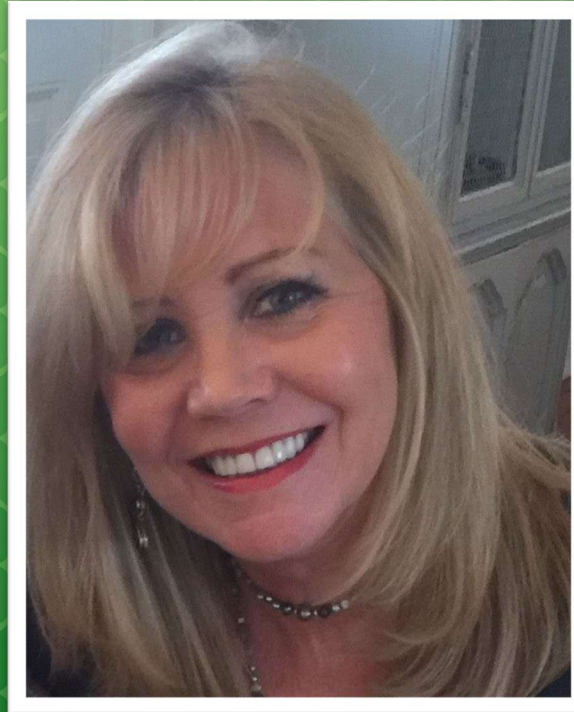


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# Today's Speaker



Kathleen Tavenner Mitchell, MHS, LCADC  
Vice President and National Spokesperson  
National Organization on Fetal Alcohol Syndrome

The Prenatal Alcohol  
Exposure and Preventing  
FASD Series Webinar  
series is hosted by the  
Healthy Start TA & Support  
Center at NICHQ.

# *Fetal Alcohol Spectrum Disorders through the Lifespan: Behaviors & Strategies*



**Kathleen Tavenner Mitchell, MHS, LCADC**  
**Vice President and National Spokesperson**

## Objectives

By the end of this webinar participants should be able to:

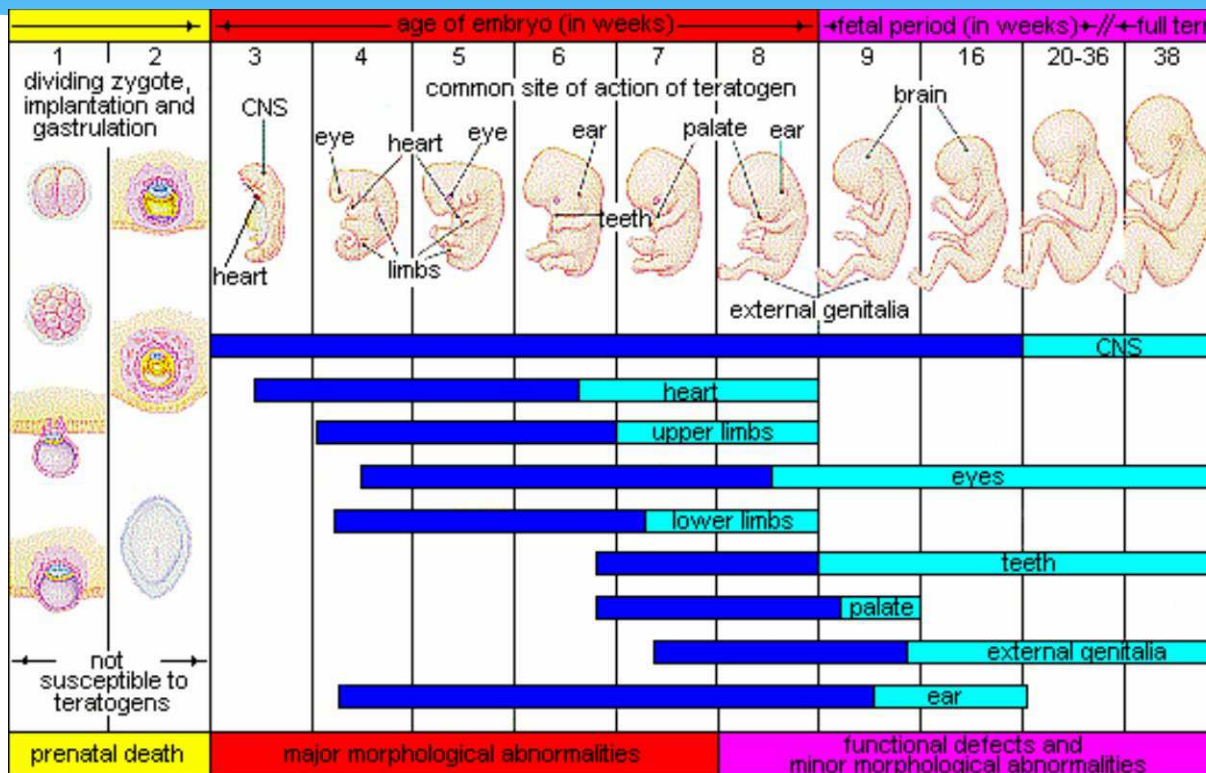
1. Describe some of the possible lifelong developmental, behavioral, cognitive and physical effects of fetal alcohol spectrum disorders (FASD).
2. Discuss environmental considerations to support and improve outcomes for children with possible FASDs.
3. List 3 strategies described in “Eight Magic Keys” training video.

