PREVENTING, IDENTIFYING & TREATING FETAL ALCOHOL SPECTRUM DISORDERS (FASD)





Funding for this document was made possible (in part) by the Centers for Disease Control and Prevention (CDC). The views expressed in written materials do not necessarily reflect the official policies of the Department of Health and Human Services, nor does the mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.

Overview of CDC Initiative:

Collaborative for Alcohol-Free Pregnancy



CDC-funded FASD Practice & Implementation Centers (PICs) and National Partnerships Goals:

- Prevent alcohol-exposed pregnancies
- Promote proper identification/referral for those with FASD
- Strengthen "research to practice" linkages through partnerships between PICs and national organizations for:
 - Physicians (Family Medicine, Ob/Gyn, Pediatrics)
 - Nurses, Social Workers, Medical Assistants
- Achieving sustainable practice-level and systems-level change through an interprofessional, collaborative model
- https://nccd.cdc.gov/FASD/

BEHAVIORAL / FUNCTIONAL CHARACTERISTICS, TREATMENT, & INTERVENTIONS FOR INDIVIDUALS WITH PRENATAL ALCOHOL EXPOSURE

Part III



Learning Objectives

- I. **Describe** and identify common characteristics and challenges for individuals with prenatal alcohol exposure
- II. Recognize individual strengths
- III. Identify treatment and intervention options to support an individual with a FASD throughout the lifespan
- IV. Incorporate strategies for improving outcomes for persons with a FASD

Behavioral / Functional Characteristics and Challenges for an Individual with Prenatal Alcohol Exposure

Alcohol During Pregnancy Can Create a Brain That...

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

...thinks like the brain of someone much younger

> ...forgets information

...responds slowly

...can't link cause and effect

> ...thinks in a disorganized way

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

...has difficulty with time and money judgment

...uses poor

Common Challenges for Individuals with Prenatal Alcohol Exposure

Very literal thinking

Slower processing pace

Difficulty learning from experience

Disruption in cause / effect thinking

Rigid thinking

Difficulty reading body language

Memory problems

Sensory integration challenges

Poor judgment

Typical Characteristics for individuals with FASD

Typical primary characteristics in children, adolescents, and adults include:

Ability to repeat instructions, but inability to put them into action

Cognitive processing deficits (may think more slowly)

Developmental lags (may act younger than chronological age)

Difficulty storing and retrieving information

Difficulty with abstractions, such as math, money management, time concepts

Impulsivity, distractibility, disorganization

Inability to predict outcomes or understand consequences

Inconsistent performance ("on" and "off") days

Slow auditory processing (may only understand every third word of normally paced conversation)

Diane Malbin – FASCETS.org

Reconceptualizing the Behavior of an Individual with FASD

From Seeing	To Understanding
Won't	Can't
Lazy	Tries Hard
Lies	Fills in
Doesn't Try	Exhausted or can't start
Doesn't care	Can't show feeling
Refuses to sit still	Over stimulated
Fussy, demanding	Sensitive
Resisting	Doesn't understand
	-Diane Malbin, I

Recognizing and reframing strengths

What strengths might an individual have (despite appearances)?

- Survival skills- (might look manipulative)
 Verbally expressive- (talks, doesn't listen)
- Curious- (doesn't focus on task in front of them)
- Wants to please- (peer pressure)
- Sense of humor- (laughs inappropriately)
- Persistence- (perseveration)
- Patience- (standing around)
- Passion- (anger)