*Why I do what I do - meet my daughter, Karli  
(age 10 diagnosed with cerebral palsy)*



**The recent U.S. prevalence study  
estimates that 1 in 20 U.S. School  
students may have FASDs.**

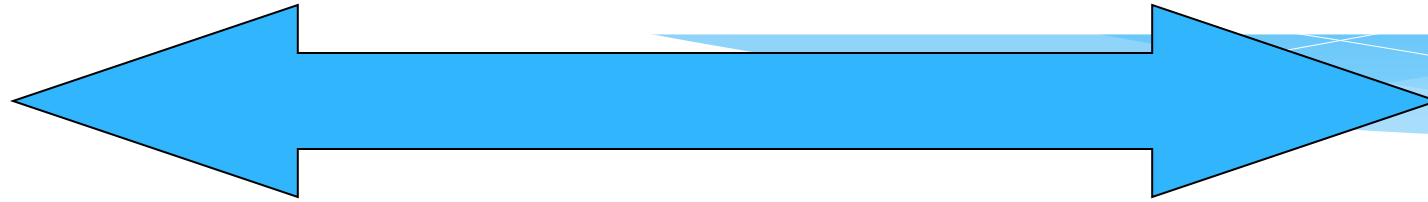
# Impact of Alcohol Use on the Developing Fetus



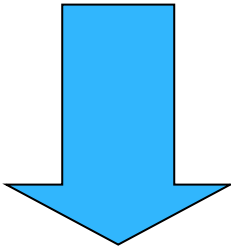
Adapted from Moore and Persaud, 1993.

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# Fetal Alcohol Spectrum Disorders

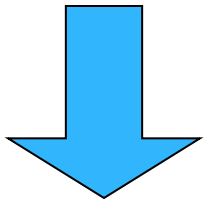


**FAS**



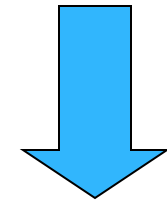
**Fetal Alcohol Syndrome**

**PFAS**



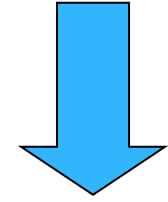
**Partial FAS**

**ARND**



**Alcohol-Related Neurodevelopmental Disorder**

**ND-PAE**



**Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure**

**Fetal and Infant Death**

# FASD: The Facts

- \* Most common *preventable* cause of intellectual disability and behavior problems.
- \* Most effects are *lifelong*.
- \* Effect development and function more so than other drugs or teratogens.

***“Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”***

***Institute of Medicine, 1996***

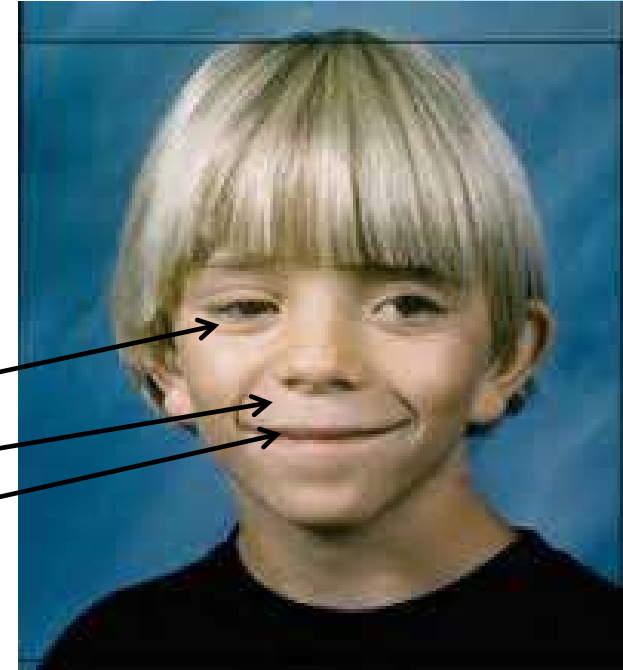
- \* Can an contribute to a range of growth deficits and structural anomalies (FASD)

**\*AAP Webinar, 2017**

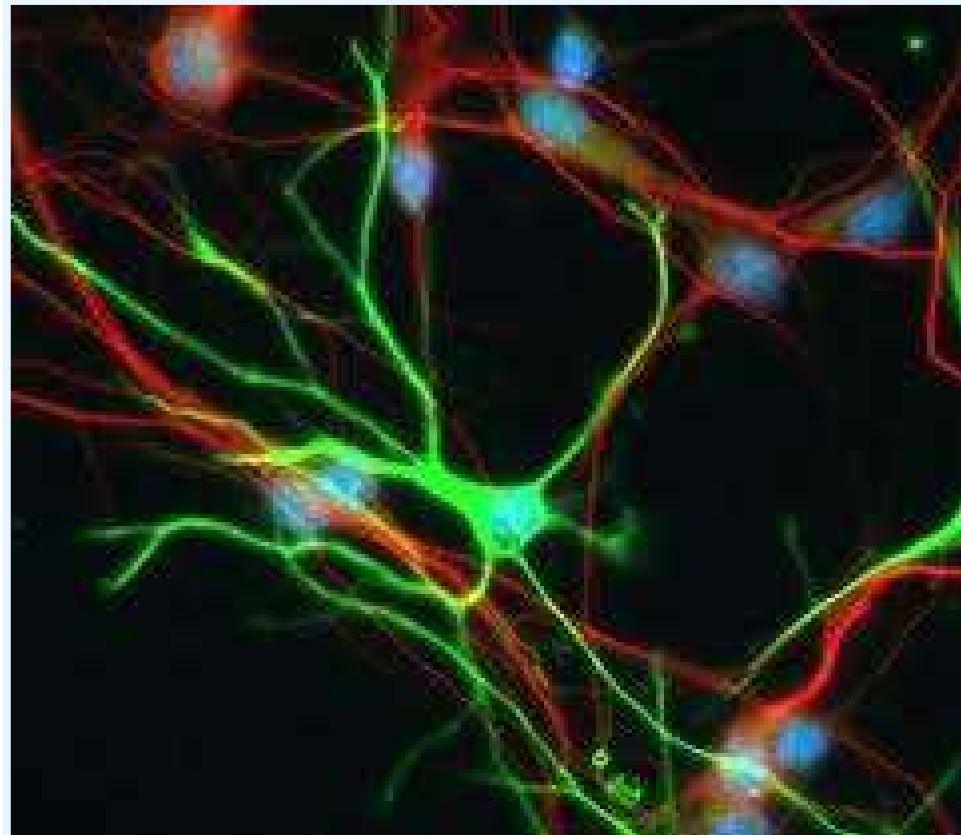


# Physical Effects

- \* Weight and/or length growth deficiency (pre or post natal)
- \* Abnormal brain structures (esp. small cranium, corpus callosum)
- \* Dysmorphic facial features:
  - \* Short palpebral fissures
  - \* Smooth philtrum
  - \* Thin vermilion border



# *Prenatal exposure to alcohol causes the brain to actually be “built” differently ...*



# Infancy

*Low birth weight*

*Failure to thrive*

*Colic*

*Chronic ear infections (acute otitis media)*

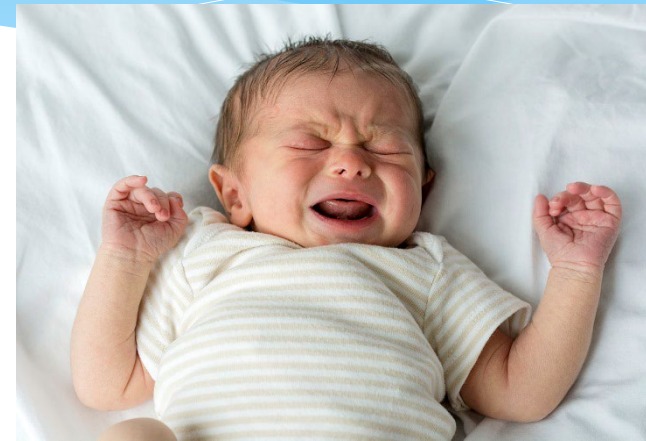
*Feeding issues, sensitivities*

## **Neurobehavioral Effects: Self-regulation problems**

- Self-soothing, sleep
- Poor suckling
- High-pitched crying
- Rigid, stiff and jerky movements