Encourage Strengths

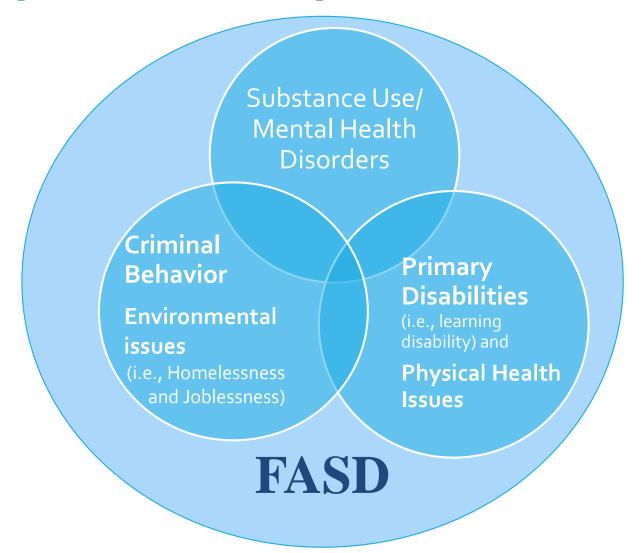
- Highly verbal
- Bright in some areas
- Artistic, musical, mechanical
- Athletic
- Friendly, outgoing, affectionate

- Determined
- Persistent
- Willing
- Helpful
- Generous
- Many are good with younger children or the elderly



LIFESPANTREATMENTS AND INTERVENTIONS FOR PEOPLE LIVING WITH FASD

FASD Impacts All Aspects of a Person's Life



Interventions & Support Through the Lifespan

Early Intervention Services

- Research supports that early intervention services (speech and language, OT and/or PT, etc.) can improve child development
- Individuals With Disabilities Education Act I.D.E.A. allows anyone who qualifies to receive services
- Speech therapy and language delays often do not require a formal diagnosis to receive treatment

Interventions & Support through the lifespan

Protective Factors

- Early diagnosis and recognition
- Involvement in social services
- Loving, nurturing, and stable home environment
- Absence of violence

Types of treatment will change throughout the lifespan

Types of Lifespan Treatments / Interventions

- Medical Care
- Medications
- Behavior and Education Therapy
 - Friendship training "Good Buddies" (Mary O'Connor and colleagues)
 - Specialized math tutoring (Claire Coles do2learn.com)
 - Executive functioning training & Parents and Children Together (Ira Chasnoff https://www.alertprogram.com/)
 - Parent-child interaction therapy (P-CIT)
 - Modified mental health or substance use treatment
 - Supportive therapy

Types of Lifespan Treatments / Interventions

- Parenting Training
 - Parenting and behavior management training (Heather Carmichael Olson
 - Families Moving Forward https://depts.washington.edu/fmffasd/)
- Linkage and Advocacy with child welfare, corrections and education, as needed
- Alternative Approaches

What We See	What We Think	What May Be Really Going On	What We Can Do
Doesn't follow rules	NoncomplianceAttention SeekingStubbornPurposeful	 Difficulty translating verbal directions into action Cognitive deficit 	Check for understandingRepeat instructionsSimplify tasks
 Repeatedly makes the same mistakes 	ManipulativeDoing it on purposeWillful	Not able to link cause and effectDifficulty generalizing	Provide assistance with organizationStructure choices
Poor social judgment	Attention SeekingPoorly parentedImpulsive	Not able to interpret social cuesDesire to be liked	Role playIdentify safe external support/sSafety planning
Easily agitated	Poor self controlDeviant	FrustratedDisappointedMental health issue	 Teach self advocacy Identify and practice coping techniques

Strategies for Improving Outcomes for Persons With an FASD

- Identify strengths in the individual, family, and providers
- Find something that the person likes to do and does well and help make arrangements
- Create "chill out" spaces in each setting
- Use literal language
- Use person first language
- Recognize that FASD impacts an individual throughout the lifespan, not just during childhood



Strategies for Improving Outcomes for Persons With an FASD

- Have short sessions as frequently as possible
- Be careful about verbal approaches as verbal receptive language is most often much more impaired than expressive language
 - Use multiple senses (e.g. role playing and computer learning)
 - Act out instructions when possible
 - Provide visual cues
 - Limit distracting stimuli
- Simplify and review routines, schedules, & rules frequently

Additional Strategies

- Check for true understanding
 - Do not just ask "do you understand" and "do you have any questions"
 - Ask questions such as "what does that mean?" "How would you do that?"
 - "Could you tell me what you just heard that I said and what that means?
 Sometimes I am not as clear as I should be and I want to be sure I was clear in what I asked you (or told you)"
- Prepare the individual for changes in schedule

Part III Conclusions

- Individuals with FASD may have difficulty with cognitive processing and functional skills.
- Reframe challenges and support the strengths of persons with an FASD
- Early intervention can improve a child's health and development
 - Interventions will change as the person develops.
- FASD impacts a person across the lifespan and undiagnosed individuals may encounter adverse life outcomes as a result.
- Typical intervention and service approaches may need to be modified for an individual with FASD.