## **Physical Birth Defects**

- Cleft palate
- Clubbed foot (other birth defect)
- Fingers, toes (malformed)
- Organs (heart, kidney)



# Early Childhood

## Neurocognitive deficits

- \* Low IQ or developmental delay
- \* Executive functioning deficits
- \* Impaired learning, memory or specific learning problems (esp. visual-spatial and math)
- \* Motor functioning delays for younger children

## Neurobehavioral deficits

- \* Difficulty managing mood
- \* Behavior management issues
- \* Attention problems (esp. shifting attention)
- \* Poor impulse control



# Childhood-Early School Age

## Difficulty learning/Delayed adaptive skills

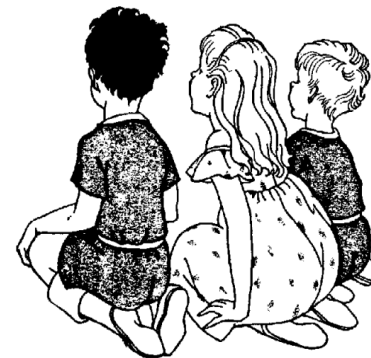
- Delayed potty training
- Poor peer interaction
- Motor issues in younger children (riding tricycle)
- May be small for age
- Delayed speech
- Memory deficits
- Verbal receptive language is more impaired than verbal expressive language
  - Chatty but unable to process or use all of what they hear
  - They will often do what they think they need to based on the pieces that they have processed (may look like purposeful, oppositional or uncooperative behavior)
- Verbal receptive language is the basis of most of our interactions with people



***Something is not quite right***

# What currently happens to most school aged children with FASD?

- \* *Early childhood - when they do the best they 're going to do in our system*
- \* *Elementary grades - we start to see problems*
- \* *Middle/Junior High - they start to fall through the cracks*
- \* *High School - we lose most of them*



# Learning Theory

*assumes that a person is capable of:*

- \* *Learning a rule or principle*
- \* *Understanding the underlying concepts of that principle*
- \* *Remembering these concepts*
- \* *Generalizing this learning to many different situations*

# School Age-Adolescents

- Difficulty taking in new information
  - \* They often remember details but not the overall concept
  - \* Can't sort what is important from trivia
- They can learn information but have difficulty recalling it and knowing how to use it
- Middle and high school are particularly difficult
  - \* School is often enjoyable until then
  - \* Recognize the possibility of truancy or disruption
- The majority of learning is auditory



# Literal-Concrete Thinkers

- \* Do “exactly” as told
- \* May not get the joke-but will laugh
- \* Difficulty with a sense of their body and space
- \* Difficulty with sarcasm and metaphors

# Adults (parents-your clients) with FASD

- \* MEMORY DEFICITS
- \* Friendly
- \* Talkative
- \* Desire to be helpful
- \* Naïve and gullible
- \* Difficulty identifying dangerous people or situations
- \* Difficulty following multiple directions or rules
  - \* May be able to repeat rules but not know how to follow them
- \* Over-reaction to stresses
- \* Interrupt or act inappropriately
- \* Don't follow the course of group discussions

## *Looking at the world through foggy glasses:*

- \* **Decision Making**
- \* **Concept of time**
- \* **Handling Money**
- \* **Seeing another perspective-point of view**
- \* **Adaptive behavior-Has no idea what to do, when he does not know what to do**
- \* **Can't see the *big picture* -only the little immediate picture**
- \* **Distinguishing between public and private behaviors**
- \* **Self expression- I know what I mean, but can't say it how I mean it**
- \* **Seeing another perspective-point of view**
- \* **Can't see the *big picture* -only the little immediate picture**
- \* **Distinguishing between public and private behaviors**

# Alcohol during pregnancy can result in a brain that:

**...can't read the emotions or body language of other people**

**responds slowly**

**...can't link cause and effect**

**...thinks in a disorganized way**

**...thinks like the brain of someone much younger**



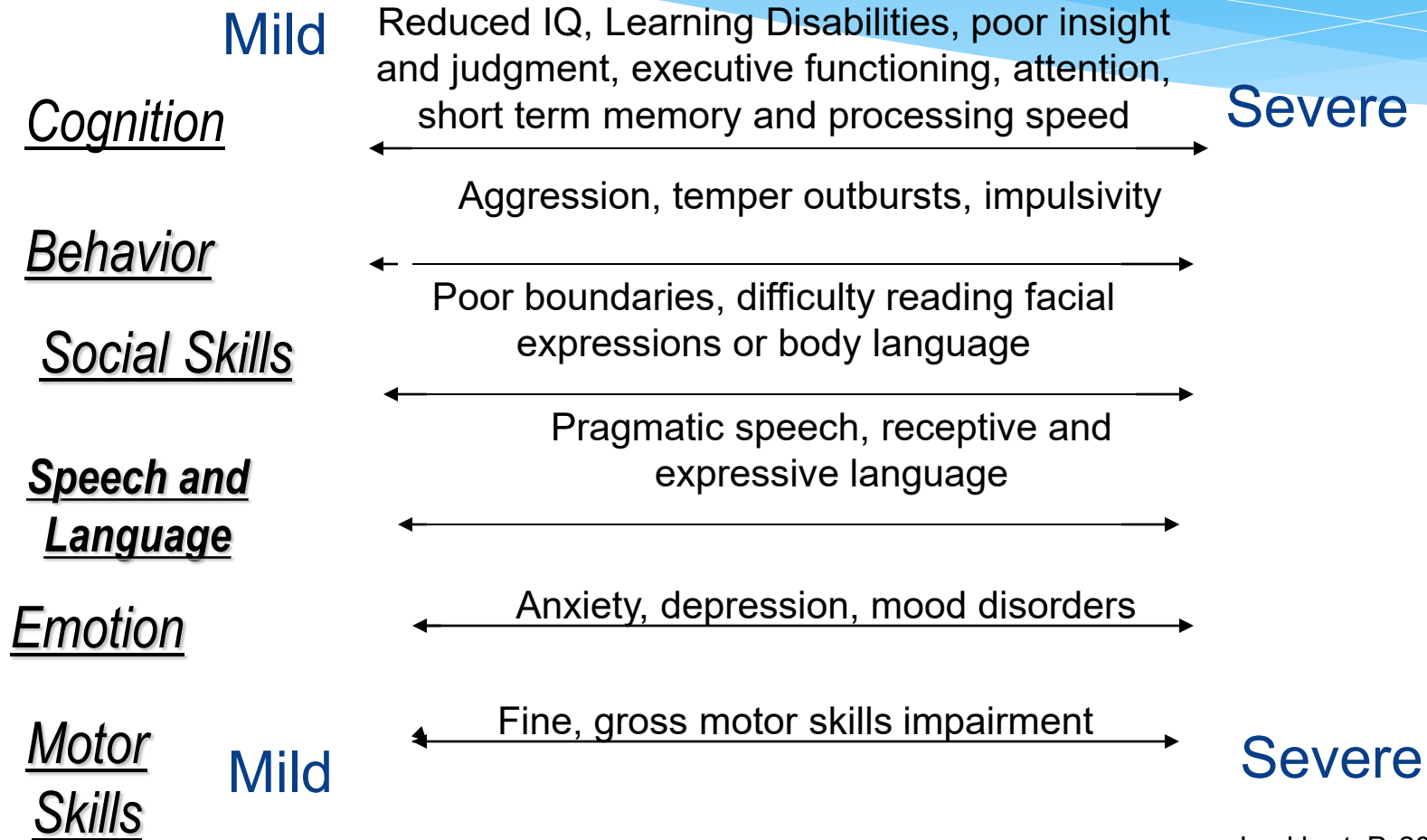
**...has trouble moving information from one situation to another**

**...forgets information**

**...has difficulty with time and money**

**...uses poor judgment**

# Screening for FASD: Lifelong Problems Appear Across a Continuum of Severity



# Common disorders identified with FASD

- \* Autism Spectrum Disorder/Asperger's
- \* Attention Deficit Hyperactivity Disorder (ADHD)
- \* Borderline Personality Disorder
- \* Attachment-Bonding Disorder
- \* Depression
- \* Learning disability
- \* Oppositional-Defiant Disorder
- \* Post Traumatic Stress Disorder (PTSD)
- \* Receptive-Expressive Language Disorder
- \* Conduct Disorder