ADDRESSING STIGMA & BARRIERS

Part IV

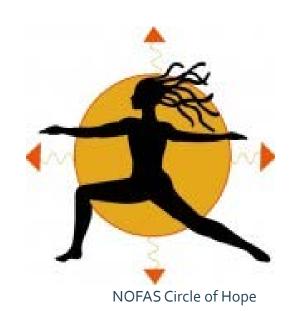


Learning Objectives

- Explain & recognize how stigma relates to FASD and alcohol consumption among women
- II. Identify how stigma & bias impact the ways providers approach, communicate, and interact with women who use alcohol
- III. **Identify** how to address barriers to care for prevention of alcohol-exposed pregnancies (AEPs)

Understanding FASD & Stigma

- Experiences of biological mothers:
 - o Guilt, denial, shame, anger and trauma are common
- Factors contributing to alcohol use during pregnancy may include:
 - intimate partner violence, mental health conditions, experiences from previous pregnancies, etc.
- Undetected pregnancies
- Different cultures may perceive things differently
- Stigma creates barriers that hinder FASD prevention and care

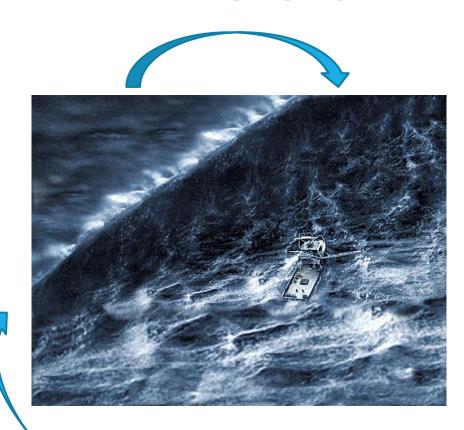


(source of support for mothers)

Stigma, Social Messages & Misinformation

A PERFECT STORM

- Many pregnancies are unplanned
- Social acceptance of alcohol
- Uncomfortable topics to discuss
- Limited access to family planning services



- Child is born; may be small with some health concerns
- Diagnosis is not made, necessary support services may not be provided
- Protective factors can be difficult to obtain for child
- Limited support or education for families

Addressing Barriers

- Recognize that stigma impacts the ways providers approach, communicate, and interact with women who use alcohol
- Implement routine alcohol screening with ALL clients
- Use appropriate and respectful language regarding alcohol consumption during pregnancy
- Establish an effective referral process

Part IV Conclusions

- Stigma regarding alcohol use creates barriers for FASD prevention & care.
- It is important to take into consideration cultural differences regarding alcohol consumption.
- Routine alcohol screening and an empathetic provider can effectively help reduce barriers for communication and treatment.



Catalyst Learning Center is a digital **learning** environment, **centered** on the learner, that aims to serve as a **catalyst** for change in the way that each learner approaches health and care delivery.

Acknowledgements

A special thank you to the collaborative partners who helped create this presentation:

- Leigh Tenkku Lepper, PhD, MPH
 University of Missouri Columbia
- Susan Adubato, PhD
 Rutgers University -Center of Alcohol Studies
- Mary DeJoseph, DO
 Rutgers University Center of Alcohol Studies
- David Deere, MSW, MTh
 Arkansas's University Center for Excellence in
 Developmental Disabilities (UCEDD)]

- Lara Oakley, MSW, MPH
 University of Missouri Columbia
- Wes Jones, PhD
 Flint Hills Consulting
- Dan Dubovsky, MSW FASD Specialist