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# Meet my friend-Morgan Fawcett

Morgan

<https://www.youtube.com/watch?v=K0VrkLQfkFg>

# Red Flags for an assessment for FASD

1. **Developmental, cognitive or behavioral concerns**
2. **Complex medical concerns**
3. **Facial features associated with prenatal alcohol exposure (PAE)**
4. **Growth deficiency at or below 10<sup>th</sup> percentile for head circumference, height, weight at any time, including prenatally**
5. **History of confirmed or suspected alcohol or drug use**
6. **A sibling diagnosed with an FASD, still-birth or SIDS, or known exposure**
7. **Self-reported or family concern about possible FASD**



An FASD diagnosis is not the end of the world~  
careful not to “awful-ize FASD”



# Potential Benefits of a Diagnosis

- \* Avoids unnecessary additional testing and non-specific referrals or interventions (pharmaceutical)
- \* Parental relief in the knowledge that the child's problems have a biological basis (it's not due to something they are doing)
- \* Facilitates access to evidence-based interventions and connections with other parents
- \* Discussing the cause with a biological mother may reduce recurrence risk in future offspring (include referrals for support for bio-families)

# Diagnosis Creates Paradigm Shift :

- Person with a developmental disability
- Can't *not* Won't
- Need support (External Brain)

*Provide HOPE for  
individuals and  
their families....*

# Change Perception:

linear to circular



One day at a time

# Strength-Based Approach

- \* Focus on small joys and achievements
- \* Identify strengths and desires in the individual
  - \* What do they do well?
  - \* What do they like to do?
  - \* What are their best qualities?
  - \* What are your funniest experiences with them?
- \* Identify strengths in the family
- \* Identify strengths in the community
  - \* Include cultural strengths in the community

# Attributes of Persons With an FASD

- \* Friendly
  - \* Want to do a good job
- \* Likeable
- \* Verbal
  - \* Kind: good with the elderly, children and pets
- \* Helpful
  - \* Not malicious
- \* Caring
  - \* Every day is a new day
  - \* Will model behaviors of those around them

# Families are Resilient

## Traits of Healthy Families

- Commitment
- Time Together
- Respect
- Spirituality
- Connectedness
- Adaptability
- Communication
- Cohesion



*“Capacity to rebound from adversity strengthened and more resourceful” (Walsh,1998)*



# Creating Resiliency

- Family connectedness
- Spiritual belief system
- Physical- sleep, health
- Social-friendships/community
- Emotional (counseling/support)
- Intellectual- informed about FASD
- Recreational/Arts/Hobbies/leisure
- Respite support
- Support and resources



# Resiliency:



Life will continue to throw us curve balls. It's how we think about and process events that will make us resilient.

*When I get a flat tire and I am not in a good spiritual-emotional place, it's something that's happening **TO** me, when I am in a good spiritual-emotional place it's happening **FOR** me.*

Mike Mitchell

# WINNING STRATEGIES

- \* **Communication**
- \* **Communication(what is working and not working)**
- \* **Humor**
- \* **Creativity**

# Be Innovative and Creative

- \* **Follow your intuition**
- \* **Watch the child and learn from the messages he sends**

## Re-Think the System

How can we adapt our home  
or classrooms to better  
support children?

# We Learn to Reframe the Behavior

Not doing the tasks may mean “I don’t know how to put the steps into action”

- Check their understanding of the task
  - Ask questions such as “what does that mean?” or “how would you do that?” or “how would you follow that rule?”
- Provide support to model the activity for the person
- Demonstrate the activity with the person

# Reframing

- \* Think younger- use “acts like” age to adjust expectations for how much an individual can independently accomplish.
- \* FASD is a brain-based disability.
- \* Life is a puzzle-provide them with the missing pieces.
- \* When you see confusion-offer a helping hand.

# Home Environment

- \* Calm colors, sounds, environments, reduce chaos
- \* Role playing-repeat, practice
- \* Visual cues, notes, affirmations
- \* EDUCATE EVERYONE in their circle (caregivers, teachers, day care providers, extended family, religious or community clubs)
- \* 1:1 physical presence-always a go-to person
- \* Use short term-immediate consequences
- \* Provide them with daily role and duties (e.g. set table)within household- they matter
- \* Calm bedtime routine: warm baths

# Clients with possible FASD

- \* Use literal language
- \* Use person first language
- Be aware of, and discuss, misinterpretations of words or actions of others when they occur
- \* Help them to identify their own strengths and weaknesses (where they need extra support)
- \* Identify strengths in the individual and family
- \* Set the person up to succeed-Identify mentor or support group



*They are right where they are  
supposed to be, and are perfect just  
the way they are today.*

- \* Help them to accept and recognize their disability in reasoning, judgment and memory
- \* Everyone has strengths and weaknesses
- \* Accept themselves for who they are “today”
- \* Ignore some of their “issues/difficulties”
- \* Recognize their effort to improve

# 8 Magic Keys

<https://www.youtube.com/watch?v=tKfV21waMeo>

1. Concrete- Literal-be aware of misinterpretations of words/actions
2. Consistency-need predictable environments
3. Repetition-Provide one direction or rule at a time/ review rules/expectations
4. Routine-charts/prepare for changes

# 8 Magic Keys

5. Simplicity-  
language/directives/environment
6. Specific-exactly what you mean (will  
not get joking, sarcasm)
7. Structure-predictability, physical  
boundaries
8. Supervision-peer support, external  
brain

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<https://www.youtube.com/watch?v=tKFV21waMeo>

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# Questions?



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**FASD United**  
THE NATIONAL VOICE ON FETAL ALCOHOL SPECTRUM DISORDERS  
Formerly NOFAS

FASD United is the national voice of the FASD community. Founded in 1990 as the National Organization on Fetal Alcohol Syndrome (NOFAS) and rebranded in 2021, FASD United supports individuals, families, and communities living with FASD and works to prevent prenatal exposure to alcohol, drugs, and other substances known to harm fetal development.

For over three decades, FASD United has led the national family support, public health, and policy response to FASD.

[www.FASDUnited.org](http://www.FASDUnited.org)



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# FASD United Family Navigator



## Our Services Are:

- Personalized
- Navigation support for medical, educational, and disability services
- Resource Referrals
- Confidential
- Free

## How to Access:

Email: [navigator@FASDUnited.org](mailto:navigator@FASDUnited.org)  
[www.fasdunited.org/family-navigator/](http://www.fasdunited.org/family-navigator/)





# Stars for Starla

Celebrating the Strengths & Talents of Youth with FASD

Stars for Starla recognizes that youth with FASD need positive, hopeful messages to counter the negative messages that many youth with FASD unfortunately receive throughout their lives as a result of either a lack of accommodations or understanding of their disability. When awards or commendations are handed out, either through school, sports, or other groups, their incredible efforts of doing their best to navigate a system not set up for them can often go unnoticed.

Youth with an FASD can be nominated by anyone in the community, and FASD United will provide a beautiful certificate recognizing their strength or accomplishment, no matter how large or small, mailed to you or their trusted adult for delivery to them.

Nominate Youth at:  
[www.bit.ly/StarsforStarla](http://www.bit.ly/StarsforStarla)





# Resources

Center for Disease Control (CDC)  
Brochures, Posters, Fact Sheets, and Training Guides  
<http://www.cdc.gov/ncbddd/fasd/freematerials.html>



American College of Obstetricians & Gynecologists  
Patient Education handouts, Videos  
<http://www.acog.org/alcohol>



PediaLink online training course  
AAP FASD Toolkit – [www.aap.org/fasd](http://www.aap.org/fasd)  
School Professionals: [www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Fetal-Alcohol-Spectrum-Disorders-FAQs-of-Parents-and-Families.aspx](http://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Fetal-Alcohol-Spectrum-Disorders-FAQs-of-Parents-and-Families.aspx)



# Evidence Based Interventions for Children with FASDs

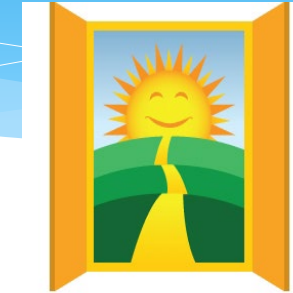
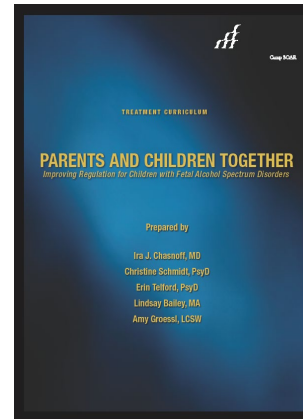


- ❑ **MILE**  
Emory University  
[www.psychiatry.emory.edu/PROGRAMS/GADrug](http://www.psychiatry.emory.edu/PROGRAMS/GADrug)

- ❑ **PACT**  
Children's Research Triangle  
[www.childstudy.org](http://www.childstudy.org)

- ❑ **Good Buddies**  
U. of California, Los Angeles  
[www.semel.ucla.edu/fas/](http://www.semel.ucla.edu/fas/)

- ❑ **Families Moving Forward**  
Children's Hospital, Seattle  
<http://depts.washington.edu/fmffasd>



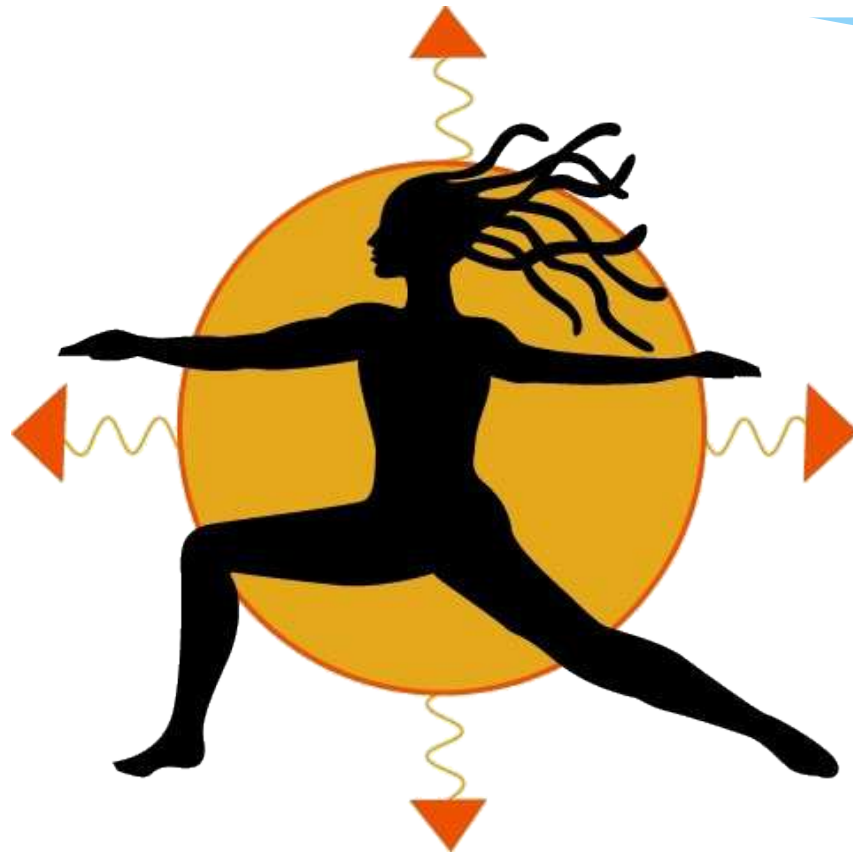
Families  
Moving Forward  
Program



FASD United Circle of Hope  
Birth Mothers Network  
[www.nofas.org/coh](http://www.nofas.org/coh)

## Recovering Mothers Anonymous (RMA)

### YOU ARE NOT ALONE!



RMA supports people that have the shared lived experience of exposing their unborn to substances that may have impacted their child's development. RMA uses *recovery* as a broad term to include recovery from alcoholism or drug addiction, recovery from childhood trauma and/or an abusive relationship or environment and recovery from having the experience of using alcohol or other harmful substance while pregnant.

[www.recoveringmothers.org](http://www.recoveringmothers.org) **12 Step Program for moms**

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# Questions?



# Thank You!



*Kathy Mitchell, MHS, LCADC*  
*FASDUnited.org*  
*Washington, DC*

[mitchell@fasdunited.org](mailto:mitchell@fasdunited.org)



# Closing

Danisha Charles

HEALTHY START TA & SUPPORT CENTER

*PRENATAL ALCOHOL EXPOSURE & PREVENTING FASD SERIES  
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**HEALTHY**  
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TA & SUPPORT CENTER

# Satisfaction Survey

*YOUR FEEDBACK IS EXTREMELY VALUABLE AND WILL HELP  
ENSURE THE COHORT MEETINGS ADDRESS YOUR SUPPORT  
NEEDS!*



# Thank you !

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